

Managing Transitions of Care: An Examination of Parents' and Providers'
Perspectives on the Transitions of Care of Neonatal Patients from the Neonatal
Intensive Care Unit

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Abstract

Objectives: Transitions of care (ToC) for a high-risk neonatal population, and in some cases inappropriate and early discharge, can have important implications for community and broader population health. As it is a key indicator of the efficiency of the system of health services, the ease of ToC has been a priority for improving care outcomes across all settings in our nation's healthcare system. Research shows that inappropriate discharges can lead to negative outcomes for patients and their families, health professionals, and the health system. Collaboration amongst the health care professionals, the community, and the patient's family is needed for an efficient transition. This research examined how interprofessional collaboration (IPC) can act as a catalyst for efficient and effective ToC from a high-risk neonatal unit to care back in the community.

Approach: Twelve infants were observed from their admission on the Neonatal Intensive Care Unit (NICU) until their discharge home. The 12 consisted of four patients discharged directly home, four to another unit within the same hospital, and four to another institution. Stage one involved a document analysis of documents related to ToC policy on the NICU. Stage two involved observation. Stage three involved interviews with healthcare professionals (HCPs) in the hospital and community (n=30) and family members (n=12). Stage four consisted of deliberative workshops with the hospital management and research participants to share the results and obtain their feedback.

Results: Including parents early in the ToC planning process helps parents feel they're a part of the interprofessional care team, in-charge of their infant's care and thus better equipped mentally to handle their infant's ToC. Knowing early on their infant's discharge plan allows parents the opportunity to ask questions regarding caring for the infant at home or to meet the new healthcare team at the new site (hospital/floor) prior to the transfer. Mechanisms need to be in place to ensure that communication regarding ToC is consistent and clear to and between all HCPs whether in the hospital (e.g. bedside nurse) or in the community (e.g. family doctor). Having a clear understanding of what information should be transferred during a ToC will prevent unnecessary tests and misunderstandings. Increasing HCPs' knowledge of available community resources will aide in transitioning infants to community care and thus freeing bed space and decreasing unnecessary costs at the hospital (i.e. A feeding and growing baby can be weighed by family doctor or Rapid Response Nurse and not necessarily the neonatologist). A consistent ToC policy across all NICUs would also be beneficial to ensuring a smoother ToC of infants.

Conclusion: It is believed that communication and education in an interprofessional context is critical for more efficient and effective ToC of neonates.

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(May 1994 – August 1994)

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List of Acronyms

CCAC	Community Care Access Centre
CDT	Community Discharge Team
CHEO	Children's Hospital of Eastern Ontario
CLSC	Centre Local de Services Communautaires
CPAP	Continuous Positive Airway Pressure
EDD	Estimated Date of Discharge
HBHC	Healthy Babies Healthy Children
HCPs	Healthcare Professionals
IPC	Interprofessional Collaboration
IPE	Interprofessional Education
IPEC	Interprofessional Education Collaborative
LHIN	Local Health Integrated Network
LOS	Length of Stay
MOHLTC	Ministry of Health and Long Term Care
NICU	Neonatal Intensive Care Unit
OHIP	Ontario Health Insurance Plan
OHRI	Ottawa Health Research Institute
OPH	Ottawa Public Health
PCMCH	Provincial Council for Maternal and Child Health
PICC	Peripherally Inserted Central Catheter
PICU	Pediatric Intensive Care Unit
REB	Research Ethics Board
RN	Registered Nurse

RRN	Rapid Response Nurse
SCN	Special Care Nursery
SPO	Service Provider Organization
ToC	Transitions of Care
TOH	The Ottawa Hospital
TTNB	Transient Tachypnea of the Newborn

Chapter One

Introduction & Literature Review

Statement of the Problem

Transitions of care (ToC), that is, the often multiple transfers patients make between health care practitioners and/or care settings during an episode of illness, are a critical element of the patient care journey (Enderlin et al., 2013). As it is a key indicator of the efficiency of the system of health services, the ease of transition of care has been a priority for improving care outcomes across all settings in Canada's health care system. It is also a critical link between the health system and the broader context of population health. Much of the current research on ToC focuses on older adults. This research has shown that older adults are at an increased risk for negative health outcomes during these transitions and that this is related to the "complex organizational practices and culture differences among settings" (Enderlin et al., 2013, p. 47). These differences include issues in communication, means of information sharing, patient education processes, medication reconciliation procedures, continuity of care services, and access to important care services post-discharge (Naylor & Keating, 2008). The ToC literature has been relatively silent on other high-risk populations including neonates. To reduce neonatal mortality it is also important to study the factors associated with neonatal morbidity. Transfers of care may be an indicator of neonatal morbidity that can be used to implement interventions aimed at improving neonatal health and survival (Mmbaga et al., 2011).

In a higher acuity unit, such as the Neonatal Intensive Care Unit (NICU), many complex care infants are admitted and their care requires the work of a number of different health care professionals. The NICU at the Children's Hospital of Eastern Ontario (CHEO), for example, admits approximately 350 babies per year, all of whom are born outside of CHEO and

transported by the Neonatal Transport Team (University of Ottawa, 2014). All babies who, in the neonatal period, require surgical procedures, complex subspecialty investigation, or who have significant congenital heart disease are admitted to CHEO's NICU. Complex chronic patients must be linked up with several community resources in order to continue their care at another unit, hospital, or home. Facilitation and coordination of this process is therefore important to assist the patient and their family once they leave the hospital. The process must also be ethically and professionally sound to health professionals, and economically reasonable to the health care system (Gaal et al., 2008; Shepperd et al., 2013).

Earlier research identified early discharge as a critical transition of care issue for the NICU (Manogaran, 2011). An early discharge refers to when an existing patient on the NICU is discharged to provide a bed for a new admission. These types of discharges carry additional risk because of both the acuity of the patients discharged and the lack of resources or preparedness at the receiving institution, home or in the community to aid in recuperation (Brooten et al., 1988). Negative consequences of early discharges include increased chances of readmission and in some cases death (Manogaran, 2011; Brooten et al., 1988).

ToC for a high-risk neonatal population, and in some cases inappropriate and early discharge, can have important implications for community and broader population health. A population health approach addresses factors outside the health care system that significantly affect health. These determinants include, and are not limited to, social support networks, physical environment, culture, and health services. Although a typical population health approach focuses on improving the health status of a population or sub-population (PHAC, 2008), the linkages between the health system and health and health care in the community – i.e., transitions between systems – is emerging as an important issue. An inappropriate discharge of

neonates back to the community without being linked to the proper resources for care may end up with their health condition worsening. As a result, the infant is re-admitted to the unit and potentially has to go through more rigorous treatment than before leading not only to suffering of the patient and his/her family, but also a higher cost for the health system.

An infant who is discharged early into the community without the appropriate connections for post-discharge care causes strain on the family. Most often, these complex care infants need multiple caregivers. For a family without a sufficient income, they might not be able to afford to pay for extra caregivers or respite care. Funding is available to assist families with obtaining this extra care. Health care professionals are aware of this funding and can assist families with applying for the subsidies – however, an early discharge might result with not enough time for the application or with the families having to go for an amount of time without help until the application is approved. Thus, it is important that the discharge planning team needs to make sure that the patient and the patient's family are connected with the appropriate resources in the health care facility and in the community prior to discharge.

Clearly, ToC are important aspects of patient care. Research shows that inappropriate discharges can lead to negative outcomes for patients and their families, health professionals, and the health system (Shepperd et al., 2013). In order for a proper transfer of care to be carried out, the discharge planning team needs to collaborate with health care professionals, community resources outside of the NICU, and the patient's family, thus increasing the need for interprofessional collaboration (IPC) in discharge planning. A previous study looking into the role of IPC in discharge planning on the NICU reported that the collaboration of all health care professionals involved in a patient's care helps to ensure that each aspect of care is covered and that the patient is well connected to the resources for his/her care post discharge (Manogaran,

2011). Each health care professional has the best knowledge on what resources are available in their field (e.g. A social worker would know best of what funding is available for respite care), and thus would play a huge role in making sure the patient is well connected.

This research examined the management of the ToC of neonates from a high-risk neonatal unit (NICU) to care back in the community from the perspectives of the parents and providers.

Research Questions

The following are the list of critical research questions that I hope to address through this study:

1. What are the historic and present structures and processes in place to enable transitions between hospitals, to the community, or to the home for infants in the neonatal intensive care unit?
2. From the perspective of health care professionals and the parents/guardians of the patients, what helps to enable or alternately poses challenges to the effective transitions or transfer of care (ToC) at the individual, professional and system level?
 - a. What are the micro-level dimensions of ToC?
 - The family's lived experience of the transfer of their infant from the NICU back to the community
 - b. What are the meso-level factors?
 - The discharge planning process (what factors enable this process)
 - c. What are the macro-level dimensions of ToC?
 - Factors that influence the discharge planning process and the experience of the family

- How do the interprofessional competencies play a role in enhancing discharge planning?

Thesis Organization

The thesis is organized into seven chapters. Chapter One provides a statement of the problem, outlines the research questions, defines IPC and ToC; examines the relationship between IPC and ToC; explores the significance of involving the patient's family in ToC planning; examines the importance of communication of all members of a team; and also outlines transition of care into the community (community/home care). The final sections of chapter one highlight the lack of studies in this area and the benefits of studying this field.

Chapter Two provides an overview of the conceptual framework guiding this dissertation and details the methodological approaches utilized for this study. Included is a discussion of the specific data sources used and the analytical technique.

Chapters Three through Six provide the specific details and findings of the analysis. Chapter Three presents how the NICU works as a system; Chapter Four presents the IPC that occurs during the different levels of transition of infants within the hospital setting via the experiences of the healthcare professionals in that system; Chapter Five presents the families' lived experience of the ToC of their infants; and Chapter Six provides the results obtained regarding ToC of infants back into the community as experienced by the community health professionals.

Chapter Seven provides a discussion of the findings and study limitations, examines the lessons learned, suggestions for ToC of neonatal patients from the NICU into the community, and the resultant contributions and suggestions for future research.

State of the Knowledge in Transitions of Care

During multiple sessions with the University of Ottawa librarian, a list of key words was used to search for qualitative studies looking at ToC of neonates in the perspective of parents and their health care providers (specifically for barriers and enablers of the ToC process). Key words from articles that best matched the research questions were used to further narrow the literature search. From the select articles that best suited this research study's purpose, I scanned the references list of each article to identify other potential articles for review.

There is a growing literature addressing ToC especially of older adults and the transition of children from a pediatric centre to an adult centre. Little research has been done to study the ToC of neonatal infants from the Neonatal Intensive Care Unit back into the community from the perspectives of health care professionals in the hospitals, community service providers, and the patient's family. This next section will start of broadly defining ToC

Transitions of Care

ToC refer to "changes in the level, location, or providers of care as patients move within the health care system" (Kim & Flanders, 2013, p. 2). As Kim and Flanders (2013) state, acute hospitalization is an important part of a patient's life and thus is important for health care providers and the patients to work together to address a myriad of issues related to the hospitalization and subsequent post-hospitalization care for a safe transition out of the hospital. The care of a hospitalized patient has changed over time. For instance, patients are sicker, the length of stay in the hospital has decreased, medical technology and knowledge have advanced,

and new models of hospital-based care have come about (Kim & Flanders, 2013). These factors have contributed to the complexity of coordinating ToC from the hospital to the community and/or home. How ToC are managed is a key indicator of the efficiency of health care services and thus effective and efficient ToC have been promoted to improve care outcomes (Fleming & Haney, 2013). It also serves as a critical link between the health system and the broader context of population health.

Key Themes in the ToC Literature

Discharge Planning

Discharge planning – a key element of transfers of care – of patients from hospital to home and/or to another hospital or unit within the same hospital is a complex process dependent upon a number of health care professionals and the patient/patient family, working collaboratively together to ensure the best outcome for the infants (Shepperd et al., 2009). It is a challenging process for health care professionals, patients, and caregivers as they are working towards connecting the patient with the appropriate resources within a short timeframe (Wong et al., 2011).

The transition of patients from a hospital to a post-discharge health care, residential or home setting has potential to disrupt continuity of care and may increase the risk of the occurrence of an adverse event due to an inadequate planning of a patient's discharge (Kripalani, 2007). The literature identifies several issues with discharge planning which need to be addressed. The challenges to efficient discharge planning will be discussed below as they apply under system factors, professional factors, and patient factors.

System Factors

Some of the key themes present in the literature that are influences to discharge planning at the system level include early/inappropriate discharge (pressure on bed availability), issue of readmissions, and a lack of guidelines or policies for standard discharge.

Lack of Guidelines and/or Policies for Standard Discharge

Having a clear guideline or policy outlining the steps that should be taken during discharge planning could ensure a smooth ToC of patients. Wong et al. (2011) identified a lack of guidelines/policies for standard discharge as a barrier to transfers of care. Wong et al. (2011) used a phenomenological approach and conducted focus groups with 41 healthcare professionals to explore the perceived quality of current hospital discharge from the perspective of healthcare professionals and identify facilitators and barriers of the discharge planning process. Based on this study, they reported that their study participants reported that when there was a slight change in the normal discharge process, there was no alternative protocol in place to take care of that change and thus there was a halt or negative outcome in their discharge planning process. For instance, the doctor was always the lead of the discharge planning process. When the doctor was away, the participants identified no protocol in place allowing the nurse to take over (Wong et al., 2011). The study by Manogaran (2011) also reported no protocol set in place to deal with an emergency discharge. Having a protocol or a set of guidelines available for the different contexts may help to ease the discharge planning process.

Early/Inappropriate Discharge & Pressure on Bed Availability

Pressure on bed availability has been identified as another barrier to successful transfers of care. In their study, Wong et al. (2011) reported that their study participants expressed premature discharge as one of the major inhibitors to discharge. Many patients reported having

short hospital stays and early discharges due to this pressure, which was a result of limited number of beds in the hospital (Wong et al., 2011).

Issue of Readmissions

Effective discharge planning could significantly improve a patient's health and reduce patient readmission. There is evidence to suggest that discharge planning combined with additional post-discharge support can reduce unplanned readmission to hospital for patients with congestive heart failure (Phillips, 2004). Shepperd et al. (2013) conducted a systematic review of 24 randomized control trials to determine the effectiveness of planning the discharge of individual patients moving from hospital. Here they report that a reduction in readmissions will decrease inpatient costs. The United States of America reports that 42% of their national health care budget is spent on inpatient care, and readmissions account for one quarter of Medicare inpatient expenditure (Anderson & Steinberg, 1984). A small reduction in readmission rates could have substantial financial impact on the health care system (Shepperd et al., 2013).

Professional Factors

Some of the key themes present in the literature as barriers to discharge planning at the professional level include insufficient communication among health care disciplines, poor communication amongst health care professionals and the community, unclear role of each discipline, and incomplete chart documentation. This section will also analyze the importance of IPC and its role in discharge planning.

Poor Communication Among Health Care Disciplines

Poor communication between health care providers was stated as one of the top reasons for unsuccessful discharges from the hospital (Shepperd et al., 2013). Health care professionals agreed that open communication was essential for successful patient discharge (McKenna et al.,

2000; Manogaran, 2011). Open communication allows for the easy transfer of ideas and opinions between the different health care professions (Hansen, Bull & Gross, 1998; McKenna et al., 2000). It also helps to avoid missing any important information regarding the health of the patient who is being taken care of by the interprofessional team (Watts et al., 2006). Bull and Kane (1996) found that inadequate communication was a fundamental source of discontinuity in discharge planning. Inadequate communication led to gaps in information transfer, redundancies and errors that impeded the effectiveness and efficiency of care delivery (CIHC, 2010).

Unclear Role Definitions

Role clarification is an important element for successful discharge planning (Wong et al., 2011; Manogaran, 2011). Understanding how professional roles and responsibilities complement each other in patient-centred care (IPEC, 2011) is crucial for efficient IPC. Health care professionals need to clearly articulate their roles, knowledge, and skills within the context of their clinical work (CIHC, 2010). This helps individuals or health care professionals to determine who has the appropriate knowledge and skills to address the specific needs of patients or clients. This allows for the “right mix” of health care professionals and ensures a more equal distribution of the work load (Suter, et al., 2009). According to the Interprofessional Education Collaborative (IPEC) (2011), being able to explain what other professionals’ roles and responsibilities are and how they complement one’s own is more difficult when individual roles cannot be clearly articulated. The IPEC also highlights that recognizing the limits of professional expertise, and the need for cooperation, coordination and collaboration across the professions is necessary to promote health and treat illness. Effective coordination and collaboration depends on whether each profession knows and uses the others’ expertise and capabilities in a patient-centred way.

Incomplete Chart Documentation

Studies by McKenna and colleagues (2000), Atwal & Caldwell (2002), Wong et al. (2011), and Bull & Kane (1996) reported on the issue of poor discharge documentation by health care professionals. It was reported that on many hospital units the various health care professionals opted to have their own set of discharge notes (McKenna et al., 2000). This leads to confusion, repetition of information, and loss of important information (Atwal & Caldwell, 2002).

Because the discharge team is often in a hurry to discharge the patient, there is the potential for the documentation of other professionals to be left out by the health care professional in charge of the discharge (McWilliam & Sangster, 1994). This often leads to the professional in charge of the discharge missing out on important information that could potentially influence the decision to discharge. Multiple discharge documentation also results in the patients being asked for the same information repetitively by different health care professionals (Bull & Kane, 1996). This proved to be frustrating for both the patients and their caregivers.

There is a need to create a standard discharge-planning document that should always be present in the patient's hospital chart. All the health care professionals who are involved in the patient's care should make sure that any notes regarding discharge planning should be recorded on that document and nothing else. Having a standard discharge documentation process will definitely help to eliminate these problems (Bull & Kane, 1996).

Importance of Interprofessional Collaboration

The World Health Organization (WHO, 2010) has identified Interprofessional Collaboration (IPC) as an innovative strategy that will strengthen the health workforce for future generations. Policy-makers are recognizing that a strong, flexible and collaborative health

workforce is one of the best ways to deal with highly complex health challenges such as epidemics of HIV/AIDS and/or tuberculosis, spiralling health care costs, natural disasters, ageing populations, and other global health issues (WHO, 2010).

In a paediatric health-care setting, IPC refers to “the continuous interaction of two or more professions, organized into a common effort to solve or explore common issues with the best possible participation of the child and family” (SickKids, 2005). IPC and interprofessional education (IPE) were recommended by the Romanow Report (2002) as an important area for research. The report identifies that new environments and new divisions of labour require new approaches to collaboration among health care providers in order to maximize the use of the health workforce (Romanow, 2002).

Research demonstrates some positive outcomes for patients/clients, providers, and the health care system when IPC is implemented. Positive outcomes for patients/clients include and are not limited to enhanced patient self-care, better access to health care, shorter wait times, and improved outcomes for patients with chronic diseases (Barrett et al., 2007; ICSIC, 2010). Barrett and colleagues (2007) identify increased knowledge, enhanced provider satisfaction, and decreased tension and conflict amongst caregivers as benefits for providers. The overall health care system also has its benefits from implementing IPC. These include and are not limited to decreased provider and patient costs, lower readmission rates, better use of clinical resources, easier recruitment of caregivers, and lower rates of staff turnover (ICSIC, 2010).

IPC for Discharge Planning

It is important for all health care professionals involved in a patient’s care to efficiently work collaboratively in order to facilitate a successful discharge (Hansen, Bull & Gross, 1998). IPC requires health care providers to use a broad range of skills, including both those specific to their clinical area of expertise and more general skills, such as communication. In her study on

IPC and discharge planning, Pethybridge (2004) reports that good team working, leadership and communication are vital to the success of good discharge planning. Poor communication during discharge planning can potentially negatively impact the post-discharge outcome for patients and families (e.g. re-admissions, increased costs for the health care system) (Hansen, Bull & Gross, 1998).

A number of studies identified strengths when interprofessional rounds were implemented in a health care institution. For example, Halm et al. (2003) demonstrated that the introduction of interdisciplinary rounds resulted in a greater participation by all disciplines in achieving patient and family outcomes, increased early recognition of patients at risk, and improved communication among members of the health care team. Baker and Wellman (2005) reported that having the different health care professionals take part in the discharge planning process has given rise to positive outcomes given the responsibility of each interdisciplinary team member to have knowledge of the community resources within their field. These studies clearly support that IPC results in positive patient outcomes.

Poor Communication Amongst Health Care Professionals and the Community

Inadequate communication between the secondary care and the post-discharge setting also serves as a barrier to successful discharge planning. Poor communication can result in key clinical information not reaching primary care providers and patients remaining unaware of information that might help them manage their condition and prepare for discharge from hospital (Shepperd et al., 2013). If the caregiver receiving the transfer is not fully aware of the patient's health condition or his/her needs this can result in the patient not receiving the proper care they need which will affect their health condition and ultimately lead to readmission back to the unit from where they came from (Wong et al., 2011). Goldman et al. (2016) used an ethnographic approach to conduct observations, interviews, and document analysis to obtain an in-depth

insight into HCPs' perspectives, behaviours, and interactions regarding discharge in a General Internal Medicine Unit. This study reported that problems with communication and discharge have been attributed to professional hierarchy and insufficient contact among professionals. Proper communication amongst the health professionals from the hospital and the community is crucial to ensure that patient information is transferred successfully and that the patient is connected with the resources needed to continue their care in the community.

Patient Factors

Some of the key themes present in the literature as barriers to discharge planning at the patient level include lack of knowledge and poor communication between health professionals and the family.

Lack of Knowledge

Lack of knowledge of the patient and/or patient family about their care process or the discharge plan that is being created is another barrier to successful discharge planning. Browne and Talmi (2005) used randomized control trials with 84 high-risk mother-infant dyads to examine how family-based interventions in the neonatal intensive care unit may change parental knowledge and behaviours and decrease stress. This study reported that educational interventions provided for the mother prior to the infant's discharge was effective in increasing knowledge, changing maternal behaviours, and most importantly, decreasing maternal stress. Helder et al. (2012) used an explorative study to conduct semi-structured interviews with parents and critical care nurses. In this study they also reported that parents experienced less stress when they were well informed in advance. Educating the family on the patient's care is crucial to assisting parents of babies in the NICU, who must cope with the unexpected birth complications of their child, be able to provide the care needed, and seek resources.

Poor Communication between Health Professionals and the Patient

The communication between the patient and his/her health professional is extremely crucial to the successful discharge planning and continuity of care (Wong et al., 2011). Studies stress that information for each patient must be tailored to the patient's communication ability to ensure that the patient is well informed about their care. It is not always the case that the patient or patient family has the language or vocabulary to communicate with the health professional (i.e. a new immigrant family may not know the language of correspondence). In such a case it is important for health professionals to take the steps necessary to ensure that they are able to communicate clearly with the patients (i.e. through an interpreter). By doing this, health professionals can ensure that they are creating a discharge plan that is beneficial to the patient and/or the patient family (Wong et al., 2011; Manogaran, 2011). Having thorough communication with the patient and/or patient family will help the family to feel secure and confident in the care that they will receive or provide post-discharge and will decrease any anxiety associated with this move out of the hospital (Ackermann, 2012).

What We Know About ToC for Neonates

ToC for neonates from a high-risk clinic to the community can also have important implications for the community and the broader population. This link between health systems and health care in the community is emerging as a new and important issue. Infants who experience early or inappropriate discharges are often not well connected to resources in their community prior to being discharged (Shepperd et al., 2013; Manogaran, 2011). When the community is not prepared to take care of this sick infant who is suddenly thrown at them, it increases the chances of the infant's health condition worsening and ultimately readmission back

to the NICU (Enderlin et al, 2013; Shepperd et al., 2013). Usually this occurs when there is insufficient communication between the health care providers at the NICU, the primary care physicians to whom care of the infant is being transferred, and the infant's family members. This leaves the health care providers, to whom care is being transferred, and the infant's family in the dark about how to care for this infant – ultimately jeopardizing the infant's condition.

Research supports that early or inappropriate discharges can lead to negative outcomes for the patient and/or patient family, the health professionals, and the system (ICSIC, 2010; Barrett et al., 2007; Shepperd et al., 2013). It is important that the discharge planning team collaborates with health professionals in the community (i.e. primary care physicians), and the patient's family to ensure that a proper transfer of care is carried out. This supports the need for IPC in discharge planning.

A previous study conducted on a NICU supported pressure on bed availability as a barrier to neonatal ToC. In this study, the health care professional staff respondents who were interviewed identified a barrier to discharge planning - an emergency situation on the unit. By emergency, they referred to a new admission on to the unit who needs to be admitted immediately in order to provide care for that infant (Manogaran, 2011). Without admission immediately onto the NICU, that infant may be at risk or unable to receive the care that they need. In order to admit this newborn in the NICU, however, an existing NICU patient must be discharged to make a bed available for the new patient (Manogaran, 2011). So, the most stable infant is identified and prepared for discharge to an appropriate bed within the hospital or to another hospital for further care. In this case, the pressure is on the medical team and the discharge coordinator to discharge an infant when the need arises in an emergency situation as defined. Rarely are other members of the team involved in an emergency discharge and thus

important information about the patient's care may not be relayed ultimately affecting the overall discharge plan (Manogaran, 2011).

Lack of Studies on the Patient Discharge or Transfer process for Infants and Children

It has been found that the majority of studies on discharge planning were focused on the discharge of elderly patients back to their home (Baker & Wellman, 2005; Corser, 2004; Day, McCarthy & Coffey, 2009; Fairhurst et al., 1996; Gair & Hartery, 2001; Hansen, Bull & Gross, 1998). The studies that were reviewed did not focus on the discharge planning for infants or children. The needs of children and infants are different from the needs of the elderly. Most elderly patients that are transferred back to the home are capable of some forms of self-care if not all. Infants and children depend more on their caregivers and thus the focus shifts to what services their parents or mothers will draw upon for their care. Moyer et al. (2014) explain the paediatric population differs from their adult population in their absolute dependence on parents/caregivers, and the neonatal population has the additional distinction of having no prior relationship with a primary care provider.

Moreover, studies conducted on ToC are largely conducted in European and American health care system and population health contexts. It is important to study the role and importance of IPC in discharge planning in Canadian hospitals. The health care systems vary nationally and provincially in terms of funding structure, the delivery model, etc. (Deber, Gamble & Mah, 2010). These factors definitely can influence how IPC is carried out in the different contexts. Since the health care delivery in other countries is different from the Canadian health care system, their results may not always be applicable to our system.

Summary of What is Known and What is Unknown

Taken together, these studies support that IPC is an important concept that plays a huge role in the outcome of the discharge planning process. Many health care workers today were trained in silo educational programs, which worked effectively for the development of a professional identity but not for collaborative practice and ultimately patient-centred care. Thus it is important to study the factors that affect IPC and use the results of this study to help professionals to work towards collaborative and effective teamwork.

The majority of the studies that were reviewed in this literature review tended to use a phenomenological approach as the methodological approach in their studies. Even though there were a few studies using an ethnographic approach, there was a lack of studies using institutional ethnography as their methodological approach. In terms of data collection methods, interviews, focus groups, and questionnaires were the most popular tools used to gain insight. In addition to this, the studies reviewed tended to focus on the experience of one level (e.g. Wong et al. (2011) studied the experiences of healthcare professionals) or a limited population (e.g. Helder et al. (2012) studied the experience of parents and critical care nurses only). There was a lack of studies that studied how different levels (i.e. the system and professional levels) influenced and/or was experienced by another level (i.e. the patient/individual level) and/or the interplay between these three levels to identify where critical breakdown points occurred in the process. Another issue to note was the lack of studies in the Canadian context. The majority of studies on the transitions of care of neonates were from the United Kingdom, Australia, the United States, and Asia (specifically Japan), which are all well known for their integration of collaborative services into their healthcare systems. Even though the studies from these countries are helpful in terms of observing what other institutions have done to tackle issues around transitions of care of neonates, it is important to have studies in the Canadian context as the healthcare systems are

different and not all findings from these non-Canadian studies are applicable to our context/setting.

From the literature review many of the studies on ToC were focused around the elderly population and how they are particularly vulnerable to breakdown in care and thus have the greatest need for transitional care services. There is some literature on paediatric ToC but that too was more focused on the transition of youth from children to adult care. Very little literature is available on the ToC of neonates from the NICU to the home/community in the perspective of the parents and the HCPs in the hospital and community. Discharge planning for infants and children should be studied as infants and children are completely dependent on their caregivers for care and thus planning a discharge for them, unlike for adults, requires more extensive and careful planning to ensure all their needs are met. It is recommended that a study be conducted looking at the role of IPC in terms of discharge planning for children to home and/or other hospitals. Table 1 highlights the knowledge gaps in the ToC literature.

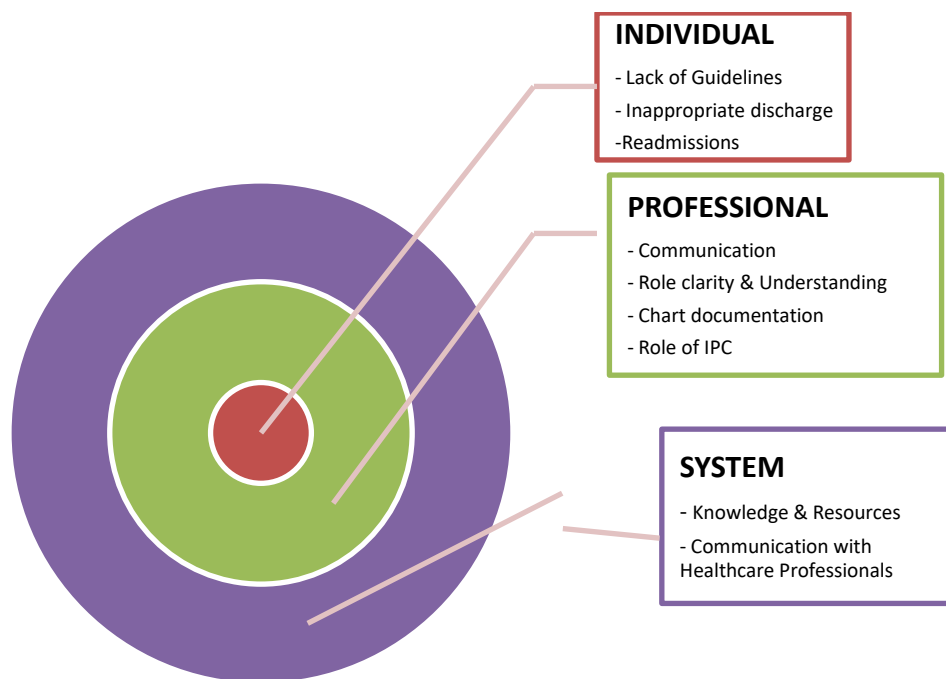
Table 1. Knowledge Gaps in ToC

	What we know	Knowledge Gaps
SYSTEM LEVEL	• Discharges from the hospital to the home have been studied for the elderly population	• Transitions between hospitals and/or units for infants and children
	• Transitions form a crucial part of a patient's care – stress and anxiety are associated	• How can IPC as a means of care ease the transfer of care and associated stress and anxiety?
PROFESSIONAL LEVEL	• IPC plays huge role in the outcome of the patient care	• How to integrate IPC competencies into the discharge planning process
	• Good team working, leadership and communication are vital to the success of good discharge planning.	• What resources are out there which support these essential aspects?
INDIVIDUAL/PATIENT LEVEL	• Transfers of care occur frequently on a NICU (frequent turnover)	• How can families be involved in the discharge planning process?

Conceptual Framework

Based on this literature review, a conceptual framework that outlines the System, Professional and Individual level factors influencing ToC was created. The subthemes within each level have also been identified. The conceptual framework was informed from a broader multi-layered population health framework (Dahlgren and Whitehead, 1991) and underpins the social determinants of health framework, which teases apart the layers of the relations of ruling: System (macro), Professional (Meso) and the Individual (micro) levels. It presents in particular the system and professional levels and how they are experienced at the micro (individual) level. Figure 1 provides an overview of this conceptual model.

Figure 1. ToC Conceptual Model.



CHAPTER 2

Methodological Approach

A sequential, qualitative methodology was employed in this research. Qualitative research methods are valuable in providing rich descriptions of complex phenomena (Sofaer, 1999). It is also valuable in tracking unique or unexpected events, illuminating the experience and interpretation of events by key stakeholders with widely differing roles, explore and develop theories, and generate explanations (Sofaer, 1999). This study was carried out in a staged approach (i.e. in sequence) where one stage followed another with each stage building upon the previous one.

This project comprised of four stages. Stage one involved a document analysis (collection of artifacts) to provide background information on all of the research questions. Stage two involved data collection through observation. Stage three involved the conduct of interviews with health professionals and family members. Finally, Stage four involved a series of invited workshops with the health care professionals and relevant stakeholders to share the results collected from Stages two and three and to obtain their comments and feedback on the results obtained. The overarching methodological approach was institutional ethnography, described in detail in the next section.

Methodological Approach

An institutional ethnographic approach was chosen as the methodological approach to frame this qualitative study. Institutional ethnography refers to an approach to investigation of the social that focuses on “textually-mediated social organization” (Smith, 1990). Institutional ethnographies are created from the study of work processes and look at how they are

coordinated, typically through texts and discourses of various sorts (Devault, 2006). Main methods of data collection in institutional ethnography include observations, interviews, and the collection of documents for text analysis (Campbell, 2013). The analytical goal of institutional ethnography is the “discovery and description of the specific organizational practices that make a setting ‘work’ as people know it, do it, and talk about it” (Campbell, 2013, p. 500). During institutional ethnography, researchers look out for what informants do and what comes of it. They attempt to answer questions such as (Campbell, 2013):

- a) What are the people in this setting doing?
- b) How do they know what to do?
- c) What coordinates their work?
- d) What texts do they consult?
- e) Where did that text originate and from whose hands did it travel?

The purpose of this method is to shift the focus of research away from questions related to administrative concerns and objectified knowledge, towards the puzzles of peoples’ everyday lives (Campbell, 2013).

Dorothy Smith developed institutional ethnography as an alternative sociology, which unlike mainstream sociology, does not use theory in research. Smith (2005) says that using a theory in research establishes “the knower’s discursive position as transcending the everyday worlds of people’s experience” (p. 50). The highlight of institutional ethnography’s inquiry is that it addresses a puzzle or problematic which is discoverable in people’s own experiences in their everyday situations and does so from the perspectives of these people (Campbell, 2013). Institutional ethnographers start their research with the aim of keeping it “outside of academic

theories, professional discourses and administrative categories...because all these may become objects of analysis” (McCoy, 2007, p. 702).

The kind of knowledge that institutional ethnography produces is ones that makes visible the order in which individuals participate in and confront those who are directly involved in it (Campbell, 2013). How the order is put together is described and analysed due to the ethnographic nature of the research. For those who struggle with not knowing how their system works, knowledge of their system is invaluable. In the case of health care institutions, studying how people enact the system allows us to see the system “in motion” and to explore its operation as a social organization (Campbell, 2013).

The range of institutional effort is what establishes how any participant in the system, such as policy makers, administrators, health care professionals, or health care recipient, is expected to and does frame their respective health-related actions (Campbell, 2013). The management of such a system is both information-based and text-mediated thus to analyze health care problems, it is crucial to understand how these texts facilitate the actions of health care personnel (Campbell, 2013). Many stakeholders such as politicians, product and service promoters, scientists, administrators, and professional practitioners make claims about how the healthcare system works when in reality, the truth of how it actually works is “hidden in (or behind) a proliferating mass of information” (Campbell, 2013, p. 499). Institutional ethnographers play a key role here by using their social organization of knowledge approach into these institutions to design and conduct studies that illuminate how things “actually work”.

Studying a problematic that is present in the everyday lives of people requires the focus of the researcher to be directed in a particular way. The institutional ethnographer must attempt to learn about the social world of actual settings from the people living and working in the

particular setting (Campbell, 2013). Institutional ethnographers examine how people's ordinary doing are hooked into the work of institutions, which is "not directly observable from within the everyday" (Smith, 2005, p. 39). Central to institutional ethnography's analysis of any institution is discovering how people's activities are coordinated. It is crucial for those individuals who work in institutions to know what to do by learning how to work in "institutionally correct" ways to take appropriate action even when policy changes and shifts in situations occur (Campbell, 2013, p. 500).

Institutional ethnography also focuses on ideology and the relations of ruling. According to the Marxist notion of ideology, the ideas and images of the ruling class are the ones that become dominant in culture because this ruling class own the productive apparatus of society (Murphy, 2006). These ideological notions become ordered and rooted into our deep consciousness (Murphy, 2006). In other words, the messages are hidden, persistent and frequent enough that people essentially spit them out without any prior independent thought. In order to understand the relations of ruling, it is important to understand the ideological context. For the ruler to rule, it would be easier if the subordinates would inherently accept the ruler's version of the world as legitimate and dismiss or suppress their own (Murphy, 2006). In the case of this study, the same sort of ideological context can be seen between the healthcare professionals (hierarchy within the profession), between the healthcare professionals and the patient's families as those being ruled, and finally between the mothers and fathers. Clashes in this relation of ruling can be due to a variety of factors such as educational status, previous experience, cultural values, etc. Smith critiques mainstream sociology to implicitly or explicitly adopt male-centred approach that supports the governing conceptual model (Smith, 1990). Smith argues that social science should focus more on the everyday experiences of people, especially those of women

and other individuals who may be in subordinate positions to society (Smith, 1990b). According to her, “All knowledge is knowledge from a particular standpoint and what which has been claimed as objective knowledge of society conceals a male bias” (Farganis, 2000, p.371).

For this study, before deciding on using the institutional ethnography approach I had considered using a phenomenological approach or a case study approach. The phenomenological approach was considered, however, I decided not to go ahead with this as it focused solely on analyzing the lived experience by way of narratives and does not allow for focus on the other levels/factors, which may affect the lived experience (in this case the system and professional levels). In terms of case studies, which are generally in-depth studies of one or a few individuals, I decided not to use this approach as it does not allow for investigation outside of the case (again, would not allow for the study of the system and how the system can play a factor in the lived experiences of the cases).

The analytic goal of institutional ethnography is “discover and description of the specific organizational practices that make a setting ‘work’ as people know it, do it, and talk about it” (Campbell, 2013, p. 500). In the case of this research, institutional ethnography was used to help understand how the NICU works as a system in terms of transitions of care (system and professional level) and how this system is experienced first hand by the parents of the neonates (micro).

Research Site

This research project took place in three NICUs at three large Canadian teaching hospitals in Ontario. One unit is a tertiary care NICU with a 14-bed capacity, the second unit is a tertiary/secondary care NICU with a 24-bed capacity and the third unit is a secondary NICU with a 15-bed capacity. There are approximately 450 to 800 admissions per year (See Table 8 in

Chapter 3). In a higher acuity unit, such as the NICU, many complex care infants are admitted and their care requires the work of a number of different health care professionals working collaboratively to ensure the best outcome for the infants. Thus due to the nature of the unit, it is important to have a discharge plan that is efficient, less time-consuming, and beneficial to staff and patients on the unit. Chapter three of this dissertation goes into more depth to map out the context more fully.

Research Ethics

Approval for this study was obtained from the research ethics boards at the University of Ottawa, the Children's Eastern Hospital of Ontario (CHEO), and the Ottawa Health Research Institute prior to commencement of the study (See Appendices I, II, and III respectively). The study went through several amendments after the commencement of data collection and approvals were obtained from all three research ethics board each time.

Stage 1: Document Analysis

Document analysis is a form of qualitative research where documents are analyzed and interpreted by the researcher to give voice and meaning around a topic (Green & Thorogood, 2010). Documents that can be included in a document analysis include public records (i.e. policy manuals, handbooks, strategic plans, etc.), personal documents (i.e. emails, calendars, etc.), and physical evidence (i.e. flyers, agendas, etc.).

Data collection during this stage included document analysis, a data accounting log, and a contact summary form. The document analysis involved the collection of documents that were passed to the family members of the cases being followed, between health care professionals,

and flyers and posters related to ToC around the unit. The documents collected were scanned with a focus on content for analysis of the data to categorize the recurrent or common themes (Prior, 2008). Other factors that were explored during the document analysis included how the document came into being and how it was being used.

The researcher used a data accounting log to keep a record of each patient's journey from admission to discharge from the NICU (See Appendix IV). A data accounting log is a management method that documents when and what types of data have been collected from specific participants and research sites (Miles et al., 2014). This type of log is highly recommended for all qualitative studies as a method of good record keeping and management (Miles et al., 2014). This data accounting log recorded data regarding each infant's discharge process such as the number of health care professionals who were a part of the infant's care, any documents that were given to the patient's family, who they had contact with regarding their child's transition, the number of appointments, and the number of transfers the infant experienced within the hospital or amongst hospitals. This data accounting log also kept track of the health care professionals interviewed and the pre and post family member interviews.

Data Analysis

A scan of the data accounting log provided an outline of the data collection in progress and, towards the end of the study, the "completed corpus record" (Miles et al., 2014, p. 124). The log was used to look for patterns in the observations that were of interest and to suggest additional forms of data needed or that should be collected. The data accounting log was used to keep track of the entire research process.

Stage 2: Observations

Observations provide an opportunity for the researcher to collect data that does not just rely on what people say they do but drawing on evidence of events first hand (Denscombe, 1998). The purpose of the observations in this study to give the researcher an opportunity to learn about the workings of the unit, how transitions or ToCs occur or are planned, and the policies and practices that are associated or affect ToC. During the observations stage of this research, the researcher was introduced by the Nurse Managers at CHEO and The Ottawa Hospital (TOH) General and Civic Campuses to the NICU team through an email outlining the study purposes and informing them of the researcher's observatory role. The team members were made aware that if they did not wish to be observed or to have their comments be a part of the observation data, to inform the researcher directly at any time throughout the study period. The parents involved in the study were also made aware of the study. The parents of the cases being observed and the health care professionals who were a part of the infants' care were required to sign a consent form prior to the start of the project. The Hawthorne effect was of concern in my study as there was an observational component. Even though it is difficult to account for this barrier, I tried to overcome the Hawthorne effect by taking observation notes after participating as an observant for a month. The purpose of doing this was to allow the participants to become used to seeing me in the room and to become comfortable with having me present.

Three cases of infants identified as either acute or chronic patients, were observed from their admission to discharge. The three types of cases included infants who were discharged: a) from the NICU to another unit within the same paediatric hospital, b) from the NICU to another hospital, and c) from the NICU to home. As the aim of this research was to study the ToC of neonates, the sampling frame was chosen to encompass the range of transitions that occur within

the Ottawa NICU mesosystem. These three types of cases were chosen as the sampling frame as these were the only possible ways the infants could be transferred out from the CHEO NICU. These 12 cases were observed from admission until their discharge into the community or to home (See Table 2 below). The unit for observation identified potential infants falling under these case categories. The neonates were recruited from the tertiary-level NICU. Infants who were excluded from the study included:

1. Infants who were transferred to a hospital outside of the 3 hospitals included in this study
2. Palliative infants
3. Infants without a clear path home within study time period (for purpose of completion of thesis)
4. Parents who were unable to communicate in English.

Table 2. Sampling Frame for Recruitment of Transfer Cases.

	Case	Case	Case	Case
Home	X (June 17, 2015) Case 3 – ACUTE 2/2 HCPs interviewed	X (Sept 1, 2015) Case 4 – CHRONIC 4/4 HCPs interviewed	X (Oct 30, 2015) Case 5 – ACUTE 4/4 HCPs interviewed	X (Oct. 31, 2015) Case 6 – CHRONIC 4/6 HCPs interviewed
Floor (CHEO)	X (Sept 8, 2015) Case 2 – CHRONIC 6/12 HCPs interviewed	X (Feb 5, 2015) Case 8 – CHRONIC 6/10 HCPs interviewed	X Case 11 – CHRONIC 4/7 HCPs interviewed	X Case 12 – CHRONIC 5/8 HCPs interviewed
TOH (General/Civic)	X (June 21, 2015 from Civic) Case 1 – ACUTE 4/7 HCPs interviewed	X Dec 15 → Civic Dec 21 → Home Case 7 – ACUTE 5/7 HCPs interviewed	X Feb 11 → General Feb 23 → Home Case 9 – ACUTE 4/6 HCPs interviewed	X Feb 18 → General Feb 21 → Home Case 10 – CHRONIC 5/8 HCPs interviewed

The researcher used a Contact Summary Form (See Appendix V) to collect data during the observations. This form assisted with jotting down the main themes or issues that surfaced during the observations and answers to any informal interviewing by the researcher (Miles et al., 2014). This document assisted in recording any issues that arose during the discharge planning (e.g. infant ready for discharge but no bed spots available in hospital near to infant's home, any policies restricting care, etc.).

Data Analysis

A thematic analysis of the observation notes charted in the contact summary forms was performed. Here, the observation notes were uploaded onto NVivo and the notes were analysed for major themes that stemmed from the observations. These themes included ToC-related communication, facilitators and barriers to the ToC, ToC-related documents, and any issues that arose during the transitions. These themes linked back to the conceptual framework, which analyzed the actual experiences of ToC of the infant's family and the healthcare professionals. These observation notes from the contact summary forms were used to assist with the identification of potential health care professionals for interview in Stage three of the study.

Stage 3: Interviews

Following the participant observations in Stage two, interviews were conducted concurrently with health professionals and mothers/fathers. Interviews in qualitative research methods help to obtain answers to questions on a broader level (Kumar, 1989). Interview participants were able to expand on observations from Stage two of this study in a more significant way by providing examples and sharing their experiences to illustrate their main point

(Kumar, 1989). Therefore, interviewing key participants on the NICU helped to further understand the data obtained from the observations.

Health Professional Interviews

The health care professionals involved in the care of the 12 cases were interviewed individually. Key stakeholders included health care professionals of the discharge planning team on the NICU, from the receiving hospitals and units, and from the community (See Table 3). Because these key stakeholders are the major players in the discharge planning process, it is believed that they will provide the most valuable information in regards to the current discharge planning protocols on the NICU as well as where they feel there are gaps in the process.

Table 3. Health Professional Participants Sample

Medical Staff	Nursing Staff	Health care Professionals Staff
• Physicians • Residents • Fellows • Nurse Practitioners	• Nurses (RNs, CSNs, NMs)	• Respiratory Therapists • Social Workers • Occupational Therapists • Dietitians • Pharmacists

Selection of individuals not part of the cases' care teams for interview was based on their specific area of expertise to ensure fair representation of professionals on the unit. These healthcare professionals were also targeted based on the degree of their participation in the rounds and in the overall discharge planning process (e.g. if it is observed that social workers contribute less during the discharge planning discussions in the IPC rounds, they will be interviewed to obtain a deeper understanding of their behaviour).

The interviews were semi-structured with questions appropriately targeted to the part of the discharge process that was relevant for the particular stakeholder. Semi-structured qualitative interviews are appropriate in this study design as they help to understand the meaning

of events or phenomena occurring in the setting (Bourgeault et al., 2013). Qualitative interviews help to seek the views of the individuals present in the setting about the phenomena of interest. In a semi-structured interview, the researcher works from a more or less determined list of question areas and probes (Bourgeault, et al., 2013).

Interview questions asked health care professionals interviewed about (and not limited to) their views on a) IPC, b) role clarity, c) information-transfer, d) conflicts, e) inclusion of the patient's family in the discharge planning process, and f) the overall discharge planning process. The interview questions addressed key topic areas identified in the research questions noted above. The interview guide was open-ended to allow for the discussion and exploration of new themes as well as to allow for discussion relevant to key informant being interviewed (See Appendix VI).

The sample size for the interviews was purposive and was based on the cases observed and on a consideration of variability in the sample and saturation. Samples in qualitative studies are usually not fully preselected but can evolve once fieldwork begins (Miles et al., 2014). In this study, the sample started off with the 12 cases and all the healthcare professionals who were a part of their care (each individual healthcare team) at the CHEO NICU and at the other sites where the infants were transferred. Later, other healthcare professionals were added to the sample to account for variability and to make sure that no one profession was left out. Some specific individuals were approached to be a part of the sample as they played an important role in the ToC of the neonates on the NICU (e.g. Nurse Managers). The types of roles that the different providers play will be conceptualized and the researcher will aim for saturation within these groups.

These key informants were invited to take part in the interview through e-mail or by telephone; in some cases, in-person. Consent to participate in the study was obtained from all healthcare professionals during in-servicing sessions (See Healthcare Professional Consent Form in Appendix VII). During these in-servicing sessions, the researcher went over the consent form by presentation and those who consented were able to return their forms right away. Prior to any interviews, the researcher crosschecked with a list of pre-consented individuals to ensure that the key informant signed a consent form during the in-servicing sessions. For those who did not (most likely because they were not present at the in-servicings), the consent form was sent by e-mail in advance to key informants and was also available at the time of the interview. They were completed and returned prior to the interview. Interviews lasted between 30 to 60 minutes in length and were conducted largely in person. All interviews were digitally recorded with the permission of the interviewee and later transcribed. In addition, concurrent note-taking occurred. This provides the researcher with an alternative record and memory trigger if parts of the audio recording are unclear (Bourgeault et al, 2013). Depending on the themes that arose from analysis of the interview data, some key informants were approached for a second interview to obtain further detail.

Family Member Interviews

The parents or guardians of the 12 cases observed were interviewed pre and post-discharge to obtain their views and opinions on their infants' transitions of care experience. These interviews were conducted concurrently with the health professional interviews. The data collected from these interviews with the parents or guardians were also used to help identify health care professionals to interview. A total of 13 parents were interviewed pre-discharge. When possible, mom and dad were interviewed separately to allow for a comparative analysis.

Interviewing the parents separately allowed for a gender analysis to see if there was a difference in their lived experiences. The interviews were semi-structured to allow for some questions to arise from the interview process.

The interview questions asked the parents or guardians for information on who approached them to discuss their child's discharge plans, what support were they given along the way, how comfortable they felt contributing to their child's discharge plan (or if they were encouraged to do so), and their overall view of their discharge experience (See Appendix VIII). The parent or guardian pre-discharge interview guide was open-ended to allow for new and important themes for discussion.

Interviews lasted on average 60 to 90 minutes and were conducted largely in person and alternatively by telephone depending on the convenience of the parents/guardians interviewed. Research reports that telephone interviews have much lower response rates than in-person interviews (Green et al., 2001). As these parents were busy with work and having to travel back and forth to visit their infant or for their infant's care, it made it difficult to be able to catch them at a good time over the phone for an interview. In addition to availability, telephone interviews are undesirable to parents as they are unable to reassure themselves of the identity of the interviewer – something that is not desirable during their stressed state (Green et al., 2001). During this stage of the research, every attempt was made by the researcher to conduct interviews in person with the parents of the 12 cases. The interviewer approached the parents through the care facilitator, bedside nurse or physician so that the parents were assured that the researcher was a "safe" individual. The researcher met with the parents a couple of times at the bedside prior to booking their interview so that the parents felt safe and comfortable with the

interviewer. As with the health professional interviews, these interviews were digitally recorded for later transcription and the interviewer took detailed notes.

As part of this research study, the same parents were approached to participate in a post-discharge interview to obtain a fuller perspective of the process. A total of 13 parents (see Table 4) were interviewed post-discharge. Interviews were semi-structured and allowed for questions to be asked about a) the parents' overall discharge experience, b) their contribution to the discharge plan, and c) if they felt any improvement in the discharge process was needed (See Appendix IX). These interviews were conducted in-person or by telephone depending on the convenience of the parents/guardians. Similar to the pre-discharge interviews, the interviews were conducted largely in-person. Once a potential discharge date was known, the interviewer contacted the parents to set-up a post-discharge interview before leaving for home. If that was not possible (sometimes discharges happened spontaneously and the researcher was made aware of the spontaneous discharge to home), the researcher attempted to conduct the post-discharge interview at the infant's home. During times when these attempts were unsuccessful, a telephone interview was conducted.

Interview Data Analysis

Table 4. Number of Interviewees

Groups	Number of Interviewees
Parents	Pre: 13
	Post: 13
Healthcare Professionals	30
Community HCPs	6

A transcriptionist transcribed both the health professional and the parent/guardian interviews. This transcriptionist signed a confidentiality agreement prior to starting the

transcriptions (See Appendix X). Once the transcriptions were completed, the researcher read through each transcript while listening to the audio to ensure accuracy and fill in any gaps left by the transcriptionist. Data collected from the health professional interviews and the family member interviews were analyzed simultaneously through systematic, documented procedures of thematic and constant comparative analysis. A constant comparative analysis was done across the 12 cases based on their acuity (acute versus chronic) and comparing their responses to see if any similarities in the experiences were evident. There was no comparative analysis performed across the different units/institutions, as that was not the intention of this study. A thematic analysis aims to present the key elements of respondents' accounts (Green & Thorogood, 2010). Here interview transcripts were examined thoroughly to categorize the key informants' responses into themes, which helped to answer the research questions proposed.

Data analysis was carried out using the latest version of the NVivo qualitative data software, NVivo 10™. The transcripts were uploaded into NVivo. The transcripts were analyzed line-by-line to find themes that represent the data (Ryan & Bernard, 2003). A preliminary coding scheme was created based on the literature review and from the observations on the unit, and applied using the NVivo software to relevant parts of the interviews by the researcher and analysed across cases (Green & Thorogood, 2010). Any new themes that emerged as the researcher went through the transcripts were added to the coding scheme (See Table 5). The identification of themes is one of the most fundamental tasks in qualitative research (Ryan & Bernard, 2003). These codes were categorised into higher-level themes and were further analysed for relationships between themes and responses of the different key informants. Thematic analysis is the most useful approach for answering research questions about the significant issues for particular groups of respondents (Green & Thorogood, 2010). Thematic

analysis is also the basis of qualitative analysis. Here, the researcher moves beyond just coding and categorizing data to thinking about how the codes relate to each other asking more complex questions (Green & Thorogood, 2010).

Table 5 - A Priori and Emergent Themes

Participant Group	A Priori Themes	Emergent Themes
Family Interviews	• Part of healthcare team • Communication • Support from care team • Contribution to infant's ToC plan • Improvements/Recommendations • Comfort level	• Last-minute notification • Internally unaware of discharge plans • Frequent staff turnover • Care vs. Care to discharge • Community Care • Unaware of discharge plan • Delayed discharge due to bed space issues
Healthcare Professional Interviews	• Role clarity • Communication • IPC • ToC Planning Contact • Definition of IPC • Key elements of Team • Weaknesses of Team • Who needs to be involved	• Advising patient families against fellow HCPs • Last-minute notification of discharge • Early Discharge • Readmission • Parent Readiness • Start of ToC Planning • Trust • Frequent staff turnover
Community Interviews	• IPC with NICU • IPC with community resources • Communication • Barriers/Facilitators	• Funding • Social issues • Fragmented resources • Early involvement of CDT • Fear to let infants into care of community healthcare professionals • Frequent staff turnover • Parental expectations • Role clarity • Healthcare professionals' lack of knowledge of community resources • Uncertainty/Underuse of community resources • Barriers with family • Barriers discharging outside Ottawa area

Stage 4: Deliberative Dialogue Worksop

Towards the end of data collection and beginning of the analysis of data from stages two and three, focus groups were held with the healthcare professionals and relevant stakeholders to share the results collected from these stages. Liamputtong (2010) defines focus groups as a data collection method based on group discussion where the participants express their views by interacting in a group discussion of issues. Focus groups have many purposes including eliciting knowledge, evaluating health care interventions, generating hypotheses, and elucidating study findings (Liamputtong, 2010). A strength to using a focus group method is that it allows the researcher to obtain a collective perspective and the capacity to capture multiple participants' views in a single interview setting (Vogt et al., 2004; Liamputtong, 2010). Four focus groups were held; three with health care professionals and one with key stakeholders (e.g. clinic manager, etc.). The purpose of the focus group in this study was for knowledge exchange and to obtain feedback on the results and to see if the participants were able to provide further insight into the results obtained. Because the nature of focus groups was such that it was difficult to guarantee full confidentiality (Green & Thorogood, 2010), the focus group participants were informed that full confidentiality was not guaranteed. This was also stated in their consent forms. The email invitation for the focus groups contained a copy of the consent form to allow them the opportunity to read through the project details and decide on their own whether they wanted to participate or not (to minimize group coercion). At the beginning of the focus group session, participants were informed of the procedures in place to maintain confidentiality of the research data and that they were not to repeat what was said in the focus group to others. Notes taken from the focus group transcripts masked the identity of the respondents (unique identifiers were used).

A date and time was organized in conjunction with the NICU to set up the focus groups. Considering the staffing schedule on the NICU, three focus groups were set up at different times on three different days to allow for the majority of healthcare professionals and stake holders to attend. Separate focus groups for healthcare professionals and the key stakeholders were set up to deal with group coercion. Group coercion is an important factor that must be considered as it may prevent a participant from presenting new ideas or their opinions, which may be very important for the study (Charles, 2013). Potential participants were invited to take part in the focus group by an email invitation. The focus group was digitally recorded with permission from the participants. This recording was used by the researcher to take detailed notes of the main or recurrent themes that arose from the discussion. Those focus group participants who had not previously signed a consent form during the in-servicing sessions at the start of the study were required to sign a consent form consenting to their participation in the focus group and also to be audiotaped.

The focus group started with an overview of the study and the study results by the researcher. The focus group then took a round table format where the researcher presented a question and then went around the table allowing those who wanted to speak to offer their opinions. The questions asked during the focus group sessions to promote discussion were developed based on the results obtained from stages two and three. The researcher also kept the presentation open so that the participants were able to offer their opinions or ask questions throughout the presentation.

Data were collected using three different data-collection techniques: document analysis, direct observation, and key informant interviews. This ensured methodological triangulation, which facilitates validation of data through cross verification from more than two sources

(Bogdan & Biklen, 2006; Denzin, 2006). In addition, triangulation was achieved via respondent validation during the deliberative dialogues where the respondents were invited back to provide feedback on results and my analysis of the results (Anderson, 2010). At times there was a lack of congruence from my different data sources. Attempts were made to deal with any incongruence that arose. For example, in cases where there was incongruence between the key informant interviews and the observations data, I took the result back to the respective informants, and others depending on the data, attempted to validate with them what I heard from the interviews and what I saw/heard during the observations was true or not.

Ethical Considerations

There were several ethical considerations within this research project. The ethical considerations are outlined in the following sections:

Informed Consent

This consent form provided a detailed description of the project, ensured confidentiality of responses and anonymity of data, and informed participants of their right to withdrawal at any time of the study. The research assistant at CHEO went over the entire consent form with each parent participant prior to having him or her sign it (See Parent Consent form in Appendix XI). The researcher made her contact details available should participants have any questions regarding the research project.

Confidentiality

Identifying information of the participants was not attached to the data. Participants were assigned a unique identifier, which was used during the observations and interviews. The list with the identifiers was kept separately from the data and was only made available to the

researcher. The signed consent forms were also stored separately from the data to ensure that no one was able to link the data to the person's identifying information. Key informants were reminded prior to the start of their interview not to mention any identifying information (e.g. patient or staff names, bed spot number, etc.). In the case when participants did mention identifying information during the interview, it was deleted from the interview transcript by the researcher. Participants were assured that their responses were treated anonymously and confidentially. They were also informed that the only exception to this would be if responses indicated that an illicit, illegal or below standard-of-care practice was currently ongoing or was about to commence; in which case, the information would be relayed to Quality and Risk Management. This was included in the consent.

Researcher Standpoint

My family is from Jaffna, Sri Lanka. I was brought to Canada at four months of age in 1986 where I was raised in Toronto. I completed my Honours Bachelor of Science in Integrative Biology and Health Studies at the University of Toronto in 2008. In 2011, I completed my Masters of Health Sciences in Community Health at the University of Ontario Institute of Technology.

Within the first seven years of immigration to Canada, my parents faced two incidences with the Canadian health care system. Their first encounter was after the birth of my first younger brother in 1989 who was diagnosed with club feet (*Congenital Talipes Equinovarus*) in both feet. Unaware of how the health care system works and confused with how to proceed with treatment, my parents took the traditional approach of "following the doctor's commands" – one that is very common in Sri Lanka.

In 1993, another brother was born. He was diagnosed with Trisomy 18 (*Edwards syndrome*) and my parents were informed of this a couple of weeks prior to his birth. My brother lived for three months and spent the majority of his entire short life in a NICU. Being only seven-years-old I remember very clearly visiting him every day on the NICU and fighting with my other younger brother on who got to hold his feeding tube while he had his milk. My parents followed the same approach of agreeing to everything the health care team threw at them – including agreeing to transfer my brother to a long-term care centre which was far from our little apartment and sadly, this centre specifically had a strict regulation not allowing children under the age of 12 to visit regardless of whether they are the patient's siblings. My brother and I were unable to visit our younger brother at his new home due to protecting the other infants at the centre, and two weeks later, he passed away. Oddly, my brother and I were allowed to come to the centre to see his lifeless body – until today I still cannot understand how our ability to infect the other infants would have differed between visiting him before and after his life ended. We three siblings lost two weeks of time to spend with each other. To me, this was not a good ToC plan.

For the longest time, I was unable to enter the hospital where my brother spent the majority of his life. In 2002, I forced myself to start volunteering at the hospital and then in 2003, I started volunteering on the very same NICU. I was an active volunteer for the next 10 years. Based on my time on the NICU, I understood the importance of discharge planning for these neonates and the need for these discharges to happen within a certain amount of time and favourable to both the healthcare team and importantly the family. As part of my time there, I witnessed a couple of issues that arose due to poorly planned discharges (i.e. readmissions). I

started getting the impression that action needed to be taken at the professional level to improve ToCs of neonates.

In 2008, as part of an undergraduate course, I carried out a study on the state of IPC on the NICU. As part of this research, I was required to distribute a survey to all the healthcare professionals on the unit, analyse the survey responses and report back to the Chief of Neonatology by way of a report. This project gave me my introduction to IPC. It also gave me an introduction to some of the issues that can arise between professionals when trying to work together. Looking at it as an outsider, I was quite confused as to why working collaboratively was not easy at this level. I understood that IPC, however, was definitely important to enhancing discharge planning.

For my master's thesis, I studied the role of interprofessional collaboration on the discharge planning process on the NICU. This study involved an online survey, observations, and key informant interviews with the healthcare professionals on the one NICU. This study demonstrated that IPC was occurring on the NICU but that it fell apart during what I termed an "emergency discharge" – when the most stable neonate on the NICU is discharged or transferred early to make room for another neonate requiring immediate tertiary level care. In this situation, the responsibility to quickly organize the discharge is that of the discharge coordinator and the attending neonatologist and thus the allied healthcare professionals (e.g. social workers, dietitians, occupational therapists, etc.) felt that they were left out of the plan. My experience during this study was quite interesting. My view changed in that it was not only the professional level that needed to be tackled, but also other levels that influenced the professional level.

For my PhD dissertation, I was interested in studying the "other side" of the ToC process, in other words, the ToC experiences of the healthcare professionals in the receiving institutions

and the community, and importantly, the patient's family. I wanted to know what those other dimensions were and how they influenced ToC. To do this, I first had to remove the lens which was my own experiences with my brother and my previous studies on IPC. This lens was definitely biased and tended to pull me in the direction that the professional level is where most of the problems were occurring. This study definitely identified that three levels influenced ToC: System, Professional, and Individual/Patient levels. It was evident that each level had its own set of subthemes and that the three levels influenced each other when it came to ToC of neonates.

CHAPTER 3

The NICU Meso System

This chapter focuses specifically on the NICUs and how they function as a system. It will start off with a broad introduction to NICUs and will go into depth of the three sites which were a part of this study: the CHEO NICU, TOH General Campus NICU and the TOH Civic Campus NICU. The latter half of the chapter will highlight the various entry points into the NICU and the transition points out of the unit.

The NICU is a specialized care unit within a hospital for newborns who have medical complications or babies who have been born prematurely (The MoTHERS Program, 2016). Here, a variety of healthcare professionals including physicians, residents, fellows, nurses, pharmacists, respiratory therapists, dietitians, physiotherapists, lactation consultants and social workers work collaboratively as a multidisciplinary team to provide care for these infants requiring multiple resources for care.

NICU's can be classified under one of three levels of care: level I, level II, or level III. Level I provides care to infants who are healthy and require monitoring before discharge. Level II provides care to babies who are born at a gestational age of 32 weeks or higher and weigh 1500 grams or more (The MoTHERS Program, 2016). These infants are considered moderately ill and are expected to recover relatively quickly or have been transferred down from a level III NICU because of an improvement in their condition (The MoTHERS Program, 2016). Level III includes all babies regardless of their weight or gestational age and provides the highest level of medical care for the most susceptible infants (MoTHERS, 2016). The criteria for distinguishing between these three levels of neonatal care include risk (gestation age and birth weight),

interventions (newborn acuity), and retro-transfer (Roukema, 2011). Table 6 below provides in detail the definitions of each of the three levels of neonatal care.

Table 6. Newborn Level of Care Definitions.

Gestational Age	Newborn Care
Level I	Level I
Greater than or equal to 36 weeks and 0 days	Expected skill level: • Evaluation and postnatal care of healthy newborn infants who are predominantly cared for in a mother-baby dyad model (rooming-in). • Phototherapy • Manage, for a limited duration, term newborn complications such as transient tachypnea of the newborn (TTNB), antibiotic prophylaxis, hypoglycaemia, and feeding difficulties. • Resuscitation and stabilization of ill infants before transfer to an appropriate care facility.
Level IIa	Level IIa
Greater than or equal to 34 weeks and 0 days	Care as above PLUS: Risk • Planned/anticipated care for infants with a gestational age greater than or equal to 34 weeks and 0 days and a birth weight greater than 1800 grams. Illness and intervention • Mild illness expected to resolve quickly. • Care of stable infants who are convalescing after intensive care • Nasal oxygen with oxygen saturation monitoring (acute and convalescing). • Ability to initiate and maintain a peripheral intravenous. • Gavage feeding. Retro-transfers • Stable neonatal retro-transfers with a corrected age over 32 weeks and 0 days, and a weight greater than 1500 grams and not requiring invasive or non-invasive ventilation, or advanced treatments or investigations.
Level IIb	Level IIb
Greater than or equal to 32 weeks and 0 days	Care as above PLUS: Risk • Planned/anticipated care of infants with a gestational age greater than or equal to 32 weeks and 0 days and a birth weight greater than 1500 grams Illness and interventions • Moderately ill with problems expected to resolve quickly or who are convalescing after intensive care. • Continuous Positive Airway Pressure (CPAP), either transitional or

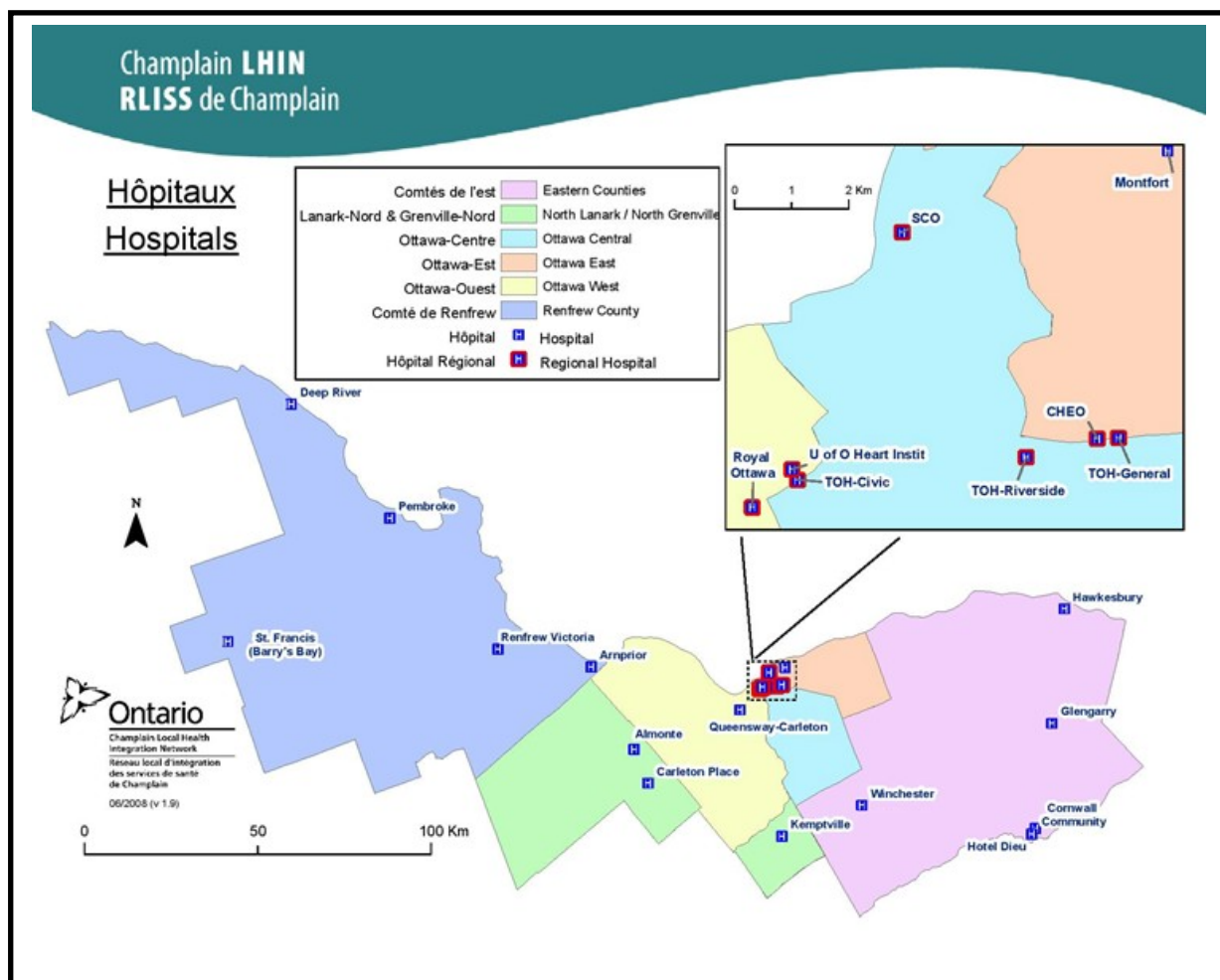
	extended stable CPAP. • May have mechanical ventilation for brief durations (less than 24 hours) • Inserts and maintain umbilical lines • Maintenance of PICC lines • Peripheral intravenous infusions and total parenteral nutrition Retro-transfers • Stable neonatal retro-transfers with a corrected over 30 weeks and 0 days, and over 1200 grams and not requiring invasive ventilation, subspecialty support, surgical support, advanced treatments and investigations.	
Level IIc	Level IIc	
Greater than or equal to 30 weeks and 0 days	Care as above PLUS: Risk • Planned/anticipated care of infants with a gestational age greater than or equal to 30 weeks and 0 days and a birth weight greater than 1200 grams. Illness and interventions • Moderately ill newborns with problems expected to resolve within a week or who are convalescing after intensive care. • Mechanical ventilation for conditions expected to resolve within a week or extended continuous positive airway pressure. • Intravenous infusion • Total parenteral nutrition • The ability to insert and maintain umbilical central lines • Maintenance of percutaneous intravenous central lines, access to PICC line insertion. • Support of babies with extended mechanical ventilation and lower gestational age may be required as a result of temporary inability to transport (e.g. geography, weather, capacity). Retro-transfers • Retro-transfers should be reviewed on a case-by-case basis between the tertiary and receiving sites.	
Level III	Level IIIa	Level IIIb
Any gestational age or weight	Care as above PLUS: • Any gestational age or weight. • Mechanical ventilation support including high frequency, and possibly inhaled nitric oxide, for as long as required. • Timely access to a comprehensive range of subspecialty consultants.	As in IIIa PLUS: • On site surgical capability.

*Obtained from *Standardized Maternal and Newborn Levels of Care Definitions* (PCMCH, 2013)

The NICU System in Ottawa

Ontario has approximately 100 hospitals and/or corporate sites, which provide maternal and newborn care services with 50 special care nurseries (PCMCH, 2016). The Champlain Local Health Integrated Network (LHIN) region (LHIN #11) has 11 hospitals dispersed throughout from Renfrew County to the Eastern Counties (see Figure 2).

Figure 2. Champlain LHIN Hospitals.



*Obtained from

<http://www.champlainlhin.on.ca/AboutUs/Geography%20and%20Pop%20Health%20Data/Geography.aspx>

Five of the 11 hospitals have Special Care Nurseries or Neonatal care. Those hospitals designated as level I centres do not actually have nurseries – mom and baby are kept together

and they provide basic baby care (HOSP007, personal communication, August 22, 2016). The level of care provided in each of the Champlain LHIN NICUs is provided in Table 7 below.

Table 7. Champlain LHIN Newborn Level of Care Designations

Corporation	Site	Neonatal Level of Care
Almonte General Hospital		I
Children's Hospital of Eastern Ontario (CHEO)		IIIb
Cornwall Community Hospital	McConnell Site	I
Hôpital Général de Hawkesbury & District General Hospital		I
Hôpital Montfort Hospital		IIa
The Ottawa Hospital (TOH)	Civic Campus	IIc
The Ottawa Hospital (TOH)	General Campus	IIIa
Pembroke Regional Hospital		I
Queensway Carleton Hospital		IIa
Winchester District Memorial Hospital		I

*Obtained from PCMCH – Ontario Maternal and Newborn Level of Care Designations (PCMCH, 2016).

Background on Three NICUs

For the purpose of this study, only the NICUs at CHEO, the TOH General Campus and TOH Civic Campus Special Care Nursery (SCN) were involved. Approximately 7,000 deliveries (6,300 in 2015-16) per year take place at the TOH General and Civic Campuses (HOSP007, personal communication, August 22, 2016). The TOH is the regional perinatal centre for Eastern Ontario, which closely follows high-risk pregnancies, fetal anomalies that may have been detected in utero, and mothers who may have severe medical issues, pregnancy-induced problems or premature labour (UOttawa, 2014).

The NICU at the TOH General Campus has 24 (14 level III and 10 level II) beds and 800 admissions per year (HOSP007, personal communication, August 22, 2016). Thirty-five percent (35%) of these admissions are of infants weighing less than 1,500 grams at birth. The SCN at the TOH Civic Campus has 15 level II beds – a decrease from 17 level II beds in 2016

(HOSP003, personal communication, July 8, 2016) and approximately 800 admissions per year (HOSP007, personal communication, August 22, 2016). CHEO's NICU has 14 level IIIa and IIIb beds and provides care to an approximate 450 high-risk infants per year (UOttawa, 2014; HOSP003, personal communication, July 8, 2016). See Table 8 for a summary of these details.

Table 8. Bed Allocation & Number of Admissions per Year

NICU Site	Number of Beds	Number of Admissions/Year
CHEO	15 Level IIIb	450
TOH General	14 Level IIIa & 10 Level II	800
TOH Civic	15 Level IIc	800

(HOSP007, personal communication, August 22, 2016)

CHEO's NICU provides care to infants born in the surrounding region of Eastern Ontario, Outaouais region in Québec, and the Baffin Island region of Nunavut for which the funding is separate - independent from the OHIP (CHEO021, personal communication, July 22, 2016). TOH also cares for a significant number of infants from Outaouais – especially at the General NICU and both Civic and General care for babies of high-risk moms from around Eastern Ontario (HOSP007, personal communication, August 22, 2016). These three centres work collaboratively together with babies born in the region with severe surgical or medical conditions treated at CHEO's NICU, premature babies treated at TOH General Campus, and moderately premature babies treated at the SCN at the TOH Civic Campus.

Funding of Beds

The beds are funded based on the acuity of the NICU. For instance, a level III bed would cost more than a level II bed. The capacity of each NICU is different from how many beds for which the unit is actually funded. In the case of the General's NICU which has a combination of 14 level III and 10 level II beds, the unit is dealing with two different costs. The funding

formulas are a little bit different since funding for a level III baby is much higher (HOSP003, personal communication, July 8, 2016). Even though the General's NICU is funded for 24 beds, there are times where the capacity has been higher (i.e. 25 or 26 infants) and the unit does not get funded for these extra patients. Due to recent multiple infection outbreaks over the last 18 months, the unit no longer admits more than 24 patients. They try to cap the number of babies at 22 thus keeping an extra room for overflow (HOSP007, personal communication, August 22, 2016). Staffing is also different amongst the units and also explains for the differences in budget allocations. A higher budget is provided to the NICU because of higher acuity and lower patient ratios as babies are more complex, premature and sicker. A lower budget is provided to the SCN as babies are more stable, are of lower acuity, and therefore higher nurse-patient ratios exist (HOSP007, personal communication, August 22, 2016).

CHEO Transport Team

CHEO serves an extra role in that it also provides the transfer of critically ill infants. The function of the Neonatal Transport Team is to provide stabilization for safe and smooth transfer of critically ill infants to an appropriate unit for care (CHEO, n.d.). This team is available 24 hours/day and seven days/week. The Transport Team will collect any baby born within the Champlain, South East, North West, and North East LHIN regions and deliver them to the appropriate NICU depending on the baby's gestational age, condition (acuity), and availability of beds. For example, if they pick up an infant at 32 weeks gestation, the infant may be transferred to the Civic's SCN whereas if it is an infant at 27 weeks gestation, they may keep them (CHEO NICU) or transfer to the General's NICU. Historically the Neonatal Transport Team was funded by CHEO thus drawing the majority of transfers to the CHEO NICU. Since 2014, the team is

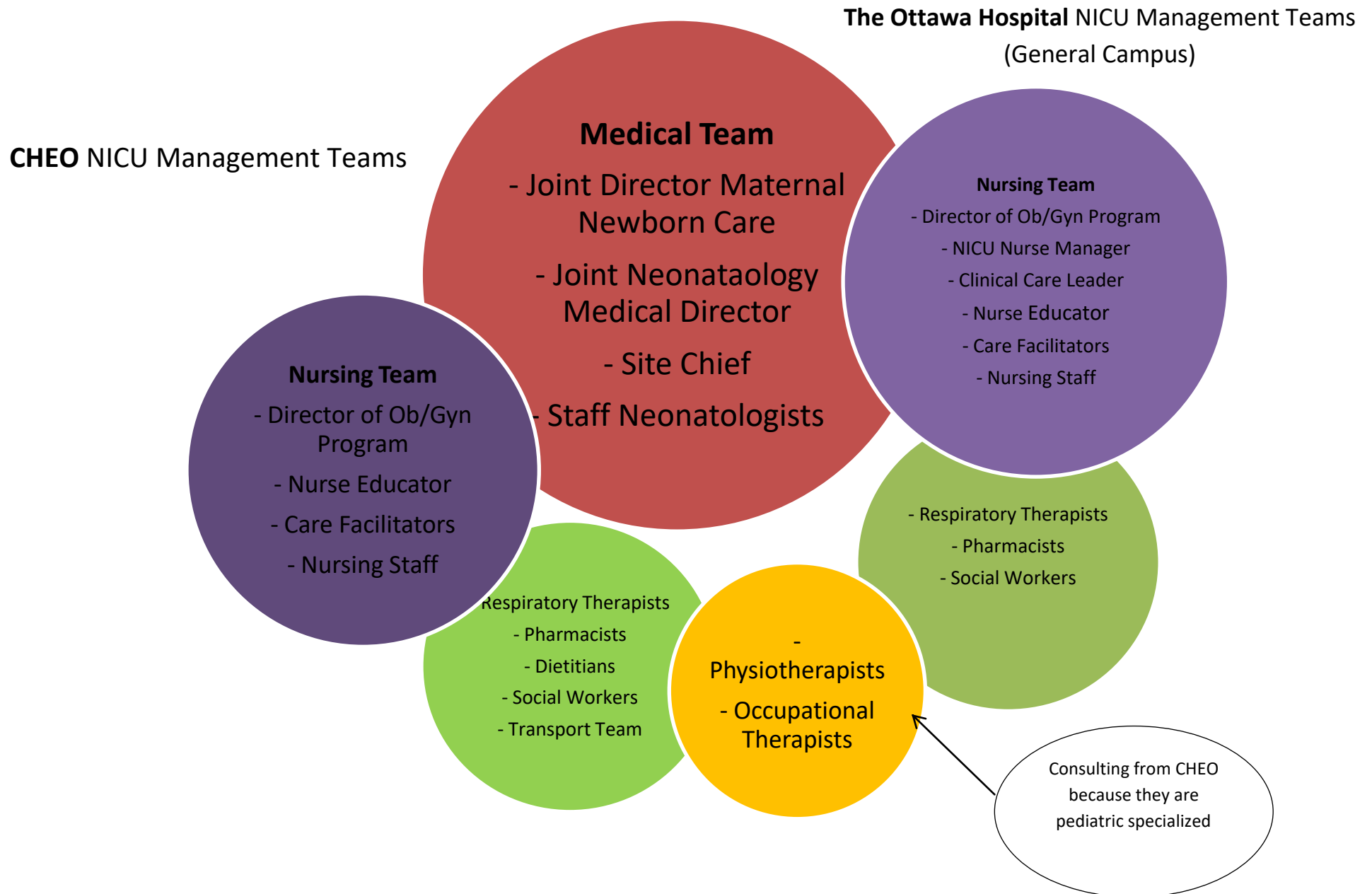
fully funded by the Ministry of Health and Long Term Care (MOHLTC), which mandated that the infant be taken to the appropriate centre based on acuity and gestational age (HOSP007, personal communication, August 22, 2016).

In the past, there was a time where patients would be transferred from the Toronto area because they were full and thus could not accommodate an infant. Presently, the Ministry has mandated all the hospitals in Ontario that they cannot refuse an infant coming from their respective regions (HOSP003, personal communication, July 8, 2016). For instance, if a mother is in labour, under extreme circumstances she is not to be transferred out of the region in which she is located. It all comes down to “right patient, right care, right place” (HOSP003, personal communication, July 8, 2016).

Management

The management team at the NICUs includes the nursing management team and the physician-neonatologist management team. There are also combined responsibilities – NICU/SCN Manager has physician lead counterpart at both sites and they are jointly accountable for the function of the unit, ensuring quality care, etc. (HOSP007, personal communication, August 22, 2016). The neonatology department is one department at the TOH and CHEO comprised of 15 staff neonatologists plus two neonatologists at TOH Civic campus who are funded outside of the alternate funding model that TOH NICU and CHEO NICU have for neonatologists (UOttawa, 2014). CHEO and TOH General campus are sharing the same physicians. The TOH Civic Campus SCN’s physicians work independently from the other two NICUs. Figure 3 below provides an overview of the management teams at the NICUs at CHEO and TOH General Campus.

Figure 3. Management Teams at CHEO & TOH NICUs.

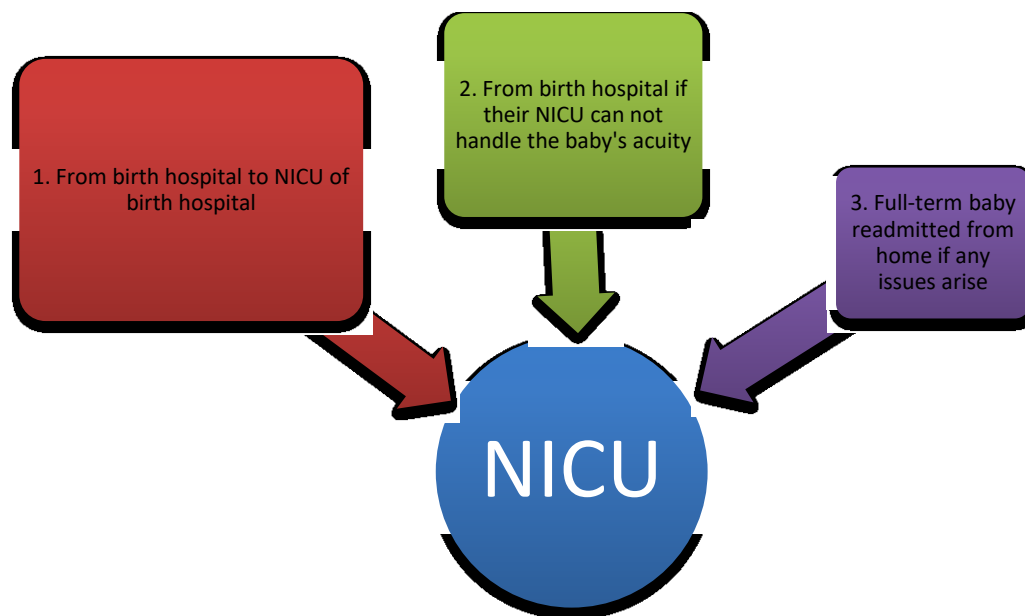


In terms of leadership, the medical and nursing management teams function as a dyad with the Nursing Managers working very closely with the Site Chiefs of each NICU. The Neonatologists overlaps across both CHEO NICU and the TOH NICU. The Neonatologists at the Civic SCN are not part of the alternate funding plan the CHEO and General Neonatologists have (HOSP007, personal communication, August 22, 2016). As far as other allied health (e.g. Respiratory Therapists, Social Workers, Dietitians, Pharmacists, etc.), they all report to their respective organizational leaders.

Entry Points into the NICU

There are many ways in which infants can enter the NICU. Figure 4 provides a glimpse at the possible entry points into the NICU. The section following will go into detail of each of the pathways.

Figure 4. NICU Initial Entry Points.



1. One initial point of entry is a baby born at the TOH and is taken to the NICU of that hospital if neonatal care is needed. The majority of TOH SCN and NICU admissions are from babies born internally. All of CHEO's babies are born externally and are transferred in (HOSP007, personal communication, August 22, 2016).
2. Another method of initial entry is if a baby is born at another hospital within the Champlain LHIN region (i.e. Montfort or Queensway-Carleton) and is taken to the NICU at the TOH or CHEO if the hospital where the birth occurred does not provide the required level of care. In this case, the CHEO Transport Team collects the baby from the birth hospital and transfers them to a higher-level NICU depending on the baby's acuity, gestational age, and availability of beds. In this program, both the Montfort and Queensway-Carleton NICUs (level IIa) have 4 beds each and can handle medically stable 34-weekers – so other NICUs can repatriate stable and growing babies to them to make room for more sick babies in the higher level of care units. In the case of babies delivered by midwives outside of hospital at the Ottawa Birth and Wellness Centre or home, they have an agreement with CHEO that if there is a problem with the baby they will bring the infant immediately to CHEO's NICU. Otherwise, babies born by midwives in hospital who require SCN or NICU care are admitted to the units in the hospital they were born in unless they require level IIIb care and are transferred to CHEO (HOSP007, personal communication, August 22, 2016).
3. A third and very rare way is to get a full-term baby who has gone home (after delivery) and is brought to the NICU through a triage in the Emergency Department if any complications arise (E.g. Bilirubin tests show elevated levels near the exchange transfusion threshold; so infant needs to be brought to NICU for possible exchange-

transfusion). Babies can also be admitted from the new birthing centre if needed (CHEO is the designated site).

4. A fourth way is a baby born, goes to mother-baby unit post-birth, becomes unwell and thus requires transfer into the SCN or NICU from within that hospital (HOSP007, personal communication, August 22, 2016).

In the case of the CHEO NICU, where birthing facilities is not available, the ways of entry include 1) those babies born elsewhere with a Nursery or NICU that is unable to care for the infant's acuity; 2) those babies who are transferred to the level IIIb unit for a higher-acuity procedure or surgery (they are then transferred back to the NICU that they came from); 3) babies readmitted after going home due to any complications (which is not a community-based acquired infection) that may arise within seven days post-discharge and 4) babies from other NICUs in the case where bed space is not available.

Exit Points from NICU

There are three different paths infants can take to exit the CHEO NICU: by way of 1) Retro-transfers, 2) direct home from the CHEO NICU, and 3) to another floor/unit within CHEO (See Figure 5 below).

Retro-Transfers

Situations where newborns are transferred out of the region for care because tertiary level NICUs in their region are unable to accommodate their care needs is a huge frustration for families, providers and policy makers (PCMCHb, 2013). Retro-transfers are a good way of keeping tertiary beds open for newborns who require this level of specialized care. That is, transferring infants who no longer require tertiary care promptly to level II centres closer to

home. In the case of the NICU at CHEO, infants who are deemed stable and no longer requiring tertiary level care at CHEO are identified by the healthcare team during morning rounds. At this point, the Care Facilitator identifies potential level II units which have space available to accept the infant. Once another level II Nursery has accepted the admission, the infant's transfer is prepared including the creation of discharge summaries to be presented to the healthcare team at the receiving institution. Handover by the respective professions are also done (medical team handover, nursing, social work, etc.). This is also true for TOH NICU who retro-transfers the most babies in the system (HOSP007, personal communication, August 22, 2016).

Transfer Direct to Home

Infants with lower acuity may be sent direct to home from the CHEO NICU and TOH. Infants are identified as ready to be discharged home by the healthcare team. Once identified, the care facilitators discuss with the family members and prepare for the discharge by completing any relevant teaching, checking car seats, connecting parents with resources, etc.

In the case of a chronic or long-term care infant, CHEO's Community Discharge Team (CDT) is involved. The team is an integrated team comprising of CHEO Discharge Planners (who are hired by the Champlain LHIN Community Care Access Centre (CCAC) and located in CHEO) and CCAC Care Coordinators who are primarily responsible for developing a plan of care to provide and link the infant/family to appropriate care and support in the community. The CDT works with the NICU and the family to assess what their needs will be at home and setting them up with equipment, and in some cases, the funding for this equipment for those unable to cover the associated costs.

Once the infant is discharged home, their care is transferred to the CCAC Care Coordinators in the community who assess their needs on an ongoing basis to provide care

accordingly. The infants and their families can also be referred to the Ottawa Public Health's Healthy Babies Healthy Children (HBHC) program for home visits by a Public Health Nurse. More details on the CCAC and the HBHC program are provided in another section below.

Transfer to Another Floor/Unit Within CHEO

Infants who are stable enough that they do not require tertiary level care but may be past the gestational age cut-off to be kept in an NICU for long-term care may be transferred to another unit within CHEO (e.g. PICU, Chronic Care Floor, etc.). The same steps as what happens when being transferred to another hospital are followed here with the Care Facilitator investigating to see if there are beds available and if the respective physicians on the floor are able to take the infant and provide care. Being transferred to the Floor also acts as a step-down unit and provides the infant's family with an opportunity to care for their infant hands-on in a safe environment before going home.

Community Care Services

This section will go over the main services that infants and their families are connected with once they are discharged from the hospital.

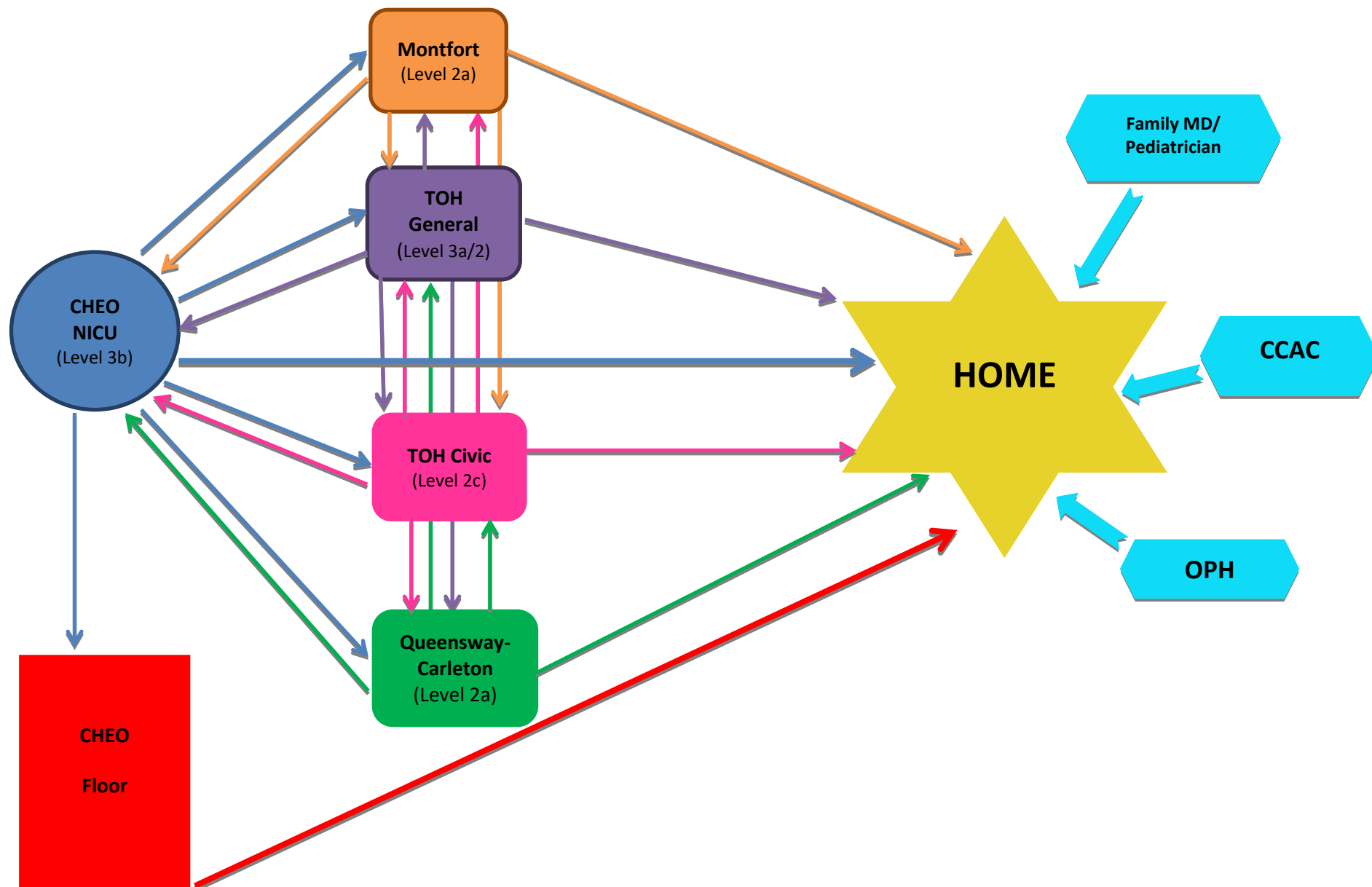
Champlain Community Care Access Centre (CCAC)

The Champlain CCAC plays an important key role in the transition of care of neonatal patients once they are discharged into the community. In the case of CHEO, the CHEO discharge planner and CCAC care coordinators both work in CHEO and have a cross-functional role - they create the discharge plan and order services and supplies, funding etc., document in the CCAC electronic client chart and notify CCAC when the infant is discharged home (COMM004, Key Informant Interview, March 30, 2016). In the past the two roles worked very

separately, however now this integrated model involves the two roles working together to provide a more smooth transition from hospital to home.

The CDT in the hospital is responsible for meeting with the parents of complex care infants ready to go home. They meet with the parents and the nursing staff and together develop a community care plan for the infant. In other words, assessing the care needs and then developing a care plan to support those parents (COMM004, Key Informant Interview, March 30, 2016). The care plan will be different for each infant and will depend on circumstances like: Does the family have support? Where do they live? Are they rural? Are there siblings? After assessing the whole “package” to understand what the care needs are, the CDT develop a care plan and order the services, make connections to community supports and get things started (COMM004, Key Informant Interview, March 30, 2016).

The CCAC is provincially funded and for eligibility, people need to have a valid OHIP card and must reside in Ontario (COMM004, Key Informant Interview, March 30, 2016). The Champlain CCAC is the LHIN that covers the Ottawa-area hospitals. The CCAC has internal and contracted service providers. These service providers are agencies in the community like Bayshore, WeCare, ParaMed, etc. The CCAC divides funding between internal providers and contracted service provider organizations (SPO). This means that the SPOs are obliged to meet the minimum services volume/ hours of care as ordered by Care Coordinators, under the SPO/CCAC contract (COMM004, Key Informant Interview, March 30, 2016). Services that are provided by the CCAC include case management, nursing, physiotherapy, occupational therapy, social work, personal care, equipment, and system navigation. The CCAC care coordinator is the person who assesses care need, authorizes services, is coordinating and monitoring all this care.

Figure 5. CHEO NICU Exit Points to Home

How the process of connecting infants with community resources happens is the Community Discharge Team member conducts a needs assessment on the patient/family during the hospital stay and creates a plan to support the patient/family in the community. That service request is sent out electronically via the CCAC system service providers who review the offer and if able to provide the necessary care can accept the offer. The service order is sent to the providers based on their market share (highest shares are approached first) and contract (e.g. not all SPOs provide pediatric or palliative care). SPOs have 30 minutes to accept a simple care plan and two hours for a very complex care plan. If one provider declines, it is automatically rotated to the next provider on the list. This process continues until a service provider picks up that service. The CCAC care coordinator will order the particular amount of service and the service provider will go to the client and provide the service that is required. The service provider will report back to the CCAC care coordinator in a written document of what care they provided, what's happening in the home, etc. The CCAC care coordinator will monitor, go home visiting and see how the situation of the patient and their family unfolds. He/she will adjust the care plan accordingly.

The CCAC also provides Rapid Response Nurse (RRN) services as well. The role of the pediatric RRN is to visit the patient within 24-48 hours after discharge. The RRN completes a full medical assessment of the patient and goes over teachings with the parents to make sure they are comfortable (COMM005, Key Informant Interview, March 31, 2016). After that, the RRN writes a summary note, which is then sent to the responsible physician at CHEO with an update of the infant's status. In addition the primary care physician receives a summary of the visits and the patient's status. The RRN offers two to three visits within the first 30 days to make sure everything with the infant is going well. In the case that the RRN notices anything abnormal,

he/she may call and consult with the responsible CHEO physician or will recommend the family to take the infant to the Emergency Department as soon as possible. The RRN also serves as the eyes of the CCAC Community Coordinator and is able to provide them with information on the actual situation at home so that care can be provided accordingly.

Healthy Babies Healthy Children

A referral to the HBHC Program offered by Ottawa Public Health (OPH) can also be offered to the parents of the infant. HBHC is a free home visiting program for pregnant women and families with children under six years of age (City of Ottawa, 2015). HBHC can offer services in the native language of families. Once a baby is born, a Public Health Nurse (PHN) will contact the families to assess the health of the mother and newborn. The PHN can also offer support and answer questions parents might have about things like parenting, feeding, safety, and development. The HBHC program can provide information about different programs that are available in the family's community, connect the family to resources, and if needed offer home visits from a PHN, Social Worker and Family Visitor (City of Ottawa, 2015).

CHAPTER 4

Hospital Healthcare Professionals' Experience of Transitions of Care

Healthcare professionals are the link between the care system and parents/patients, but are also the key actors in the transitions of care process. This chapter presents the findings obtained from the interviews with healthcare professionals at the three hospital sites who were a part of the healthcare team of the 12 cases under observation. The purpose of these interviews was to understand transitions of care of neonates within hospitals (inter-hospital) and within units of the same hospital (intra-hospital).

Three key themes from the healthcare professionals' interviews emerged from the thematic analysis reflective of the system, professional and patient level framework that emerged from the review of the ToC literature. First, the ToC System Challenges theme highlights what ToC for neonates in the hospital looks like and some of the challenges that are faced by the hospital healthcare professionals during these transitions. Second, the IPC theme addresses issues raised surrounding the collaboration of healthcare professionals when it comes to ToC planning. Finally, the 'Complex Communication Field' theme highlights the complexity of issues surrounding ToC-related communication. Prefacing this discussion of challenges, I present first what are considered the policies and best practices around ToC according to the healthcare professionals.

The Policies and 'Best' Practices of ToC Planning

One of the most spoken of and somewhat controversial topics in the field of ToC is when discharge or ToC planning should begin for a patient. The CHEO Corporate Discharge Planning

Policy for In-Patient Units (2015) states that discharge planning for a patient must commence upon admission of the patient:

“EDD [estimated date of discharge] will be established pre-admission or on the day of admission for predictable length of stay (LOS) and elective admissions. For complex or medically fragile and /or technology dependent patients, where LOS is less predictable, the EDD will be established with team input as early as possible or at least 3 weeks before the EDD.” (CHEO Corporate Discharge Planning Policy for In-Patient Units, 2015, p. 1)

As part of the interviews, healthcare professionals were asked if they were aware of any ToC-related documents (i.e. policy documents or educational material) that were currently used on the NICU. The majority of the healthcare professionals indicated that there were no documents of that sort that they could think of:

“I don’t remember anything that we have. I am not aware of any. The only thing I’m aware of is the discharge planning team. So I’m not sure if they have certain things that they give to the parents.” – *CHEO001*

“There are no policies.” – *CHEO008*

In one interview, a healthcare professional did point out that there was in fact a hospital-wide discharge planning policy in place – the CHEO Corporate Discharge Planning Policy for In-Patient Units. This policy explains detailed roles and responsibilities of who does what when it comes to discharge planning (See Appendix XII). After analysing this document, the remaining healthcare professionals were asked if they were aware of this document. One healthcare professional responded that there must be a policy document in place for discharge planning but also said that it was most likely applicable to the residents and other trainees:

“Yeah, there is. I mean I don't know what you mean by policy but there is certainly some written documents. I’m sure that it exists for the residents and the fellows because they are responsible for doing the discharge. They sign on. So yeah, there is policy.” – *CHEO007*

The same healthcare professional also went on a little further to say that the lack of proper documentation on discharge processes was a challenge when it came to ToC. He also seemed unsure of whether there is actually a lack of documentation or if he just has not seen all of them:

“Well, you know, yeah, look at that because I have not seen all those documents. That’s part of the problem. You know, we do... We take the ultimate decisions. We are asked whether he can be transferred. We talk to the physicians on the floor. But the whole process, you know, checking the box, newborn screening done, drugs, IV, all these things that need... Whether there is appropriate documents where, you know, we track, we code it, list it, check, blah-blah-blah, I have to admit I suspect there is but I have not seen them, right. So I may be wrong, right.” – *CHEO007*

From these responses it can be understood that it is important to have documentation detailing ToC processes in place and equally as important to make sure that the healthcare professionals are aware of what documentations are in place which list these processes. Having a unified understanding of what steps should be taken when planning a ToC may help to deal with some of the challenges that are faced among healthcare professionals when planning a ToC.

When the healthcare professionals were asked about when ToC planning should commence, the majority of them acknowledged that discharge planning was not always commenced upon admission:

“Not really. So usually we start after... If the baby is we consider stable, meaning he doesn’t need respiratory support, he doesn’t need cardiac support, and then in that phase where we’re trying to feed the baby, we’re just going to make sure that the nutrition part. We don’t usually think of discharge when we admit the baby. Because you never know. Like there’s many things could happen.” – *CHEO001*

From the response above, it can be understood that ToC planning is not always commenced right at admission for neonates as it is recognized that their health status can change during their time on the NICU. Whether the infant is a short or long-term patient also influences when discharge planning should start. In the case of long-term infants, ToC planning does not start right away:

“As soon as possible. It depends on the acuity of the baby. If it's a baby that we know is going to be here for a long time, it's not talked about initially.” – *CHEO009*

Again, the reason for this can be linked back to the fact that a longer-term infant's health status can change over the course of their stay on the NICU and thus, in the healthcare team's perspective, might be worthwhile to wait a bit until they are sure of the infant's diagnosis and what the infant's long-term needs may be.

System Level Challenges.

During the interviews with the healthcare professionals, several system level challenges to ToC were highlighted.

Organization of the Five NICUs in Ottawa

During an interview with one of the healthcare professionals, the way the five NICUs in the Ottawa area are organized was brought up as longstanding systematic barrier. Going back to Chapter 3 which outlines the way the NICU system is organized, CHEO and the TOH General and Civic NICUs provide level IIIb, IIIa and IIb care respectively whereas the Montfort and Queensway-Carleton both provide level IIa care with only four bed spots each. According to CHEO007 (and my observation notes), the original plan was to have three main nurseries with about 30-35 beds each and two smaller or level IIb NICUs to be able to take the transfers from the level III NICUs (step-down unit) with 15-20 beds each. Somewhere along the way this plan fell through (I was unable to get further details and was told it was too political). Hence, now with Montfort and Queensway-Carleton hospitals having such low bed capacity, they cannot justify having any specialized healthcare professionals. For example, if a certain procedure is performed on average only once a month at these hospitals, what is the use of having a person trained for the specifically for only four beds? According to one healthcare professional, this is

the ultimate discharge problem. If the structure/organization of the NICUS were to change it would be easier (e.g. Many high level NICUs available in Toronto for transfer) as currently there is not where to transfer these babies to in Ottawa. Thus, level III NICUs end up hanging on to these babies longer resulting in unnecessary spending of healthcare dollars and use of higher level bed spot by a patient who does not need it.

Lack of Bed Space.

The lack of bed space at the NICUs and/or other units was also identified as a challenge to the ToC of neonates:

“The actual availability of beds becomes a barrier. Because even though the baby is ready to go to another site, there may not be a bed that’s available. So lack of bed space at the appropriate site.” – *HOSP003*

Not having bed spots to transfer neonates can act as a problem in several ways. One way is that the lack of bed spots at other sites means that the NICU has to hold on to the infant longer or possibly change discharge plans and discharge the infant home earlier than what was originally planned. This can prove risky if the parents are not ready to handle the infant at home or if the infant’s health status becomes worse after being discharged home. Hanging on to the infant at the NICU until a spot is free means that another infant who requires higher level neonatal care is unable to obtain that care. A healthcare professional highlights an example of where lack of bed spots can end up having a huge impact of the parents or families of the neonates:

“Like because our unit is...they are mostly sick babies, sicker babies. So if we have a baby who is just feeding and growing, we need to transfer them out. The problem is, oh, there’s no bed. There's no bed. Like especially when parents... Like we had a baby here stayed 7 days. He was from North Bay. He stayed 7 days just feeding and growing. The parents had the twin in North Bay, and they had to stay here beside this one, even this one wasn’t sick at all, just because of lack of beds.” – *CHEO001*

The cost of keeping an infant on a level III NICU is higher compared to lower level NICUs and other units. Thus, keeping an infant on a level III NICU who no longer requires that care can be considered not good use of healthcare dollars.

Lack of Resources

In terms of the lack of resources at other sites, mainly human resources and services, a mixed response was obtained. One healthcare professional mentions that in some institutions, bed spots may be available but they might not have the resources needed to care for the infant and that can serve as a barrier:

“So transferring to other centres that may not have the same level of collaboration can be a barrier. Because I can just think of a couple of instances where we’ve wanted to send them to one of our regional partners, and, you know, it was at 7:00 at night and they said, “No, it’s too late because we don’t have this, this or this.” So they may have had a bed but they don’t have the same level of resources as we do.” – *HOSP003*

Another healthcare professional points out that human resources team tends to decrease at nights and over the weekend which makes it harder to plan or carry out a ToC – another possible reason for why “Friday at 4:30” discharges may occur:

“And there’s another thing which is the medical team shrinks. So there’s like two people, sometimes one person at night. And sometimes there are two people but the most senior one is the one coming from another service just to cover. And the junior might not be aware of everything that the baby had. So that’s kind of the downside of it. And babies end up going somewhere where they shouldn’t have been discharged.” – *CHEO001*

In contrast, CHEO020 states that resources are not as big a problem as people like to say it is. In her words, there is no set rule that only a particular person can carry out a task. If that person is away on vacation, then another member on the team can step in and take over that role until the person returns:

“Yeah, like somebody else on the team can do it. They’re not the usual person but they can do it, or they just tell us to do it, or whatever. But I’ve never seen it significantly hold up a discharge.... So no, I don’t think it’s a resource issue.” – *CHEO020*

This difference in opinion is quite interesting and at the same time hard to understand why this difference exists. Personal characteristic or values may be a possible reason in the sense of how likely is the receiving end willing to smudge the policy lines. One respondent highlights the issue of lack of resources with the competencies needed to care for the neonates once discharged out as a barrier:

“A really big barrier is the lack of experience and knowledge from the outlying community dietitians. They have very little experience with these neonates with complex care needs. And therefore they feel anxious, they’re uncomfortable, they don’t necessarily always know what to do. And it involves some education on our behalf and a lot of phone calls and emails and hand holding and coaching. And I think the parents feel that too. They start to feel anxious and a bit frustrated.” – *FLR005*

Here this healthcare professional highlights that the lack of competencies required of healthcare professionals to care for neonates in the community is a barrier that causes stress for the hospital staff and anxiety for the families as well.

Different Organizational Practices

An interesting challenge to the ToC of neonates that was highlighted by healthcare professionals is the different organizational practices amongst the different hospitals and/or floors. A healthcare professional provides an example:

“They’re sort of level 1 ½, 1 B/2. So there’s only a certain kind of baby that we can send there. But yeah, they sort of... They’re a part of our regional program but they march to the beat of their own drum.” – *HOSP003*

HOSP003 further highlights that the fact that these organizations follow their own set of rules and are not very flexible, it makes it harder for the other units to carry out a ToC:

“So even though there are some provincial and regional guidelines, they dictate what... So you know, the fact that we can’t transfer a baby after 7:00. Well, if a baby needs to be transferred or should be transferred or could be transferred at 8:00 at night, because there isn’t a physician who is able to accept the baby physically, that’s not...you know.” – *HOSP003*

From informal conversations with healthcare professionals during observations as well as during key informant interviews, I heard different accounts of these organizations not necessarily conforming to the regional guidelines:

They just do things the way they want to do it. And some of the babies that we want to transfer, the physician is like, “Well, I’ve gone home now. So you can’t send that baby because I’m not there to receive it.” Well, you know what, you’re receiving dollars to be on-call. If the baby comes at 8:00, maybe you should just put your knife and fork down or finish eating your dinner and come back to the hospital. You are a physician, right. And if this baby needs to be transferred to this level of care because we need to make bed space to accommodate something else then, you know what, get off and get to the hospital. But no, because they’ve left the office for the day. So that’s why we’re not allowed to transfer after 7:00 at night. – *HOSP003*

Why this is the case is unknown and hard to explain. When thinking of this situation, it raises questions of why is it that regional guidelines are in place but these organizations have the freedom to choose how they want to practice them? It is quite possible that this is the case because no regulatory-like body exists to control these factors.

Unique Challenges Discharging Infants Outside of Ottawa

Healthcare professionals identified discharging infants outside of Ottawa a challenge to ToC of neonates. This is another common theme, which was prevalent amongst the results of the family and community healthcare professional interviews. During informal discussions with

healthcare professionals, I did hear a lot about this issue. Here is an excerpt from my observation notes:

“It is significantly easier to discharge infants into the Ottawa area versus the outer areas. There are more resources allocated in the Ottawa area due to its population density compared to other areas such as Baffin. As CHEO’s catchment area is quite large and so there are different services and criteria amongst the different areas making it harder to discharge as you need to research what is available in those areas. For those areas that do not have the services needed you need to either negotiate with a neighbouring town to provide care or think of an alternative plan.” (Observation Notes, March 11, 2016)

These notes not only highlight the point that discharging infants out of the Ottawa area requires a lot of work, but also that it takes a lot of time. This is another reason why it is crucial for healthcare professionals to be notified early of any ToC plans so that the services can be lined up in time for the infant once they are discharged home.

Symptoms of System Challenges:

‘Ownership’ of Patients.

Interestingly, ownership of patients was another challenge to ToC that was brought up. In this case, it is thought that hospitals/units have a sense of ownership of their patients since they have invested money and resources for their care and so tend to cling on to them longer. One respondent explains that this is often a result of the way the healthcare professionals are paid:

“Ownership. So some people want to hold onto patients, right, because it’s money in their pocket. So take for example, this site. This site, even though it’s a part of the

Ottawa Hospital, it's a fee-for-service. So whereas the doctors at the General and CHEO, that team is all...they're salaried. These guys are fee-for-service. So the more patients, the more they're billing. And that again is just speculation. So why is it that we always have a full house here? You know, why is it that there's always babies that maybe potentially could go somewhere else? Why is there such resistance when we say, you know what, this baby...the parents live in Stittsville, the baby is only going to be here for about another week, let's send the baby to Queensway. They've got space. So that sometimes there's resistance there. So money is a driver and a barrier too." – *HOSP003*

This sense of ownership over patients can act as a huge barrier to transitioning patients out of the units. According to the policies of the NICUs, once a patient no longer requires the level of care offered at that NICU, the patient must be transferred to a lower-level unit or home. By practicing ownership or keeping bed spots full for the purpose of money it can definitely create a block in the ToC flow of patients.

Early or Inappropriate Discharge.

Another symptom of poor ToC planning was early and/or inappropriate discharges. This was a challenge that was brought forward by the parents interviewed as well. Early or inappropriate discharges can be the result of the units trying to free up bed space. As the following healthcare professional mentions, pressure from the unit administration to transfer infants who no longer require tertiary level care can result in earlier than planned ToC:

"Sometimes it's a real pressure because you just don't have beds and you have admissions to come. On the other hand, sometimes it's mainly an administration pressure they set us under. So I mean especially at CHEO, there's a lot of pressure to transfer not level 3 babies at the earliest time you can, no matter if you have beds or not. Just transfer them." – *CHEO016*

An almost inappropriate or maybe even an inefficient discharge for the infant almost carried forth due to administrative pressure on the unit was witnessed for one of the infants observed in this study. Case VII in this study was born in one hospital, and then transferred to three different NICUs. From my observation notes:

“During the transfer from ____, the physician was unsure as to where the baby should be transferred. He had the option of transferring the infant to hospital X, but it was known that the infant would require a test to be done which was not available at hospital X. Therefore, the infant would have to be transferred back to CHEO/TOH to get the test done and then transferred back to hospital X. This would have resulted in more stress on the infant and the parents as well. So the parents and the physician together made the decision to wait until a bed spot was free at hospital C (where the testing service is available) and then transfer the infant there to avoid multiple transfers. According to hospital staff and the parents, admin staff were adamant on sending infant to hospital X to free-up their bed spots (keeping infant was seen as waste of resources). Parents and the physician argued for a transfer “in the best interest of the infant” and not the hospital admin staff. Infant eventually kept until spot was available at hospital C.” (Observation Notes, February 3, 2016).

Many challenges when planning a ToC do exist. This section presented system-level challenges such as the organization of the NICUs in Ottawa, lack of bed space, lack of resources, variation in organizational practices, and discharging infants outside of Ottawa. Of course, part of the issues the healthcare professionals raised that they faced during ToC dealt with professional level factors. These issues are discussed in the next theme.

Professional level challenges

The healthcare professionals interviewed identified challenges to ToC planning that existed at the professional level. These challenges include the occurrence of IPC, who healthcare professionals thought were key members of the theme, the need for respect and trust amongst healthcare professionals, and the involvement of healthcare professionals (especially non-medical and non-nursing professionals) in ToC planning. These four challenges are presented in this theme.

Interprofessional Collaboration (IPC)

Healthcare professionals were asked whether they felt that IPC was occurring in the unit.

The majority of respondents indicated that they felt it was occurring:

“Yeah, it's everywhere. So within the team and outside the team. For example, when we have complicated babies, we call other services when we feel that they are more expert than us. And that's how we collaborate with the other physicians. Like when if you need the neurologist, if you need a cardiologist, it works very well. And as I said, everyone who has the baby's best interest in their mind, they try to make that work very well with the other team. Within the team between us, the dietician, and the RT, and pharmacist, we have been working together for a long time. So it's working.” – *CHEO001*

“Oh, yes, every day. Well, we make rounds every day. The rounds are attended by the doctor, in our case, the resident, the medical student, the bedside nurse, the charge nurse, quite often the RT, social worker. And we all make rounds on all the babies and make a plan for that baby for the day.” – *HOSP005*

Healthcare professionals who work across many units or between hospitals were able to compare how IPC worked amongst the different care teams:

“Yes, on most units. Some units, very poorly.” – *FLR005*

“Yeah, I think there's a strong inter-professional milieu here. Like I see it more in out-patients because we have a feeding team and I think everyone is able to come together all at once at a specific time.” – *FLR004*

“Yeah, at CHEO, I think it works okay. But... Well, I think we have improved the situation. There is still some room. I mean at TOH, actually it does not work very well.” – *CHEO007*

This difference in how IPC occurs between the NICU and the different floors can be explained by how frequently the other floors accept a transfer of a neonate from the NICU and the number of specialities who collaborate on the unit. Based on the responses, it was understandable that there are a few units who are more likely to accept a transfer compared to others, as they are

better equipped in terms of material and human resources to care for the neonate. One healthcare professional explains further:

“I think they’re more comfortable and they have a longer history of getting the neonates that come up, and they know the process of consulting early. It’s like a well-oiled wheel where they know all of the pieces that need to happen for discharge. And so we tend to be consulted a lot sooner. There’s a lot more communication. And often we hear about the children that come up. Especially if they’re coming up under complex medical care, we hear about them before they come up and we can start to be ready before they even come up. And we get to meet the families right from the beginning.” – *FLR005*

Key Members of the IPC Team

Key informants were asked to state what they thought were the key characteristics of their team. Many key elements ranging from good collaboration to sharing a common goal were listed. The most common characteristics that were listed amongst the healthcare professionals at the different care sites were communication, respect, and trust:

“I think definitely trust needs to be there. And the way you build trust is through good communication. So I think ongoing communication is key throughout the process. Another key I think it just the willingness to collaborate and being available.” – *FLR001*

“Well, trust, communication, and respect are important.” – *CHEO007*

“Communication. The ability to communicate respectfully and effectively. I guess respect. And it’s having a common ground. So knowing what the goal is, what the overall outcome is, and working towards that. So doing that with effective communication, respect. What else? Trust is another. I think as a member of a team, you have to be able to trust the decisions that are made.” – *HOSP003*

Frequent Physician Turnover.

Frequent physician turnover was identified as a challenge when it came to ToC planning. The service time differs amongst the units with some physicians rotating every month and others every week. According to observations and informal discussions with healthcare professionals, it was noted how this can be a challenge to ToC planning:

“Staff physicians who come on the unit are often returning to service after a long period of being away. When they return, they often have forgotten the ToC process or have to learn a completely new process because the old had changed while they were off service. This makes it hard to plan transfers quickly and/or efficiently as the staff physician has to “prepped” or re-learns the ToC of process which can take time – in some cases, by the time they are comfortable with the process it is the end of their service period. The time put in by other healthcare professionals to help the physician re-learn the process has gone to waste.” – (Observations Notes, March 11, 2016).

Respect & Trust Amongst Healthcare Professionals

Respect and as a result, trust were both identified as key elements of working collaboratively as a team. Key informants identified that it was crucial to respect each other’s profession and experience, which would then give rise to trusting their opinions regarding an infant’s care plan:

“And then another thing is respecting the opinion of the other services. For example, the RTs have been working on their field for some of them for 15, 20 years. They know...they know what... Like in that area, they’re very expert. So respecting their opinion even if it’s different from mine...And it’s very important for them to accept my point of view, and I accept their point of view. So respect and acknowledging people’s expertise...” – *CHEO001*

Lack of trust amongst healthcare professionals resulted in healthcare professionals doubting whether they could trust an infant in another healthcare professional’s care:

“But then the issue is...and there is an issue of trust, not really with the physicians but certainly with the nursing staff. You know, are they capable or do they have the expertise to take the baby back?” – *CHEO007*

This lack of trust when transferring an infant to another healthcare team’s care could be the result of lack of knowledge of the expertise of the receiving team. The result of this lack of trust can result in a healthcare team clinging on to and prolonging an infant’s discharge when, that tertiary level care bed can be used by another infant who requires it. For example, key informants raised the issue of infants requiring tracheostomies¹ being sent home directly from the NICU instead of being transferred to the floor. Even though healthcare professionals on the NICU felt it made more sense in terms of the comfort level of parents and cost to the system, other healthcare professionals, including community healthcare professionals (See Chapter 6), felt that is was a reflection of the lack of trust of the expertise and competencies of the healthcare professionals on the other units.

“I’m saying it’s easier because, as I said, the parents already know everybody who is in that group already. They don’t have to learn a whole different group on another unit. So we’ve already established the trust...And not that they’re testing you but when they know their child better, to try and explain every day to a different resident or a different nurse who’s coming on, it becomes tedious....it’s faster and that’s why you offset the cost. So a bed in neonates is much more expensive than a bed on the wards. But if they’re going to stay there weeks, few weeks than if they were on the wards, I think it balances it out to maybe cheaper, even though the bed is more expensive.” – *CHEO08*

Lack of trust as a challenge was identified during transfers to another healthcare team in hospitals, ToC of infants to community care, as well as within team members. This lack of trust can be linked back to the issue of healthcare professionals in other units being consulted last

¹ **Tracheostomy** – a surgically created hole through the front of your neck and into your windpipe (trachea). When the normal route for breathing is obstructed or impaired, a tracheostomy helps to provide an air passage for an individual to breathe.

minute – which could be a cause of an infant being transferred last minute due to pressure from the unit’s administration. In this case, the healthcare team is required to transfer the most stable infant out of the NICU to make room for another infant who is requiring immediate tertiary level care.

Involvement in ToC Planning

Key informants were asked if they felt that everyone who needed to be involved in an infant’s ToC planning was often involved. Healthcare professionals identified that it was easier to do so on the CHEO NICU, as most of the professions were present during the morning rounds. They did identify, however, that it might be a bit harder to do when other sub-specialities are consulted for certain patients:

“I think it depends a bit on... I think often yes. Of course it happens that especially if you have other sub-specialities involved, it becomes...it gets difficult to involve them all. And just in terms of efficacy, not a very efficient process sometimes because you have to get in contact with all those and get the answer that they are really okay with discharging a baby. And that’s again a bit easier here since it’s mainly the team which is present during rounds. The social worker is more present at CHEO. But it’s somehow a bit limited and a clearly defined team here for all the babies. While at CHEO, you have a larger team and the team consists of different team members for all the patients, depending on the involved sub-specialities.” – *CHEO016*

“Most of the time. I wish we had a few more meetings, I think, with families like as a group. It happens but it tends to be with the more complex kids...Oftentimes the surgeons aren’t able to come to meetings. And I feel like that would be important. I understand everyone is strained with time. But I feel like sometimes I end up explaining things to families in meetings because the surgeons can’t be there...We just can’t get all the subspecialists together sometimes.” – *FLR004*

The difficulty with getting other subspecialties, or everyone on the infant’s care team involved when it comes to making discharges around ToC can be attributed to time (the schedules of the individual specialties involved) and their respective caseloads. In this case, using appropriate documentation of care notes would help the most responsible physician make decisions

regarding the ToC of the infant in the absence of the respective healthcare professional. A case, who was observed for the purpose of this study, went through a similar issue where the parents of the baby was told that the infant can go home once she had a holter monitor test done. This information, however, was not relayed to the neonatologist by the cardiologist and the neonatologist was preparing for the infant's ToC to the floor without a holter test being performed. The parents shared that they had in fact pointed it out to the neonatologist who then consulted with the cardiologist and then changed their plans to discharge once the holter monitor test was performed (See Chapter 4). Healthcare professionals were also asked who they felt should be included in planning ToC. A mixture of responses were received:

“Parents. The bedside nurses.” – *CHEO009*

“Well, maybe people like OT [occupational therapist] and PT [physiotherapist], they wouldn't find out as quickly. So they would come in and we'd say, oh, we transferred that baby. But they're okay because it's upstairs. But if they transfer to another hospital, that would be a different story.” – *CHEO004*

“So social worker, dietician, lactation consultant. Sometimes the pharmacist for sure. The respiratory techs for sure need to be involved in those situations where oxygen is required.” – *HOSP003*

This mixture of responses suggests the differing values that each healthcare professional has in terms of who should be included in an infant's care. Who should be involved in an infant's ToC plan depends on the individual values of each professional. As the neonatologist is the most appropriate healthcare professional of the neonate on the NICU, this decision lies in their domain. Thus, it is not intentional that other healthcare professionals are left out of the ToC but simply that the understanding of the role of each healthcare professional differs amongst them and possibly unconsciously influences their decisions on who to involve in the care team.

In this theme, healthcare professionals presented their ideas of what is required for successful IPC amongst their team members. They also go in depth to highlight issues around respect and trust amongst healthcare professionals, the involvement of the team in ToC planning and specifically who should be involved. This led to the identification of some challenges when it came to including everyone at the table including time as a factor. It is important to understand that it is crucial to recognize all the healthcare professionals involved in an infant's care as part of the care team; this is similarly true in the case of the infant's family. The next section highlights family-level challenges to ToC.

Family-Level Challenges to ToC

Based on the results several family-level challenges to ToC of neonates were identified by the healthcare professionals during their interviews. These challenges have been organized as subthemes and presented in the following sections.

Difference in Parental Responsibilities

Several healthcare professionals identified the difference in parental responsibility requirements on the various units as a barrier to ToC. This comment was more prevalent for healthcare professionals working on floors other than the CHEO NICU. For instance, an excerpt from my observation notes after an informal conversation with one healthcare professional:

“When on the NICU, parents are encouraged to relax or stay home while their infant is cared for by healthcare professionals. Situation is different on the floor where parents are expected to care for their infant themselves...Could be a shock for families coming from the NICU as they may not be aware of this change in responsibility.” – *FLR005*

Here, this healthcare professional's comment reflects the challenge they face with family members when receiving an infant from the NICU. The change in human resources numbers on

the floor means that the healthcare professionals rely on the parents to care for the infants while they take care of the medical aspects of the care. Parents not used to caring for their infant or unaware of this may be shocked and may find it difficult adjusting to this new role. This may, however, prove useful for parents as it's a way for them to practice caring for their infant in a safe environment (See Chapter 6). Another healthcare professional brought up the fact that it is sometimes practiced on the NICU to allow the parents to get comfortable with caring for their infant suggesting that they acknowledge the importance of getting the parents comfortable right in the NICU:

“We just kind of encourage the parents’ level of comfort....Just the nurses will keep kind of caring for that baby. And they’re just dragging things along. And it depends. It depends on the experience of the nurse.” – *CHEO001*

Parental Readiness

Parental readiness was also identified as a barrier to ToC of neonates. Parents who are not comfortable or do not feel ready to take their infant home present as a challenge as they are the ones who will be fully responsible for their infant's care on a daily basis once home. A healthcare professional shares an experience of a mom who was not ready to take her infant home:

“Sometimes it's our parents not actually coming in. Because we haven't empowered them, right. So they don't... Recently, we had a family that said... Mom actually left the day the kid was supposed to go home. You know, some of it was out of fear that she was taking home this child, and she was afraid of apnea and... The child kind of had a rough go. But we didn't set her up to succeed. We, you know, with our actions and our words, we pretty much sent her home. And she showed up 2 days later when she felt better. She came to discharge her kid.” – *CHEO002*

Another healthcare professional also comments on the same issue:

“And also there's a big thing, which is the parents' readiness. So if the mom is not ready, that might just... You know, we consider that and we support the mom. And if that means like another day for the baby to stay in then we consider that.” – *CHEO001*

An incident like this brings about different situations. For instance, the first red flag is whether the mom is actually ready and if she says she is, will she actually be able to care for the infant at home? Thus, as these healthcare professionals state, the importance of empowering the parents to care for their infant is very important and should begin right at the start in the NICU.

This theme portrays the key challenges that healthcare professionals faced at the family-level during an infant's ToC. The challenges that were often brought forth by the healthcare professionals were the difference in parental responsibilities in their infant's care between the various units and/or hospitals (i.e. NICU vs. complex care unit) as well as how ready parents were to take their infant home or to transfer their infant to another unit or hospital.

In this chapter, the healthcare professionals interviewed highlighted the challenges that they faced during a neonate's ToC at the system, professional, and family levels. System-level challenges included the organization of the five NICUs in Ottawa, lack of bed space and resources, different organizational practices, unique challenges discharging infants outside of Ottawa, and the symptoms of system challenges. The professional-level challenges highlighted include IPC, key members of the IPC team, frequent physician turnover, respect and trust amongst healthcare professionals, and involvement in ToC planning. Difference in parental responsibilities and parental readiness were identified as family-level challenges. When looking at these challenges and the symptoms of these challenges in more detail, it is prevalent that the complex communication field cuts across the system, professional and family levels and acts as

causal agent of all these challenges and symptoms. The complexity of this multi-layered communication field is discussed next.

Complex Communication Field

Communication has been a constant theme brought up by all the key informants in this study. It is not only identified as a challenge to the ToC of neonatal infants but when looked in depth, it actually is a cause of many of the other challenges identified in ToC of neonatal patients.

First Contact Regarding ToC Planning

Hospital healthcare professionals were asked to identify whom their first contact was when it came to discussing an infant's ToC plan. Many of the healthcare professionals on the NICUs identified their care facilitators as their first contact regarding ToC planning:

“Find out from Care Facilitator who is ready for discharge.” – *CHEO006*

“...And then there's also one nurse during the day who's kind of like the head nurse, the in charge nurse – I can't remember her specific role or name. Like the health... There are different names in every unit I go to. It's like the healthcare facilitator or healthcare provider or nurse in charge. Someone who just has the kind of eye, eagle view of everything that's going on in the unit.” – *HOSP001*

“So my first contact? We'd probably be talking with the care facilitators and sort of what their sense was. Because they have... At one point, we had 3 care facilitators who covered. There was always one on 7 days a week. They had a really good sense of how that family was doing and moving through towards discharge. So that would be one of my first go-to people.” – *CHEO003*

This is different when compared to responses from healthcare professionals on other floors within CHEO (e.g. 4E), who identified CHEO's CDT members and/or the family of the infants as their first contact when it came to discharge planning:

“Whoever comes forward. Usually they [CDT members] are most of the time on the floor. I could see them or I could do... If I don’t see nobody, I usually do fax the CDT form for them. And then whoever picks up that because I guess they divide the patients between them. So I usually call whoever. I know all of them so I try _____ or _____ or _____. So that’s what... I go directly to them.” – *FLR003*

“My first contact? Well, I usually talk to the family.” – *FLR004*

“I need to make sure that the discharge planning team has been consulted for them to be discharged. So I guess they would be my first point of contact. Educating the family. So I guess they would be the second point of contact.” – *FLR005*

This difference can be explained by the differences in responsibilities or roles and/or processes when it comes to ToC planning between the NICUs and the other floors. It was apparent from the interviews with the healthcare professionals on the NICUs and from the observations on the NICU by the researcher that the care facilitator played a huge role in facilitating the whole ToC process for each infant on the units. The care facilitator participates daily in a call every morning at 9am with all the other NICU care facilitators across Ontario to provide updates on bed availability (Observation Notes, November 2014). With this information, the care facilitator can plan for the ToC of infants who no longer require tertiary or secondary level neonatal care. One healthcare professional points out that who the first contact is depends on the care needs of the infant:

“So it's usually the care facilitator on the unit that we have these tentative discussions about. It depends again on the needs – medical, nursing, social needs of the baby. It depends on who needs to get involved, taking everything into account. Sometimes it’s just the family, you know, if there's no significant medical needs. If it’s a complex infant then it would be there would be a provisional meeting, a multidisciplinary meeting first, involving the players who need to be there, you know, just to even entertain discharge processes. And if it’s a child who’s ultimately in that case, they’re usually going to be coming...returning to CHEO at certain points. That has involved previously discharge planning from the... I can’t remember, they're called... Is it CCAC? I can’t remember what they’re called.” – *CHEO015*

Here, this healthcare professional describes that the majority of the time, the first contact is the care facilitator. In cases where the infant does not have significant needs, however, communication with the parents alone is sufficient. Whereas with complex needs infants, the first contact can be the care facilitator or the CDT member. In addition, I found the last line of this response from this healthcare professional quite noteworthy where she states:

“That has involved previously discharge planning from the... I can’t remember, they’re called... Is it CCAC? I can’t remember what they’re called.” – *CHEO015*

Here, this healthcare professional could not remember the name of the CDT. This made me think back to my interviews with the community healthcare professionals who did bring up that the healthcare professionals in the hospital were unaware of their services and did not understand their role clearly. Considering the major role that the CCAC (Community Care Access Centre) plays in the community care piece of neonates being transferred home, it is interesting that this hospital healthcare professional had a hard time trying to remember the name of the team.

Communication Methods of ToC Plans

Healthcare professionals were also asked how they communicate their ideas or suggestions regarding an infant’s ToC plan with the other healthcare professionals who are a part of the infant’s care team. The most common method was by way of the daily bedside morning rounds. This response was true for healthcare professionals on the NICUs at the three hospitals, and amongst the floors at CHEO:

[laughs] “We’ll just... I will just say... I’ll state on rounds. It depends on the case. But often it will be okay, the baby is improving, no longer needs ventilator support or the TPN is finished, where are they from, they wouldn’t need our level of care, can we start thinking about looking for beds?” – *CHEO014*

“Well, we make rounds every day. So this baby is approaching 35 weeks. So what do you think? Do you think it would be a good idea to discharge this baby? Where are we

at? Like does the baby meet all the criteria for discharge? You know, the right age, the right weight, eating, all that good stuff. So it's... How do I approach it?" – HOSP005

Healthcare professionals who are common or shared across multiple floors find it harder to participate in the rounds of floors where their patients are situated due to conflicting times:

I don't attend rounds. So conflicting time schedules. I also work in another area where I attend rounds. And I can't be in 2 places at once. – *FLR005*

Because of the conflicting timings of the morning rounds, the allied healthcare professionals are left to communicating their ToC-related information via written notes, verbally, and electronic medical records where applicable:

"Verbally with the family, with the nurse, medical orders, charting." – *FLR005*

This can act as a challenge as these healthcare professionals end up being left out of the ToC communication and possibly missing out on information (i.e. an estimated date of discharge, etc.).

Parents Unaware of ToC Plans

In the interviews with the parents of the 12 cases that were observed as part of this study, they identified being told of their infant's ToC last minute as one of the biggest challenges faced. The prevalence of this theme was brought up to the healthcare professionals during their interviews to hear their perspective of the situation. One healthcare professional explains that she always finds it hard to understand why parents always comment on being unaware or notified last minute about their infant's discharge:

"Yeah. And we find that really difficult to understand because we talk about the baby's discharge home weeks in advance. So we're planning for your baby's discharge. So they know that it's coming. And then usually about a week before, it's like, you know what, we're looking at the end of next week if everything goes well, if your baby continues to feed well, whatever. So we always are confused when parents say that." – *HOSP003*

Parents, understandably, are anxious with having their infant admitted on the NICU. Also, as mentioned in a previous chapter, parents are bombarded with information when they are on the NICU by a variety of healthcare professionals about their infant's care. The case may be that their anxiety may not allow for them to take in all the information that they receive calling for different methods of making sure parents are taking in the information that is given to them. A healthcare professional points out that it is possible that the information is not relayed to the parents and this could be due to the fact that some parents are not present during morning rounds and thus do not receive updated information on their infant's ToC plan. She also admits that staff can do a better job at relaying to parents that their infant will be transferred to another centre once they are deemed to not require tertiary level care anymore:

I can see that sometimes it might feel a little bit rushed. Because the parents come and we don't necessarily tell them, you know, you will go back somewhere else. And we probably should be we're supposed to be a tertiary care centre, not lower level of care. I think that sometimes there's discussion mostly on rounds... So parents that aren't at rounds when the rounds take place, it does get brought up and it does get discussed, and they do get involved and informed. It's more of a challenge for parents who are not at rounds. And I can see that sometimes it might come as a surprise. – *CHEO014*

Another healthcare professional explains that being unaware or surprised about their infant's discharge is understandable for parents of infants who are in the NICU for acute care issues but not understandable for longer term infants on the NICU:

“So those ones are going to be the really, really short stay. Where they come in and you're like this is either something or nothing. And so you decide it's nothing, and so now we want to send you home. So you were only here for a day or two, and we didn't really have time to prepare you for that. And then all of a sudden, it's like, “Well, no, you're right, they didn't get worse. They meet our criteria. You could go home today.” But I can't see a longer term kid being a surprise.”

She further explains that healthcare professionals do tell parents of longer-term infants of the steps or milestones that their infant needs to reach before they can go home. This healthcare

professional insists that parents should be able to predict themselves when their infant will possibly be transferred out of the NICU based on when their infant has reached the milestones:

“Mostly I don't know what it's a surprise. Because I mean we've got some long-term kids and I can't tell you when they're going to go home, right. But it's pretty obvious they're not going home. And fairly often we have trouble nailing down the actual day. But you know, we'll say to them, they need to not need a tube feed for 2 or 3 days. And so to me, if I've told you once you don't need tube feeds for 2 or 3 days, if you're the parent and you've seen that your kid hasn't needed tube feeds for 24 hours, you know, do you need me to say, “Hey, you're up. You might be going home tomorrow if you don't need tube feeds again.” Like why is that a surprise? Like you've been told multiple times...” – *CHEO020*

Last-Minute Notification of ToC

The healthcare professionals interviewed did bring up the issue of being told last minute of an infant's ToC. One healthcare professional describes discharges on the NICU as being “precipitous” or spontaneous and as a result leaving healthcare professionals scrambling to complete necessary preparations for the discharge:

“I find often discharge, it's precipitous. You know, like it's hard sometimes to have a plan. You know, sometimes the team says okay, like we plan for discharge by the end of the week. And sometimes I'm on rounds, this baby, okay, his halter is off and ready to go home. And you're like ahh!” – *CHEO018*

Two healthcare professionals raised the issue of being consulted last minute prior to an infant's discharge:

“So often there is that concern of last minute consults. So for some children, the medical team is like, okay, this is a child who's easily managed, maybe they are tube fed but they're growing, things are great. They're teeing them up for discharge. And then it's Friday afternoon, and they go, oh, wait, for them to be discharged home on a tube feed, they need a dietitian to write a plan for the community dieticians and then they need a prescription. And they need the nutrition products' paperwork and the pharmacy and teaching. And so that happens last minute as well. It does happen.” – *FLR005*

“Probably earlier... earlier involvement of the transport team for some of these complex transfers.” – *CHEO010*

Lack of time to make preparations for the infant to go home is not the only challenge, but healthcare professionals receiving the infant to their site also experience problems when they are told last minute of a ToC or receive a last-minute referral. The problem can do as much to having to deal with upset parents. One healthcare professional spoke to a situation that had occurred with one of the cases in the study who was transferred from the CHEO NICU to another Floor in CHEO. In this situation, the parents of the infant were told that as soon as the baby was transferred to the floor, she would receive the care from the allied healthcare professional that she needed and then would be able to go home. That healthcare professional on the floor only received the referral the day before the baby was transferred and thus due to her workload was unable to attend to the infant immediately after the ToC:

“So I got a referral, right for this baby but it was like the day before they were going to the floor... Like I really think the family was told in the NICU that we’re sending you to the floor so that you can feed and grow.... So then it puts pressure on me. Because then once the family finally got to the floor, they were like, “Well, where’s OT [occupational therapist]? We need OT right now.” Because apparently everything rests and relies on me feeding this baby, right, who’s continuously fed. So that’s where a lot of the frustration came from.... But it seemed like a whole lot of unnecessary drama. Like drama, right, for really...or crisis for not. Like I just feel like maybe it could have been handled a bit better in terms of communication. I mean it was the communication piece.” – *FLR004*

In this case, had the allied healthcare professional on the floor known earlier that this baby was coming, it would have been easier for her to prepare for the infant’s arrival by possibly meeting with the infant’s healthcare team to obtain more information and she could have met with the parents before the ToC. This situation really points to the issue of miscommunication both in terms of notifying the healthcare professional late and also miscommunicating what the parents should expect when they are on the floor. Another healthcare professional explains the actual

situation a bit further in response to this situation. She states that the “Friday at 4:30pm” discharges are simply the perception of the receiving healthcare team and that in actuality, there are other challenges that the NICU faces when trying to transfer an infant out of the unit:

“And like we don’t do that. That’s their perception. But we don’t. We probably started calling for the bed on Tuesday, and we don’t get it until Friday. And then, you know, Friday at 10:00, we call for the bed, we call for the senior [resident]. And if the senior doesn’t come down until 4:30, what are we supposed to do about that? Right? So yes, there’s some frustration.” – *CHEO020*

She also highlights the different communication processes that are required to transfer an infant to certain sites which often lead to most of the miscommunication on ToC:

“And the General peds people have insisted that we do staff physician to staff physician for acceptations. Which is different than anywhere else. So it just adds another layer of confusion, right, because we have to pick up the phone and call staff to staff to get them accepted. But then they don’t necessarily tell their seniors. And now we have to pick up the phone and call again, to call a different person to get them to come. So it’s more cumbersome and complicated than it... They complain about our transfers a lot. And when we look into them, usually we have requested the bed in a timely fashion. And it has fallen apart somewhere in the complicated process.” – *CHEO020*

This theme highlighted the complex communication field which exists when planning a ToC. With many different key players in the care teams, it is easy to miss out on communicating with everyone or not communicating at all. With different communication methods (i.e. morning rounds, patient notes, etc.) available and everyone using whatever method they are comfortable with creates this complex communication field. Considering the time pressures as well as the pressures of each healthcare professional’s job demands, it is hard to spend time ensuring every possible tool is updated which adds more to this complexity. The implications of this complexity are healthcare professionals and parents not being aware of ToC plans and last-minute

notification of ToC to healthcare professionals, which in turn hinders the ToC. This same issue will be reinforced by the experiences recounted by the parents in the next chapter.

This chapter highlighted the many challenges that are faced during a ToC of neonates from the point-of-view of the healthcare professionals who provide care for these neonates. Analysis of the interviews with the healthcare professionals revealed challenges at the system, professional, and family levels.

Where there were differences were when interviewing healthcare professionals on the floors and the other hospitals. For instance, experience caring for neonates on the floors was a factor when it came to IPC. In other words, floors that receive neonates from the NICU on a regular basis felt that their collaboration with the NICU was smoother compared to floors that received neonates every so often. The nature of the unit almost mattered when it came to bed spot availability. For instance, floors that tended to have more complex care needs children who spent long periods of time on the unit which could be a reason for them not often having free bed spots open. This factor might not be interpreted correctly by the NICU when they keep raising lack of bed spots on the floors. The same goes for the NICUs in the other hospitals in that those NICUs are not located in a pediatric hospital, which means that not all the facilities available at CHEO are necessarily available at the other NICUs. For example, CHEO's occupational therapists and physiotherapists are consulted whenever those services are required at the TOH NICUs.

CHAPTER 5

Family Experience of Transitions of Care

This chapter presents the findings obtained from the family experiential interviews. The purpose of these interviews was to understand how the families of the neonatal infants experience the transitions of care process. The parents of the 12 cases followed in this study were interviewed pre and post discharge. Parents were asked for information on who they were approached by to discuss their child's discharge plans, what support were they given along the way, how comfortable they felt contributing to their child's discharge plan (or if they were encouraged to do so), and their overall view of their discharge experience (See Appendix IX). Post-discharge, parents were asked about their overall discharge experience, their contribution to the discharge plan, and if they felt any improvement in the discharge process was needed (See Appendix X).

There was variability in the background of the parents who were a part of this study (See Table 9 for summary of parent demographics). The majority of the parents interviewed were in their thirties and were first-time parents. Eight of the 12 cases were living in the Ottawa area and the remaining four were from rural areas (at least one hour away from Ottawa). Only two of the 12 cases were from a non-Caucasian background and another two cases were primarily Francophone with minimal English-speaking ability (enough for the purpose of the study). Of the 12 cases, the parents of only one case were unapproachable for interviews due to the circumstances during their stay at the hospital and inability to contact them via the phone number and email provided on the consent form. The observations and healthcare provider interviews collected as part of this case, however, were included in the sample after consensus from the thesis committee.

There were three key themes that were most salient from the thematic analysis undertaken. First, ToC/Discharge Process, which highlights some of the key issues surrounding ToC in the point-of-view of the family. Second, Family-Centred Care, which presents the parents' experience of the family-centred care dimension of the ToC process. Finally, Community Care which highlights their experience of transferring over from care in the hospital environment to care in the community. The themes are presented in this order as it highlights both the most prominent themes and the temporal arc of the discharge process from initial discussion to transition to community. These sections highlight the main experiences that the parents reported on in terms of their experience of their infants' transition of care (their experience of this system).

Table 9. Family Demographics.

	CASE			
Home	Case 3 – ACUTE • 2/2 HCPs interviewed • Interviewed Mom & Dad separately pre and post • 1st child • Parents were in 30s • Lived in Ottawa	Case 4 – CHRONIC • 4/4 HCPs interviewed • Single mom; Ottawa interviewed pre and post discharge (late 30s) • Has other children • Social works	Case 5 – ACUTE • 4/4 HCPs interviewed • 2nd child • Pre & post with parents together • Parents in 30s • Ottawa	Case 6 – CHRONIC • 4/6 HCPs interviewed • 3rd child • Pre & post with Mom (post via email). Dad was working • Rural area
Floor	Case 2 – CHRONIC • 6/12 HCPs interviewed • New immigrant family (African descent); father does not speak English well (mid 30s) • Parents were not interviewed (due to difficult issues) • 1st child; Ottawa	Case 8 – CHRONIC • 6/10 HCPs interviewed • Pre and post interviews with Mom and Dad separately • 1st child • Parents in mid 30s • Ottawa	Case 11 – CHRONIC • 4/7 HCPs interviewed • Parents were Francophone with minimal English • Rural area • 1st child • Interviewed parents together	Case 12 – CHRONIC • 5/8 HCPs interviewed • Young parents (20s); 1st child • Social works involved • Ottawa
TOH	Case 1 – ACUTE • 4/7 HCPs interviewed • Twins; 1st child (20s) • Francophone with minimal English; interviewed pre and post together • From rural area (2 hours away)	Case 7 – ACUTE • 5/7 HCPs interviewed • Pre and post discharge with Mom and Dad (post was at home); Ottawa • Mom is PT; Parents were in 30s; 1st child	Case 9 – ACUTE • 4/6 HCPs interviewed • 1st child, parents in early 30s, South Asian background • From rural area (1 hour away) • Parents are working	Case 10 – CHRONIC • 5/8 HCPs interviewed • Unexpected case; parents in 30s; Ottawa • 1st child • Social works

The Transitions of Care/Discharge Process

The transitions of care (ToC)/discharge process of neonates from hospital to home is a complex process occurring within a complex system as described in Chapter Three. It involves the collaboration of a whole array of healthcare professionals and the patient and/or patient's family. Based on the complexity of this process and the amount of patients that healthcare professionals have to care for on a daily basis, it may not always be possible to assess the experience of the patient and/or patient's family. This theme highlights what parents experienced about the general ToC/discharge process in general.

Discharge/ToC Communication

Communication was one of the main themes that emerged from the interview findings. It acts as a crosscutting theme where each of the codes/themes discussed in this chapter have some sort of connection with communication. This section will review the responses of parents when they were asked about discharge planning-related communication specifically. The responses received were a mix of both positive and negative experiences in terms of discharge communication. Many of the parents stated a positive experience in terms of when discharge was discussed with them and getting answers to their questions:

“They tried to, if they didn't have the answer, they tried to... The nurse, if they didn't know, to ask the doctor and to tell me after.” - *FAM001*

“Discharge plans discussed right from the first day. If anything needed further clarification someone would come afterwards.” - *FAM013*

“The plan was discussed many times, I was very appreciative to the staff and making sure we understood.” - *FAM012*

There were also reports from parents that even though there was a lot of opportunity for communication, it did not happen properly. It was found that this was often the case with

parents of acute care infants. These infants were usually kept on the NICU for a very short time and thus because their discharges happen quickly, are not as complex as for chronic infants, and most of the time happen spontaneously, there are chances that healthcare professionals did not have enough time to thoroughly plan the discharge to the community. Whereas with chronic infants, because they will be on the unit longer and require many services when being transferred or discharged, their discharge plan often started earlier and involved a lot of communication with the parents. Other parents stressed that unclear communication resulted in them missing out on important information that could have decreased some of the hassle they went through:

“Well, they gave us a lot of heads up. Like they gave us multiple times that they would talk to us about discharge. So there wasn’t a whole lot of... Like there was a lot of opportunity but there wasn’t a specific set discussion. It was just a lot of little bits.” - *FAM009*

“It was just that the whole incident was like a little bit of lack of communication with not having... It sucks being a parent for the first time and not knowing when your child is going to come home, especially when they were taken away, sort of thing.” - *FAM016D*

“Well, like I said earlier, it was kind of confusing because there was that lack of communication. So I feel, you know, nobody actually... It gets confusing and stuff. And I don't want to put down anybody but like they were ready to put her to Montfort if I didn't speak up. And, you know, it would have been confusing, right.” - *FAM015D*

One mother recalls not getting proper information about the medication for her infant. She acknowledged that the pharmacist explained the medication to her and also provided clear instructions on how to administer the medication to her infant. She explained, however, that not being informed that the CHEO pharmacy was a compound pharmacy meaning that the medications were sent to the unit pre-prepared and that this would not be available in the community. This issue was pointed out to her by her family physician post-discharge. She explains the hassle of having to re-learn how to properly prepare and administer the medication to her infant:

“.... Because when you leave the hospital with medication for your child but you’re so used to giving to her at a certain amount already pre-done for you, when it’s given to you, you’re kind of like, oh, am I doing the right thing? I don’t have the same syringe. It’s not the same colour. You know what I mean? Like you’re kind of lost...So it was a horrible experience for us. We ended up going back to CHEO and getting the concentrated one. We would have done that to begin with had we known it was going to be different, depending on... You know what I mean?” - *FAM015M*

Parents also stated frustration from not understanding exactly why certain decisions were made and the decisions not being communicated fully to them. Some of these decisions included their infant was being transferred to the floor instead of a hospital near home to why a certain feeding pump was recommended compared to one the mother was more comfortable with as in the example below:

“The only thing that I was kind of not happy about was the fact that it was...the feeding pump. I didn’t like the bag. I didn’t know... Like I didn’t like it when I got home and tried it. But it’s like a huge bag that you have to clean. And it’s very... It takes a lot of time. And I’m a student so it’s not really easy to do like 8 times a day. I wanted the one with the syringes. But I didn’t get it. That’s the only thing that I wish I had but didn’t. I wasn’t really convinced that it was, oh, not convenient. I think it would have been because I would be really comfortable with cleaning it. It’s super easy. Yeah, I liked it. That one is kind of annoying.” - *FAM008*

Unaware of Child’s Discharge Plans

One of the most common finding across all the interviews that were conducted with the parents (and at all the possible sites) was the lack of awareness of ToC plans. According to the parents interviewed, they stated that they themselves were unaware or not updated on their infant’s discharge plans and that healthcare professionals were also unaware of the ToC plans of their infant. The following subsections present the lack of awareness of ToC plans of both parents and healthcare professionals.

Parents Unaware of Discharge Plans

Almost all the parents complained of being given last-minute notification of their infant's discharge or transfer date. One family reports not being notified at all of their infant's transfer to another hospital:

“They said they can call me before to transfer the baby because I didn't know. I was here, and the baby was already here. They were supposed to call me but they never called me. I Just want to know because I live far from here, and now I would like to know before because I can...if I go here before because I was thinking he's going to be here because they told me they're going to transfer him in the night or in the morning. We could have planned. Yeah. Because if I was to go to CHEO and he was not there, then I do...I travel for anything.” - *FAM001*

This same family experienced almost the same issue at the second site where they learned about the infant's discharge to home the day before. They only found out because the study's investigator had called them to inquire about a potential discharge date:

“And when you [the study investigator] asked me, I asked the nurse. She told me, “Oh, you go tomorrow.” Oh, okay. It all last minute – Okay, you go. It's very last minute.” - *FAM002*

Another family reported being notified last minute of their infant's transfer:

“We got a call at 6:00 in the morning from A to say that our daughter was being transferred to B. Up until then had no idea. When asked if it was due to a medical reason, was told that that was not the case. So couldn't really understand why she was being discharged.” – *FAM013*

This mother reported being told the day of that their infant was being discharged home and for them to be ready:

“So yeah, it hadn't been brought up. So it was just the day that we were leaving during rounds, they just said, “Would you like to go home?” So up until that point, it hadn't really been discussed. I mean I guess basically, you know, they were discussing sort of medically how she was and how she was feeding, and they were asking questions about that, about how she was feeding. And then it was basically like, “Would you like to go home today?” So... And then from there, it just went to, you know, “Bring your car seat up and have it checked.” And they made sure we had pediatrician follow-up and that sort

of thing. And it was just I think just kind of done more unexpectedly or hurriedly than we thought.” – *FAM005M*

Parents also explained the hassles they went through as a result of the last-minute notification. One family was told on a Saturday that their infant was being discharged home the next day. They were left to find a pharmacy, which would supply them with the liquid form of a medication that their infant needed at home. Because it was a weekend, they were unsuccessful in trying to locate a pharmacy that the hospital’s pharmacy can touch base with before being discharged. Because they were far from the hospital, it was necessary to make sure that the required medication was available on a regular basis:

“We have a medication to give liquid, and I need to find a pharmacy to have the liquid. But nobody tells us where we can have it because they need to compound it because it’s a tablet. We need to put it in the liquid. I think all the pharmacy closed for the weekend... He [physician] can order a few for us before we go home because after we don’t know where we can find a pharmacy for that. Yeah, for after try to find a place who have it. Because I think they don’t have a lot of pharmacies who are compounding stuff. Well, like today, we don’t even have some medication. Everything is closed. If they would have told us Monday, we could have went.” - *FAM002*

Another mother explained that because she was told about the discharge the day of, she was left scrambling to prepare for the discharge including pulling her husband out of work:

“I mean we were ready but, you know, my husband wasn’t there. So I had to get him home from work. And you know, ended up having 2 cars at the hospital. So I had to go back and pick one up later. And I mean like little logistical things that in the end don’t really matter. But you know, might have...” - *FAM006M*

Her husband’s account:

“So yeah, I’m not even sure what sort of discharge plan there was. I sort of just got a phone call halfway through the day saying we were getting released...or our daughter was getting released. So come with the baby seat. I was like, oh, okay.” - FAM005D

Healthcare Professionals Unaware of Discharge Plans

Another frequent finding was parents stating the fact that a lot of the healthcare professionals they spoke to were not sure themselves of the patient's discharge plans. Parents reported frequently hearing varying reports of the discharge plan amongst the healthcare professionals:

“But you know, up until that point, you know, one of the nurses on nights be like, “Oh, you know, I’m sure you’re staying here for a couple more days in order to get feeding.” And someone else, you know, would say, “I think she’s probably close to going home.” Or you know, you’d hear the nurse manager saying, you know, “Well, we have to move the beds.” So I mean you’d kind of get different stories along the way.” - *FAM005M*

“He speaks with me and tell me more about what is going to happen because some nurse told me something and another nurse told me another thing.” - *FAM002*

Some of the parents shared that there were times where certain decisions were made which affected a discharge and were not communicated to the healthcare team. For instance, one mother reported that a cardiologist told her that her daughter can go home once she had a holter monitor² hooked on for 24 hours. The neonatologist, however, did not know this information and the discharge arrangements had been made. Had the mother not pointed this out to the neonatologist, the baby would have been sent home without the test done. This mother reflects on the staff not knowing that the holter monitor had to be put on before the infant was discharged. She also expresses feeling bad for having to point it out:

“Yeah, they didn’t know that she had to be monitored. It was going to be on the following Monday. At that time, they weren’t aware. So again, I’m not...I can’t say that, you know... Like I feel bad saying, you know, they would have sent her because I don't know. It could have... You know.” - *FAM016M*

² Holter monitor - a portable device that records the rhythm of the heart continuously, typically for 24–48 hours, by means of electrodes attached to the chest (Medline Plus, 2016).

Another family reported being asked by hospital staff at the second site why their infant was transferred to that hospital:

“We were asked by staff at B why baby was transferred to B instead of to D (secondary level NICU).” - *FAM013*

Overall Experience

Parents were asked during their pre-discharge interview and post-discharge interview to comment on their overall experience at their respective sites. The majority of parents had positive comments to share:

“Yeah. So my experience was it was as good as it can be having a child in the ICU. Yeah, the staff was really great. Our room was in a nice sort of ideal location for us. It’s nice to have a little bit of privacy, and the room was a good size that you can...for when you’re staying there such long hours and overnight, that sort of thing. Yeah, we don’t have anything bad to say about our time.” – *FAM005M*

“It was good. Like they always had time. Even though it wasn’t about the discharge but they were always working on bringing [child] home. So that it was pretty great. It was excellent. It was excellent. Yeah, everything was well taken care of. I went home and they gave me all the appointments, they gave me everything. Like they talked with the pharmacy. They did everything. I did absolutely nothing. ” - *FAM007*

“Yeah, everything went as planned. There was nothing that was miscommunicated or when I got home and like something wasn’t right. No, everything was the way it was supposed to be. Everything planned happened. They took care of everything.” - *FAM008*

Parents also took the chance to express their gratitude for the care their infant received and also stressed, once again, that they were confident with the decisions that the healthcare teams made regarding their infant’s discharge.

“I mean, you know, it wasn’t stressful being discharged. I know when they went to... They were going to send her over to Montfort because...from the NICU because there wasn’t anything else that she needed.” - *FAM016M*

“I thought it was a good experience, like with the care team for the most part. I was just saying that your staff, the staff at CHEO, everybody from the parking guys to the janitors to the nurses, everybody was very welcoming. It makes it a good experience. As good as it can be, I guess.” - *FAM010*

There were also a few parents who highlighted that there was a difference in their discharge experience between hospitals (one being better than the other). For instance, one of the study's cases was born at the Civic Hospital and was transferred to the General Hospital's NICU as she was having 'spells'³. She was then transferred to the CHEO NICU and then back to the SCN before being discharged home. Because these parents went through four transitions, they were able to comment on the differences between each institution's ToC processes. For instance, they commented on one institution being better at discussing their infant's transfer plan with them more regularly compared to another institution:

“Transition from B to C was better than A to B. Transition was brought up more constantly at B - no surprises.” - *FAM013*

There were also some who were a bit unsure of how to express their overall experience. These vague comments of their experience could be the result of several factors including not being satisfied with their experience but feeling uncomfortable to share it with the researcher and possibly not being present on the unit as much to be able to comment. For instance this father was not able to spend a lot of time on the unit with his infant due to work commitments:

“I guess it was good. I guess, yeah, no, it was good. We came in and everyone was friendly.” - *FAM005D*

Frequent Staff Turnover

Several parents commented that the frequent turnover of staff as a challenge. This made it difficult for the parents as the different staff (primarily the physicians) had different ideas or

³ Spell – Includes either or all of the following: desaturation, bradycardia, apnea, colour change, and/or stimulation required to help baby recover (HOSP003, August 12, 2016).

protocols to follow for discharge/transition, which may cause changes in the discharge plans. For example, one physician might think that an infant is ready to go home within a few days, but another physician might think that the infant should stay for a week longer in observation. Also, with the frequent turnover of for example, bedside nurses, it was harder for the new staff to stay updated on the discharge plan and also, their observations may be different and can result in affecting the discharge plan (e.g. a bedside nurse who is caring for an infant for the first time may be more likely to flag issues that a nurse who cared for the infant for a while would pass on as being normal for the infant). Some parents expressed frustration over having to learn a new face (i.e. different nurse on rotation) and starting all over again:

“Sometimes 2 days, and after they changed. Because one for the night and one for the... I think every 2 days it changed [nurse rotation].” - *FAM002*

Other parents expressed frustration with the lack of staff over the weekend and thus not being able to receive the support that they need versus during the work week:

“But I felt on the weekday, it was more of, you know, okay, here’s what’s going on and it was more organization. They had the students. But everybody was nice, and introduced themselves, you know. And then we had our questions and they were able to answer them.” - *FAM016D*

The unavailability of staff on the weekend meant that parents were most likely unable to get information about their infant’s discharge plan, or had to wait until the week for the infant to be discharged (once checked and validated by the respective healthcare professionals).

Gender Differences in Overall Experience

It is interesting to note at this time the differences in the overall experiences of mothers versus fathers. In interviews where the mothers and fathers were interviewed separately (two families agreed to be interviewed separately), it was very clear that mother’s took a lead role in

the care of their infant while at the hospital. From staying at the hospital with their infant overnight to making decisions regarding their infants' discharge plan or care, mothers were at the forefront. Healthcare professionals had remarked on this as well saying that it was almost always the case that the mothers were more proactive. During the interviews, this was also evident – even though the interview was with the father, it was noted that he would turn to the mother for support when answering the question or when it came to recalling certain details. In cases where the parents insisted on being interviewed together, moms tended to do most of the talking. When the investigator looked over at the father to answer a question, he would quickly glance over at his wife/partner waiting for her to answer! One father constantly referred to the fact that he trusted whatever his wife said and did with regards to their infant's care. In the quote he mentions that because his wife was there on the unit he expected that everything with regards to the discharge would be arranged and the only problem they would face is his lateness getting to the NICU with the baby's car seat:

“Once again, you know, I trust my wife. So if she had concerns then I probably would have voiced them then. But since she didn't, I felt... I was okay with it. I figured everything had already been done, and I was just late.” - FAM006D

“To be honest, I figured my wife was going to deal with... She kind of has a bit more knowledge about all that kind of thing. So I was just sort of kind of in the background and going with the flow. So like whatever she thought was best, I was going to support that.” – FAM005D

Juxtaposition Between Parents and Healthcare Professionals

An interesting concept that was raised by the parents is the notion of caring for the infant versus caring in order to discharge the infant. In other words, caring for the infant with the infant's best interests in mind versus discharge being the ultimate and only focus of the care plan:

“What I didn’t enjoy was that it [the NICU] was really strict on numbers. So when we came in, our son had some issues with his lungs. He was a bit early when he was born so he was very small. And so when he was there, he lost a fair amount of weight. And so while we were there, we had to make sure that he was gaining weight. Which was of course important to us but it made it so that we...it made it hard for me to want to breastfeed while I was in the presence of these nurses and doctors because we needed to focus so much on numbers rather than on making sure that I was able to experience that breast feeding and bonding and all of that stuff that should happen. So it was like... It was just strange, the focus on the numbers to get to the discharge point rather than the actual caring for the baby while I was in there.” - *FAM010*

This family explained their struggle to argue with hospital administration to prevent a transfer that was not in the best interest of the infant’s care even if it resulted in delaying the discharge:

“Had to persuade admin to keep the baby at hospital B to avoid transfer to D and having to come back for a test that was required. Better for baby to be transferred to C which did not have available bed space at the time. Had to argue with admin to keep the baby at B until C had a spot available. We wanted a transition that was in the best interest of the baby”. – *FAM014*

This theme on the ToC process provides an overview of some of the issues raised by the parents interviewed in terms of their personal experience of the ToC of their infant. It is important to observe that what was mainly noted by parents were challenges but they did speak, although less frequently, of the family-centred nature of the discharge process – A key theme to which I now turn in the next section.

Family-Centred Care

Family-centred care can be defined as “a partnership approach to health care decision-making between the family and health care provider” (Kuo et al., 2012). Henneman and Cardin (2002) similarly define family-centred care as a philosophical approach to care that acknowledges the needs of the patients’ family members. This philosophy is initiated on the

collaboration of the family and the healthcare team to plan, provide and evaluate care, and is grounded on the central idea that the family is a constant in a child's life (Saleeba, 2008; Neal et al., 2007). The goal of family-centred care is to support the parents to be able to care for their infant. This is done by honouring and acknowledging diversity (understanding various influences of social, economic, cultural and spiritual aspects), the exchange of complete and biased information between family and health care team, and enabling and empowering the parents (Saleeba, 2008). Based on 11 Critical Care Family Needs Inventory studies from 1986-2002, the top 10 needs of families were (Parker, n.d.):

1. To know the prognosis
2. To have questioned answered honestly
3. To be called at home if any changes occur
4. To be assured the best possible care if given
5. To know the facts concerning patient progress
6. To receive information about the patient once per day
7. To feel there is hope
8. To feel hospital personnel care about the patient
9. That explanations are in understandable terms
10. To know the patient is being treated medically.

The parents of the 12 infants interviewed in this study expressed a range of opinions about the family-centred nature of the care their infant received. First and foremost, they felt as part of their infant's health care team.

Felt Part of Team

Parent participants were asked whether they felt as a part of the healthcare teams, which were responsible for their infant's care. The majority of parents interviewed indicated that they did feel as part of the team:

“I felt like I was part of the team as soon as I stepped on the Unit.” – *FAM011*

Participants also mentioned that the healthcare team made them feel as part of the team by including them in their team meetings and discussions about their infants:

“Well, they always came to us and said this is a team meeting, you know, you're welcome to come, if you have any questions, you know. They were very supportive for sure.” – *FAM015D*

Parents also shared that they always felt that their opinions regarding their infant's care was respected and valued by the healthcare teams. They also reported that healthcare professionals made efforts to ensure that they were comfortable with their infant's care plan:

“Yeah. Yeah, yeah, my opinion was very...like it mattered a lot to them. And like they were always making sure that I'm comfortable with every decision they make.” – *FAM007*

Comfort Level Talking About ToC/Discharge Planning with Healthcare Professionals.

When parents were asked about how comfortable they felt talking about their infant's ToC/Discharge plan with their infant's healthcare team, the majority of them indicated that they felt comfortable:

“I found the process very easy to understand but if I had any questions I felt comfortable to ask.” – *FAM011*

“Yes, absolutely. When they had like the team meetings, the rounds, sorry, you call them, I had absolutely no...I had no reservations about talking about anything.” – *FAM015M*

Parents were appreciative of the healthcare team being open to including them in the morning rounds. They also pointed that as the best medium for them to pose any questions that they had about their infant's ToC plan:

“I think out of everything, I thought the fact that they actually come in and ask, you know, we're here to do rounds, if you wish to come and partake. I thought that was awesome because that right there is your opportunity to ask the questions but also hear what they have to say, you know.” – *FAM015M*

“Yes, absolutely. When they had like the team meetings, the rounds, sorry, you call them, I had absolutely no...I had no reservations about talking about anything.” – *FAM001*

Parents also reflected on the healthcare team being open to any of their ideas or suggestions. They also commented on liking that they always felt comfortable asking questions and/or posing any concerns:

“They were very open to accepting any ideas, answering any questions, and explaining anything. Like there was no issue.” – *FAM015M*

Nurses were identified as the healthcare professional with whom parents had the most contact with regarding their infants' ToC plan:

“It was the nurses more than the physicians because the physicians I didn't see a lot. The nurses were always there.” – *FAM007*

Parents also expressed feeling confident with the decisions regarding ToC that were made by the healthcare team:

“Yeah, I mean I think if we had not been ready, I think they probably would have been receptive to us not leaving that second, you know.” – *FAM005M*

“I was confident in that she was not just being kind of like kicked out of the hospital. You know, okay, you're good to go, have a good day. You know, I knew there were reasons why we were in there for that period of time.” – *FAM015M*

There were, however, a couple of parents who indicated not having a chance to discuss ToC/discharge planning with the healthcare team or not receiving clear information:

“...we really hadn’t discussed discharge really up until the day we left. So it’s hard to answer.” – *FAM005M*

“I think a couple of the nurses that were there sort of had hinted that, you know, at the time it would be...you know, don’t worry, it will be a couple of days before discharge. So I figured, you know, we had another day or two to kind of finalize all that stuff.” – *FAM005D*

First Discharge Discussion

When parents were asked who first approached them regarding their infant’s ToC/discharge plan, the majority of parents responded stating it was a nurse:

“Bedside nurse was first to approach.” – *FAM013*

“... the nurse. She was the first contact that I had.” – *FAM015D*

The hospital discharge coordinators were also mentioned as the first point of contact regarding ToC/discharge planning:

“It was a woman from the discharge team called _____. And she came to see me like several times and like preparing everything for me at home and... Like contacting everyone. She made it really easy for me.” – *FAM007*

Several parents referred to the medical team (physicians/residents/fellows) as their first contact regarding their infant’s ToC/discharge plan:

“The cardio....because when we enter, the cardio for the baby was going to see my baby at the same time as us.” – *FAM001*

“It was during rounds. And so it was the resident and the fellow.” – *FAM005M*

Involvement in Discharge Planning

The parents of the 12 cases observed were asked to comment on the amount of their involvement in their infant's ToC/discharge planning process. The majority of parents indicated feeling involved in planning process only when needed. Parents also commented on being proactive and forcing their involvement in the discharge planning process for the betterment of their infant's care:

“No. But because I asked to know when we're going to be discharged and how long he's going to be there. It's me who asked all the questions to...” – *FAM001*

“Persuading admin to keep baby at current location until bed spot available at transition hospital – argued for transition in the best interest of the baby and not that of the staff or system.”- *FAM013*

Support from the Healthcare Team

Participants were asked how much they felt supported by their infant's healthcare team. Parents replied positively acknowledging that healthcare professionals supported them by answering their questions and ensuring they were comfortable with what was happening. They also expressed their feelings of gratitude towards the healthcare team for the support they received:

“Yeah, of course. Definitely everybody was very helpful and pretty supportive. So whenever we sort of had any questions, they would, you know, answer them for us if they knew the answer. Or they would go find I guess the resident or whoever was on staff to sort of clear things up as well. Yeah, no, I think everybody was very supportive.” – *FAM005D*

“I think the support went well past the point of expectations, the staff was amazing and I am forever grateful.” – *FAM011*

On the other hand, there were also some parents who indicated that they had to ask the questions themselves to understand what was happening with their infant's ToC:

“They didn't tell me. I needed to ask for information.” – *FAM001*

One father's comment below demonstrates the anxiety and worry that they faced and the number of questions that they had about their infant's care that was a result of lack of support and not having the questions answered:

“So it was like we had one question, for example, was like how's her... It was like one concern for me was is she getting off the morphine okay? And there would be a couple of times that I would say... You know, okay, is she doing well? I might be getting paranoid or something.” – *FAM016D*

Parents expressed gratitude for the work that their infant's healthcare team did to facilitate their infant's ToC/discharge:

“...they took care of everything. They made it super easy for me. Like I practically did nothing, you know. So they talked to me about... She took my insurance card and she called the insurance company. Like she took care of everything. I had nothing to do except learn how to give him his medicine and his shots and how to gavage him. So they taught me that. And everything else she took care of.” – *FAM007*

Parents were also happy with how much their opinions were accepted by the healthcare team. One parent highlighted that the healthcare professionals respected her wishes to discharge her baby direct to home instead of to the floor (which was the original decision of the healthcare team) because of a previous negative experience and also fought for her decision to be accepted:

“And they did respect my wish. I told them that I didn't want him moved to the floor because he had a previous horrible experience there. So they did help me with that. And they fought for me staying in the NICU, and just discharging him from there.” – *FAM007*

Some parents also highlighted that most of the support they received was from the nurses:

“Yes, mostly by the nurses. The doctors were okay. We really liked the nurses though. They did a really good job.” – *FAM009*

“RNs were approachable at the NICU.” – *FAM013*

A parent pointed to the fact that doctors were not present most of the time and thus had a sense of doubt when it came to the opinions of the medical team:

“The doctors could be more hands-on. They don’t touch the babies. Which makes it seem strange that they’re giving all their opinions on what to do but they have never actually barely looked at the baby.” – *FAM009*

Parents also pointed out that they had more support from healthcare professionals on the NICU versus other wards in the same hospital and feeling a sense of worry because of this. One mother recalls her experience:

“Yes. I found there was more immediate care obviously on...in the NICU than on the floor. I mean that’s quite obvious because of, you know, the nature. I felt... Maybe it’s how I think but like, you know, when your child goes up on the floor, especially like a smaller baby, they’re in a room. You know, out in the nurse’s station, you know, it’s far enough away that I feel sometimes like, you know, are they going to hear her cry? You know what I mean? Like you have those worries. I ended up staying there for a couple of days until she was discharged.” – *FAM015M*

“I’ve never given medication. I’ve never had to take medications. So it’s like... Like it’s kind of scary, you know. Because I was like this is not the same colour, this is too much. Like I don’t understand what’s going on.” – *FAM015M*

Parental Contribution to Discharge Planning

When asked about how much parents felt they contributed to their infant’s ToC/discharge plan, there was a mix of responses. Most of the parents indicated that they contributed a lot their infant’s discharge plan and that they were satisfied with this contribution:

“We contributed the whole time. Very satisfied.” – *FAM012*

“Okay, he’s my first baby. So I was kind of crazy. [laughs] But yeah, I did fight for him a lot. But like so did... Like they did that too. So it wasn’t just me. So they were fighting for him too. The nurses were amazing. And like all they cared about was [child] being comfortable and me being comfortable with [child] at home.” – *FAM008*

There were also some parents who felt that they did not contribute as much or that there was no real opportunity or need for them to do so. These were often the parents whose infants were of acute care needs and did not stay on the unit very long. Also, because their infants were not on the unit for chronic issues, their situation was a bit straightforward and thus is why they did not have much to contribute or say about the infant’s discharge plan:

“I’m not sure we had a lot to say about it. But I mean we didn’t have a whole lot to contribute or say. It was sort of we’re going home today and sort of we’re just taking in all the information.” – *FAM006M*

“Was very straightforward; not too much to discuss.” – *FAM014*

Feeling overwhelmed

Some parents mentioned feeling overwhelmed at times especially when more than one service was involved in their infant’s care. This often left them confused and thus more difficult for them to keep up with their infant’s care plan. A father mentions below that there were three different things happening at once with his baby:

“You know, they were trying to wean her off. And we were waiting for genetics. There’s like 3 things happening with [baby].” – *FAM016D*

While speaking with this dad it was evident that he was stressed with trying to keep up with the different “things” happening with his baby. A possible reason for this stress could be the result of poor communication by the healthcare professionals. If time was taken to explain to the parents what their infant’s care involved, or even the steps that needed to be taken before the

infant can be transferred or discharged, it would eliminate a lot of the stress and confusion that parents face. A step further would be to provide parents with a check list of the steps that their infants needed to complete while at the NICU. This list can be kept at the infant's bedside and updated by the staff or parent every time a step is completed.

Feeling Included by Healthcare Professionals

Parents were asked if they felt they were being included in their infant's ToC/discharge planning. The majority of parents did feel that the healthcare professionals included them when it came to discharge planning:

"No, they were really good. They included us with basically everything when it came to the discharge. So I felt good about that." – *FAM010*

"I mean we were included in that part of things for sure." – *FAM005M*

"Well, they brought us into team meetings as well. But they had team meetings and they let us know." – *FAM016D*

Happy with Care

While providing comments on how to improve or retelling their experience during the interviews, many parents did not hesitate to strongly state that they were very happy with the care that their infant received. They attempted to make it clear that any comments for improvement had by no means anything to do with the care that was provided. Parents were also pretty understanding of the situations of the healthcare professionals. They acknowledged that they had busy schedules and other infants to care for and that it is expected for some things to go unattended such as not communicating a potential discharge date or an update to the discharge plan. Here are a few examples:

“I’m not trying to disrespect anybody. I’m pretty sure they’re busy with a lot of other children. So I’m pretty sure they’re dealing with life-threatening issues. So I’m just thankful to have CHEO. Just make sure when you do your report, make sure you thank everybody because they are awesome.” – *FAM016D*

“Maybe. You know what I mean? So I don’t... Like I’m not playing...blaming anybody for anything.” – *FAM016M*

Discharge-Related Teaching

When asked about their experiences with any discharge-related teaching there were mixed responses. Some parents were happy with the teaching that they received and commented that it was sufficient enough for them to be able to carry out the tasks at home:

“And you know, the nurses made sure they went through the checklist of all the stuff and made sure we, you know, knew how to give her a bath and temperature control and all of that kind of thing. So I think kind of the list of things to cross off the list, they made sure we knew and were comfortable with leaving, was done.” – *FAM005M*

Parents stated that the teaching was either done last-minute or was not sufficient enough for them to feel comfortable doing the task at home. For example, these parents share their experience where they were taught how to check their infant’s heart beat on themselves with a stethoscope versus on the baby, which they felt would have been more beneficial:

“She teach me over there, just teach us for 5 minutes, me. But no baby. Just tried with the stethoscope. We think we have to learn for the baby, we need to learn before we go. Not the same day.” – *FAM002M*

“She (mom) showed me there. But I guess it would have been nice if somebody from there would have showed me there.” – *FAM001D*

Responses ranged from parents who were very satisfied with the level of family-centred care that they received to parents who had more challenges than positive feedback to share. It is important to observe that the difference between parents with an acute infant and chronic care

needs infant brought about differences in their experiences with those with chronic care infants feeling the most involved in their infant's care. A good start to get them prepared before the transition to the community where they will be spearheading the majority of their infant's care. The transition to the community is the next theme that I will discuss.

Community Care

Parents were asked to discuss about their experience with their infant's transitions from the hospital to the community. The parents stated that they were given a discharge summary and instructed to pass it on to their family physician or baby's pediatrician. When asked if the healthcare team will help with getting in contact with their family physician, many of the parents commented that they felt pretty well equipped to contact their family physician on their own to set-up an appointment:

“Well, yes, I had everything I needed to give to my.... I had what I needed to give to my doctor, which took her on. So that was fine. I just had to give that and then set up an appointment with my doctor. Which I had called the Friday before and she said she would take her on anyway. So I had everything I needed to give to my doctor. And that was pretty much it.” – *FAM016M*

“No, I just need to call.” – *FAM002*

Some of the parents also commented that they did not feel the hospital healthcare team was very helpful with getting them set-up with resources in the community. Families who already had a family physician or pediatrician commented that the unhelpfulness did not affect them:

“I don't know if they were specifically helpful. Like we have such a good relationship with our family physician that we kind of just...we were able to care for that ourselves on that portion.” – *FAM010*

Families who were told last minute of their infant's discharge and also did not have a family physician or pediatrician ready felt a bit more stressed about taking their infant home. For instance, one infant was unexpectedly discharged over the weekend (when parents were initially told that it would be some time before discharge. When asked by the researcher if their family physician was made aware of their infant, the mother replied that the family physician was not informed because they did not know about the discharge themselves:

“No, because I was not known.” – *FAM002*

When it came to knowing what resources were available to them in the community (See Chapter 3 on the NICU Meso System for outline of community services available), it seemed that many of the families did not know what was available. With the information that they provided, however, it seemed that some of them were agreeing to services which they did not fully understand the purpose. From the account of this family, it seems like they are referring to a Public Health Nurse:

“No. [Were not told of resources at the hospital] But I write down a letter for if a nurse want to come at home. And me when we do a course together, and a nurse told me she can come at home when the baby is going to be discharged. But I forget her number. But I am going to call. I have signed a letter if the nurse wants to call us.” – *FAM002*

This family stated that they were well connected with community services and that they received their services as soon as they were discharged home with the infant. From the following account, it's evident that the mother is talking about services she received from the centre local de services communautaires (CLSC):

“And just right after I was discharged, my baby was discharged, they came from Montreal, like a woman for the pump. They took care of everything right away. There was no waiting or anything.” – *FAM008*

The following family stated that the only service that was provided to them was that of Public Health:

“They were good with making sure we were in contact with the public health though. And so public health did contact us a couple of times for follow-up, which was nice. So that was good, yeah.” – *FAM010*

Previous comments from parents also support that Public Health was a service that was recommended to them quite often compared to that of Rapid Response Nurse (offered by the Community Care Access Centres). From the document analysis and observations, it was noted that the discharge check lists from all three hospital sites had a section asking if public health referral is needed. Towards the end of the study, Public Health joined with one of the NICUs to pilot a project where healthcare professionals on the NICU would refer patients to Public Health upon admission so that the Public Health Nurse can visit the family at the hospital and thus not missing out on potential families due to the infant staying at the hospital past the six weeks requirement.

The section on community care was an add-on to the study and thus is why not too much information on that part of the ToC of the infants observed is available. The responses received were mostly from parents with chronic care infants. The responses demonstrate that even though there were a few hindrances during the planning of the ToC to the community, parents were pretty comfortable and well equipped to navigate the community healthcare system on their own.

Summary of Key Findings

Based on the responses from the pre and post discharge interviews with the parents of the 12 cases observed, it is obvious that lack of communication is the biggest challenge for the parents on the NICU and that it was often the cause of many of the other challenges outlined in this chapter. Not receiving information by healthcare professionals on their infants' discharge

plans and being notified last minute of their infants' discharge were the common challenges outlined by the parents. These results support the studies that have been cited in the literature review but also differ in that all the parents interviewed in this study brought up the issue of last-minute notification of discharge. Many made recommendations that are discussed more fully in the conclusion section of the thesis (See Chapter 7).

Parents showed no difference in their responses when reflecting on the care and the work that was put in by healthcare professionals to care for their infants – especially the nurses which made most sense as the nurses were the ones that the parents had daily contact with regarding their infant. In terms of experience, where differences arose were in the background of the parents. For example, a parent with a healthcare background was more likely to be more involved in their infant's care and was also more likely to point out almost every challenge that they faced as a huge issue. Compared to parents without this healthcare background, they tended to point out only the challenges that made the biggest impact in their experience. Having previous children also made a difference. These parents appeared better equipped to handle their infant's care and also seemed to have a bit more knowledge compared to first-time parents who were more anxious. Culture also made a difference. One of the families in this study was relatively new to Canada and had a hard time collaborating with the healthcare professionals because they could not grasp the difference between their country's healthcare system and the one in Canada. Interestingly, my choice to purposively sample acute and chronic care infants in this study displayed the biggest difference which was that families with acute care infants had little opportunity for family-centred care and those families with chronic infants had longer stays and thus more opportunity for involvement – this was reflected in their responses.

Even though parents identified lack of communication as a challenge, they nevertheless stated feeling involved in their infant's healthcare team by the healthcare professionals and were satisfied with the amount of their contribution to the infant's discharge plan even if ad hoc and last minute.

CHAPTER 6

Community Healthcare Team's Experience of Transitions of Care

The whole goal of ToC is to shift the care location from hospital to home/community/primary care. The goal of this chapter is to present the findings obtained from the interviews with those members of the health care team that assist in the hospital to community transition – member of the Champlain LHIN CCAC. Augmenting their perspectives are elements of the parent interviews that support and/or build upon the issues that were raised by the care coordinators.

Similar to the previous results chapters, three overarching clusters of themes from the community healthcare professionals' interviews emerged from the thematic analysis reflective of the system, professional and patient level framework reflective of the broader ToC literature. At the system-level, participants provided some background on the Community Discharge Team (CDT) and their members as well as, common challenges faced by CDT members when planning a ToC. At the professional-level, some of the challenges are those that arose during collaboration between the NICU and the community healthcare team. Finally, at the family-level, challenges include issues that are faced because of and by the family of the infants being discharged into the community are presented in the theme. This theme is augmented with data linking back to the family experiences discussed in depth in the previous chapter. These sections paint a picture of what community healthcare for neonates looks like and some of the challenges that are faced by the CCAC and parents during the transitions into the community.

System-Level Challenges

This section starts off with some background information on the role of the CDT and some of the members that they work together with to facilitate an infant's ToC. It then goes into detail on some of the challenges that the CDT face at the system level when planning a ToC of neonates back into the community.

CDT Background

The definition for the CDT as set out by the CHEO Corporate Discharge Planning Policy for In-Patient Units (2015) is:

“The team that leads the most complex discharges/transfers from CHEO, by coordinating team communication, family teaching and organizing community services, resources, equipment and supplies for the patients at CHEO for a safe and smooth transition to home.” – *CHEO Corporate Discharge Planning Policy (Section 4)*

The role of CHEO's CDT (discharge planners) was understood to be as the intermediary between the CHEO hospital staff and the CCAC in the community with the aim of helping patients and their families continue to get seamless care in the community. Some of the HCPs defined their roles as:

“So what the care coordinators in the hospital do is they're responsible for sort of meeting with the parents, for somebody who's going home, the complex needs. So if it's meeting with the parents and the nursing staff, and determining what the care plan...developing a care plan. So assessing the care needs and then looking at what sort of care plan you develop to support those parents.” – *COMM004*

“It's planning for education, following through that education has been done, making sure resources are in place, the supports are there for parents, making sure parents understand what's been put in place, that the team understands what's been put in place. We coordinate for equipment, supplies. We sometimes help with funding.” – *COMM003*

Some provided additional details with specific examples to clarify the important of their role

“So when we have a complex baby, and of course anybody who’s in NICU is usually pretty complex, and we’re looking at possibly discharge, it’s our role to identify what are their needs going to be at discharge. For example, for a neonatal baby, if they’re going home with an NG [nasogastric] feed or maybe they are going to be on an ostomy, so they’re going to require all the equipment that is associated with caring for an ostomy. You consider socioeconomic factors as well. Because when you have a child going home with medical needs and equipment needs, there’s always going to be some financial stressors for them. So it’s our job to sort of okay, identify are they on any special medications that are expensive? And do they have a drug plan that covers the cost of those meds? Because some of our babies have gone home on meds that might cost \$3,000 a month.” – *COMM006*

The Complex Care Team

Participants also highlighted the role of CHEO’s complex care team and how they collaborate with them for patients going home with multiple complex needs. In the specific case of patients with complex needs, the role of the CDT is particularly important:

“So we work closely with complex care team in-patient. The kids that get accepted to complex care as out-patients, we don’t... They’re in the same hallway as us. Which is great because if they have questions, you know, we can bounce questions back and forth. But there’s not a set mechanism of... You know, we don’t round every week with complex care out-patients, for example. So in-patients, we’re closely allied with the complex care team because we are the discharge planners. When they’re out-patients, the complex care team nurses essentially then own those cases.” – *COMM002*

Discharge Planner and Community Care Coordinator Collaboration

The collaboration that occurs between the hospital discharge planners and the care coordinators in the community was highlighted as crucial to the smooth transition of care of neonates into the community. Both the hospital discharge planners and the care coordinators work by way of a central CCAC system with the hospital discharge planners submitting orders for care for a neonate and updating all their notes about the particular case into this database. The care coordinators use this information to provide care once in the community. Each CCAC

provides community care services to the residents in the area that they cover (e.g. the Champlain CCAC – see chapter 3). Infants being discharged in to the community need to be connected with their respective CCAC to obtain community care. The central system obtains the referrals from the CDT members at CHEO and sends it off to the respective care coordinator in the CCAC which covers the home location of the infant being discharged:

“So what happens for them is they’ll get a task saying there’s a new admit. Because it’s all by region and things like that. So once I’ve done all my work, I send it off and then it gets assigned geographically, and then they get a note – You have a new admit.” – *COMM001*

The discharge planners in the hospital connect with the community care coordinators in situations where the case being transitioned is complex or has an extraordinary issue that needs attention. Similarly, if an infant ready for discharge home is flagged as one with complex care needs, the discharge planners may invite the care coordinator to attend multidisciplinary meetings on the unit so that they can get a better understanding.

“Some complex kids... sometimes we have asked for the community care coordinator to come in...If I have a complex kid with a lot of social issues, I tend to touch base beforehand. Some of our kids that are very complex, like tracheostomies, with oxygen and feeding tubes, and social issues on top, I will talk to them [care coordinator] in advance. But so far like I think the communication has been pretty good with all our assessment notes and all the information we put in.” – *COMM001*

Similar to the complex communication field noted by the healthcare professionals of the acute care for neonates, communication between the discharge planners and the community providers was identified as both important to providing the continuity of care and also has occurring between the two sites:

“We’ll get often phone calls from multiple people – from the care coordinator, from like the rapid response nurse who’s visited who’s like, “I have this concern,” or, “Was this done?” You know, like she’ll report back to us just because we know then well. And then

we'll refer them back to the DTC, the district care coordinator. But no, there's constant communication.” – *COMM003*

“We work like a team. Like sometimes I'm not sure about certain things because I'm in the hospital, they're in the community. And like where do you think I should go with this, or should go with that?” – *COMM001*

This section highlights the different roles and/or teams associated with community healthcare for neonates when transitioning from hospital to home and how they work as a team with the CDT to provide community care.

Common Challenges Faced by CCAC Hospital Coordinators When Planning a ToC

The hospital coordinators interviewed identified several challenges that they commonly faced when planning a discharge of an infant into the community. These challenges included fragmented resources, lack of funding, social/family issues, and transitions outside of Ottawa/Ontario.

Fragmented Resources

The issue of fragmented resources outside of the hospital environment was brought up as a challenge to discharge planners when trying to connect families with the needed resources:

“The resources in the community, resources are fragmented and it's a stumbling block for families. Okay, say someone who goes home with NG [nasogastric] feeds, a feeding tube. So they'd get set up with a dietician through home care, through CCAC [community care access centre]. But those dieticians really are only mandated to set up a teaching plan. They're really not mandated to follow them indefinitely. But kids don't necessarily fit the criteria for OCTC [Ottawa Children's Treatment Centre] where they could get a dietician through there. So there's a bit of a disconnect between community services.” – *COMM002*

In contrast to this, another coordinator pointed out that it's not that the resources are not available; the real deal is that the CCAC has a chunk of money that they must use for every case that they get. So, they offer services based on need:

“If they need a feed, yes, we can put somebody in for that. Or if they need some special nursing care. But we're not just going to put a nurse in there because you just kind of would like a nurse in there. It's got to have a purpose or a role. Maybe respite so the parents can sleep through the night...We wouldn't provide that 7 nights a week.....But then people see that as not having the resources. It's slightly different...” – *COMM004*

One care coordinator also points out the issue that not every infant qualifies for care from the CCAC and that the result of this are parents left to care for their child unsure of where to go for resources or how to navigate the system to care for their child:

“So sometimes people fall in the middle. Which is where the complex care team is very helpful because that helps to bridge some of those gaps. But not everyone qualifies for the complex care team. So you know that lots of parents are to a large degree going to be struggling on their own. And it's hard to know how to manoeuvre the system. So even for families that have questions about, well, I want to go back to work but my child has seizures, what should I be...how do I find specialized daycare? I don't know. Who do you ask to go find specialized daycare? I don't even know who you ask, and I'm a discharge planner. So if I don't know who to ask, how are parents going to know who to ask or what the right question to ask is?” – *COMM002*

She acknowledges that the CCAC provides great services to families with complex care infants, but points to the fact that healthcare is not the only piece that families require help with:

“Like they do have great services. But not every child that's complex needs those particular services. Sometimes people need a system navigator. So my child is going to have developmental issues but right now she's drinking and right now she's eating, and it's not apparent yet that the baby is not meeting its milestones. But who do I call to ask about daycare?” – *COMM002*

Lack of Human Resources needed to Foster effective Relationships

Another challenge identified by the care coordinators, was the inability to foster relationships with the hospital staff:

“One thing that I find hard here with the CDT team is that we all take cases from all over the hospital. So I’m not fostering relationships specifically with one team.” – *COMM001*

To deal with this, care coordinators indicated having a discharge planner assigned to specific floors would help deal with this issue of creating relationships with hospital staff:

“If I was assigned to a certain floor then you’d know everyone, you’d see them every day, and you’d kind of get a pulse for what’s going on on the team, and the flow.” – *COMM001*

“I agree, like one person per...one discharge planner per floor would be the ideal. And I think if you participate in rounds with the physicians and you’re that known presence on the floor with the nurses, then things may go quicker and things would be identified sooner, and discharge may be quicker and not delayed.” – *COMM003*

They also pointed out that doing this would require more human resources that they do not have access to:

“We just don’t have the manpower to do it. There’s way too many beds. We’ve talked about here as a team as to how perhaps we should divide our work by floors. And so people would get used to knowing like who that person is for that floor. But then you can’t control numbers. Like sometimes 4-east or 4-west can get like 15 consults, and then the next week get 2. So how do you work that out with your team? I mean you can help out but there’s... And then we just don’t even have enough staff to be divided up to do that. So then some people would have like extremely heavy workloads while others might have, you know, quieter workloads. And so how do you balance that out?” – *COMM003*

It was also identified that the general lack of human resources in the hospital played a role in delaying discharges. For instance, a care coordinator said:

“Just lack of stuff... Like lack of people sometimes. People on vacation. You know, sometimes poor communication as to how that kind of follows through if that one is on vacation. So we’ve had instances with a new tracheostomy. Like ____ used to be the only...he’s the trach educator. So he does the trach class. He’s off for one week. That means that my trach class with that family is delayed by one week. There’s no one else.” – *COMM003*

Funding Challenges

This challenge can be classified as both a system-level issue and a parental-level issue. Here, funding challenges are presented as an example of a system-level challenge in that funding cuts to the system have resulted in additional challenges faced by the care coordinators to help the family. For example, previously the CCAC used to be able to loan equipment temporarily to families until they get funding to purchase the equipment but that is not available anymore thus leaving the care coordinators scrambling to try get immediate funding to cover the cost before the infant goes home.

The families of infants going home with equipment or requiring services usually face a big bill. Those with private insurance can find some financial relief, but those without are left struggling to find funds to meet their infant's care costs. The care coordinators identified some of the struggles they go through trying to find funding for these parents:

“I find the majority of our families don't have private insurance. And equipment is expensive.” – *COMM001*

“Well, finance is a huge barrier to a lot of families. So especially kids that would have, a tracheostomy or that would need suctioning at home, NG feed.” – *COMM002*

Care coordinators also highlighted the amount of time it can take to apply for and receive external funding:

“When you apply for provincial grants, they take 6 to 8 weeks. Now, for some kids, it will take them 6 to 8 weeks to be stable. Some kids, they're ready to go after 3. So what are we going to do to bridge until then? So that's a big discharge barrier, just trying to find the money. We can ask the CHEO Foundation and things. But then a lot of... What's the word I'm looking for? Foundations, they run out of money. PC Financial, some of them have wait lists, and things like that. So I think funding is a big one.” – *COMM001*

“So there's Ministry programs that help fund. But they rarely cover everything. So there's almost always an outstanding cost. So I think cost is a huge barrier for family.” – *COMM002*

“Equipment-wise, these children, it's whether they... CCAC lends equipment for 30 days. So after that time, either people use private insurance or they apply for funding. And sometimes that funding process can be a little bit time-consuming and difficult if somebody hasn't got their funding or if they've got something really strange and unusual – meds or something – that they need some special sort of process for approval. ... And sometimes the family is deemed to have the money but they actually don't. So they don't qualify. So that can be difficult as well. That can be a barrier to providing care.” – *COMM004*

Social/Family Issues

Aside from equipment and funding, social/family issues surrounding the infant were another challenge in discharge planning that was identified by the care coordinators:

“But a lot of parents, for a child who needs supervision 24 hours a day, and sometimes single parents. So you have a single mom, not a lot of family support, dad's not around, not involved, not present, and we're asking mom to do those 2 nights? Like those are hard. Those are really difficult to discharge.” – *COMM001*

“But I know from there, like some of the barriers for children here are things like children who are going to be fostered. They're children who tend to stay here, stay around for a long time because we're waiting for foster families. Which I mean I don't know if you're looking at length of stay or anything like that but those children seem to really push it [the length of stay in hospital] up.” – *COMM004*

One care coordinator explains the burden of care that is placed on families when taking their complex care infant home. She goes on to explain how the lack of resources takes a toll on these families in many ways:

“And burden of care. So the expectation that say... A child with a tracheostomy can't be unsupervised ever. So I mean all babies need supervision. But you could pop your sort of mainstream baby in a crib and go to the bathroom. But a child with a trach or a child that's ventilated, this burden of care... I mean when do you get to go shower? You don't. So burden of care is a barrier because you know how hard it's going to be for these families. And you know that they don't know that yet, and they're in for a big surprise. And what's available in the community is useful but... You know, it's fine to be able to set someone up with 5 nights a week of nursing, maximum. And not everyone gets that. But what happens for the other 7 days and 7 evenings and 2 nights a week? Families

really need to stand on their own two feet. It's a huge burden. So I think services for complex families in the community is definitely lacking. You know, even kids that you know need physio and OT, but they may not necessarily be candidates for OCTC.” – *COMM002*

Medical fostering, where “children with chronic and multiple medical disabilities in appropriate foster, and often permanent, homes” (CAS, 2016), was opted as a last resort for families in a very complex social situation:

“Some parents opt for medical fostering. So it's kind of they go through CAS. And CAS kind of apprehends the child, if you want. But it's just for... Mom can still go... Mom can still be present. But mom just... If mom can't do it, or dad, whatever....At that point CAS covers everything.” – *COMM001*

Transitions of Care Outside of Ottawa

Care coordinators went further into explaining how the ToC becomes a bit difficult when they are dealing with transferring babies who are from out of the Ottawa area. This is a salient theme for hospital-based healthcare professionals as well) in that healthcare professionals indicated transferring infants to areas where required services were not available meant that the healthcare professionals were often left with having to train the community healthcare professional over the phone (see Chapter 4). The care coordinators made it clear that this was the case not only just for infants being transferred out of the province, but also for those infants being transferred to an area outside of Ottawa that is not under the Champlain CCAC:

“But that's another barrier to discharge because I can ask everything that I want but that CCAC also has their policies and guidelines. They're not necessarily the same as Champlain's.” – *COMM003*

“If somebody lives in a very, very rural location, that's when we can have some...they may not have a huge amount of staff with those skills living in that area. That can be... And that's often when they go into South East CCAC and they're very rural, that can be challenging.” – *COMM004*

One of the biggest challenges with transferring outside of Ottawa was identified as the availability of resources – especially in the more rural areas:

“So some CCACs will offer supplies for different things. Some won’t. So you have to ask. But then until you ask, you can say, you know what, you’ve asked but we can’t. So then you have to deal with the can’t. Right? So we have a kid right now who needs shift nursing support at night. Like a nurse to be there overnight. They live in the boonies, nowhere. So trying to find a nurse to drive... Like the closest centre, let’s say, I don’t know, would take the nurse 2 hours to go. Well, who wants to drive 2 hours to someone’s house to go do a shift, and then 2 hours back? So finding nursing for that patient has been a nightmare. But we’re stuck dealing with that. And we’re stuck dealing with it with another CCAC.” – *COMM003*

One care coordinator also expressed frustration over having to deal with issues like this and not having any control:

“Like we can’t even directly manage. So you kind of become that circle of little pigeons kind of communicating back and forth and all around, and trying to do that from a distance, you know. And it’s hard to communicate that to families. Because you’re like, “Well, the other CCAC tells me they can’t do this.” You know, like you’ve kind of become the messenger of that process that you don’t entirely know of. I always tell families, well, it’s being coordinated by another CCAC so I don’t truly 100% know what will be offered to you at the end of the line. It might be more than what you would get in Ottawa, it might be less. So it’s hard.” – *COMM003*

She also goes into detail to explain why there might be a difference in the services offered. For instance, the case with how many shift nursing hours can be provided to an infant:

“So in my mind, if it’s a provincial program, what you get in Ottawa, you should be able to get in North Bay. But it comes back down to resources. So here in Ottawa, we offer less shift nursing hours. But we’re also servicing people from Deep River to Hawkesbury. And so our population is huge. So we have to disperse that through everybody. So if we have 5,000 kids, we still have the same budget. Well, I mean we probably get a little bit more. But we have to disperse that between 5,000 kids. And so North Bay might have 1,000 kids, and their budget is a little less. But they only have 1,000 kids. They can offer more because they’ve never had more than 1,000 kids on their program at one time. And then Ottawa being that central place that it is, we have... Like

CHEO and stuff, we service all of those outside kids that we tend to see more than what North Bay Hospital sees.” – *COMM003*

Other difficulties include dealing with a system, which is different from that in Ottawa. For example:

“Yeah, if the services don’t exist then it is difficult. There's not a lot we can do. It's another province. So they’d probably have to go to hospital there and then work it out from there.” – *COMM004*

“So on the Quebec side, they have the CLSC. But it’s not the equivalent of CCAC. The CLSC – centre local de services communautaires. They don't have care coordinators like in Ontario. It’s very, very different.” – *COMM001*

The CCAC staff does, however, recognize this as a barrier and stated bringing this issue up to higher authority:

“Yeah, with going to Quebec, we try to look at what is available there. We really feel like this is... It’s certainly spoken with _____, who’s the director of the program, and my director as well, and saying we need to push this up to the Ministry and say this is the gap. Like what... I think children have stayed here longer. Yeah. You know, how do we meet this child’s needs?” – *COMM004*

There are multitude of common challenges that the CDT experiences when trying to plan a transition into the community. Responses ranged from trying to connect infants with services to attempting to find funding to cover these services for those families who can are not able to afford it. The major source of where information for planning a ToC into the community is obtained from the most responsible healthcare professionals on the NICU. The partnership between the NICU and the care coordinators, as we shall see next, is critical. This partnership is what will help the community to understand what the care needs of the infant are in order to ensure proper services are in place when the infant reaches home.

Professional Level Challenges

Care coordinators were asked to comment on the ToC that they get involved in specifically with the NICU. The cases that they tended to get involved in were those complex needs infants going directly home from the NICU or being transferred to another floor before going home from CHEO. While the care coordinators elaborated on their positive experiences with the NICU they also shared some of the common challenges that they faced when planning a ToC for a neonate.

ToC Communication

Care coordinators indicated that communication with the NICU regarding ToCs of their neonatal patients was not ideal:

“So the biggest one I feel like is the communication of the team that has the ability to make or break a kid getting home on time or not. For example, if the... I’m just making this up. Like if respiratory had some sort of qualms that they hadn’t well communicated to all the team members, maybe the baby needed a sat [oxygen saturation] monitor or something, and that hadn’t been fully communicated to, I don’t know, the main team following that baby, and then there’s a delay in getting that discharge planning referral sent because someone didn’t know that the baby needed a monitor. So then there’s a delay because then the discharge team actually has to do their work. Meanwhile the baby is sitting in the hospital when he could have gone home because it just wasn’t well communicated what he needed.” – *COMM005*

These care coordinators also acknowledged that this lack of communication amongst healthcare professionals on the NICU and the CDT was due to uncontrollable circumstances such as workload:

“Do we always communicate clearly as to what we need? No. Everybody gets busy and caught up. And so sometimes you get your answers a little bit later than what you had wished. But it’s just the reality of healthcare and workloads.” – *COMM003*

Collaboration

When it came to the collaboration with the healthcare professionals on the CHEO NICU during a ToC, the care coordinators had mainly positive comments to share. The participants acknowledged that they required the collaboration with all the healthcare professionals on the NICU in order to plan an efficient transfer back to the community:

“I need everyone. I’m not a nurse. I’m not a dietician. I’m not an RT. I need to have that team there to say this is what they need, this is what they need or what they might need. And I can go from there.” – *COMM001*

Some of the care coordinators also pointed out that the nurse was their first and constant contact for the most updated information on a neonate’s discharge plan:

“So the nurse at the bedside in neonates usually kind of knows the perspective of, you know, what the dietician’s plan was going forward, what the neonatologist’s plan was in terms of discharge. So the nurses [have] more ownership over the discharge plan.” – *COMM002*

The nurse becomes the point person in neonates as opposed to on the floors, we often become the point person – the collector of information. – *COMM003*

Participants also stated that when compared to their experience on other units in the hospital, their experience was better on the NICU:

“Although the care facilitators, they always have a really good handle on what’s happening. Which is another kind of difference between the floors and neonates. Because the care facilitator on the floor doesn’t necessarily have the same appreciation, I guess because the volumes turn over more quickly for the care facilitators in neonates. So I think it’s a key role because there is a go-to person. And they’re really focused.” – *COMM002*

“So when you work within the intensive care units, whether it be PICU or NICU, they also have...like the RTs are there. They’re right on the floor. Which isn’t necessarily what you have on the other units here at CHEO. So we’ve come to work with those team members more closely because they’re kind of there 24/7. Versus the floors, they go between floors and they rotate and they do all those things.” – *COMM003*

When asked what they liked specifically about collaborating with the NICU and what they would like see more of, the majority of the respondents referred to the Discharge Rounds on the unit:

“I like discharge rounds. I wish we had them more often. Not more often. I think twice a week would be good. Like on Tuesdays and Thursdays. Because kids can change like this.” [snaps fingers] – *COMM001*

“I think that the neonates does discharge planning rounds on Tuesdays. That works very well. But it's not always on our radar. It would be helpful if they'd phone us and go, “Can you come?” You know, we're hit and miss of whether we get there. When we get there, it works very well. So their rounds work very well.” – *COMM002*

“I feel like the discharge meetings that I went to, that new checklist they had was something that was...it seemed like it was a good tool. I'm not sure how it's been working for them in practice. But it just seemed like kind of cueing everybody to start thinking about certain things that have to happen to those babies before discharge early. So it's better to think about those things early than later.” – *COMM005*

Part of Child's Care Team

When asked if the members of the CCAC CDT team felt a part of the infants' care team, there was a mixture of responses. Some respondents agreed that they felt a part of the team:

“Oh, definitely, yeah. And we have a really good relationship with the doctors.” – *COMM001*

Others thought differently about being a part of the team:

“So because neonates is kind of its own sort of little world, we tend to be more almost feel like we're added in. Like we're added in as opposed to part of the core team. We feel more like a consultant service as opposed to full on member of the team. Or at least that's how I feel.” – *COMM002*

“NICU is probably one of the different... Like they're kind of their own little unit within the hospital just because they have different members like a nurse practitioner and those things. So we don't tend to get involved probably as much as other units where they don't have those kind of key players. But yeah, I think they've come to appreciate what we've done. I think it's been a work-in-progress.” – *COMM003*

Role Clarity

Care coordinators stressed the importance of the NICU healthcare team understanding their role as hospital care coordinators and thus a need for role clarity:

“I think one thing that I think is missing that would make us better, I don't think the hospital staff fully understands our role. I think that's still unclear. I think a lot of our time as a team is wasted asking for information that should be on the initial referrals.” – *COMM001*

“I think people need to be more aware of what we do and how... So it's pretty clear when you start working in discharge planning that no one has any clue of what discharge planning does and how certain things take time to coordinate in the community.” – *COMM003*

One care coordinator further clarified that with better role clarity, the CDT would be able to focus on getting the family connected with community resources:

“Because for CCAC to have joined with the CDT, that's only been in the last 2, 3 years. And historically I think it was a little bit vague what the role was. So I find for some things we've taken on a little bit of everywhere, and certain things could be a bit more streamlined and we could be more focused on the actual just finding the equipment, the funding and the community support.” – *COMM001*

Another care coordinator clarifies that this is not the case with everyone on the unit:

“I mean I have some nurses who are quite aware of what we do in discharge planning even, and then there are others who, you know, it's almost like they're a little hyper-focused on what they do in the hospital.” – *COMM006*

A care coordinator expressed frustration over the healthcare professionals on the unit not understanding what they are able to do in terms of discharge planning and that teaching should happen to facilitate that:

“But I think nurses think physicians need to do referrals to discharge planning. And so there probably needs to be a bit more teaching as to you are capable of identifying discharge needs also.” – *COMM003*

Many of the care coordinators expressed frustration over not being involved for cases that actually qualify for CDT services and that the issue of role clarity may be the reason why this is the case:

“Like this week I went to the NICU rounds. I only had 2 kids. And they were talking, and I was like I should have a referral for this kid, and I should have one for that one as well. So sometimes they think, oh, yeah?” – *COMM001*

“I’ve had to find patients ourselves and saying like that would be good for rapid response.” – *COMM006*

Care coordinators also brought up the issue of being brought into a case too late into the discharge plan – in some cases, a few hours or days before the discharge:

“Here’s a barrier to discharge. Sometimes they remember us a bit too late. If you get me involved in the beginning, I can put certain things in place from the beginning. And even if you don’t need me at the end....Because some, you’ll get a referral for, I don’t know, a CPAP machine and an NG, and as we’re waiting for the funding, they’re getting better. And by the time they’re discharged, they don’t need anything. Great! That’s fine. I don’t mind following something and closing the file. I’d rather that than be rushed to get stuff in.” – *COMM001*

“We need to be involved early because for funding, it’s... there’s always a waiting period for everything.” – *COMM006*

Another care coordinator further explains what the ideal referral protocol should look like:

“So it’s not even chronic. Discharge planning should be anyone who came in the hospital that now needs something different that they didn’t need when they came in. So whether that be supplies, equipment, like therapy, like a nutritionist or an OT. Yeah, that’s how discharge planning consults should be. So if you came in and you were a perfectly healthy person, and now this happened and you need something, if anything has changed, like we should be consulted.” – *COMM003*

Last-Minute Notification of Discharge

One of the key issues that care coordinators expressed was the last minute notification of discharges:

“So we go to rounds let’s say on Tuesday. They’re not ready. We’re going to look at next week. And then all of a sudden I get a phone call at 3:00 on Friday – He’s doing better, we want him gone now.” – *COMM001*

“The process. Just things. Yeah. And taking for granted, “Well, they’ll figure it out. But I’m just going to give them 2 days.” You know?” – *COMM003*

“If we don’t get enough time to prepare the discharge, that certainly is the barrier.” – *COMM004*

This point was quite interesting as the document analysis revealed that as set out in the CHEO Corporate Discharge Planning Policy (2015, Section 2.3):

“For patients expected to be discharged with complex care needs at home and/or community health care services, a consult to the Community Discharge Team will occur within 24-48 hours of admission.” – *CHEO Corporate Discharge Planning Policy*

When asked about whether any policies existed regarding discharge planning in the hospital, only one care coordinator (FLR002 - a non-health care professional) pointed out the CHEO Corporate Discharge Planning Policy. The remaining care coordinators stated that no such thing existed demonstrating a lack of awareness of the policy. It was suggested that the lack of CDT role clarity, no understanding of the community process, and miscommunication as reasons for these last-minute notifications:

“I find sometimes we’re not always kept up-to-date or that little communication piece is missing. And then we get all of a sudden – Okay, we want him out now. I’m like, well, he wasn’t ready yesterday. What happened overnight?.....I think sometimes people don’t appreciate that getting funding in place, getting the equipment sorted, and finding providers in the community to do the work, I can’t do that in an hour.” – *COMM001*

Care coordinators identified not having enough time to plan the discharge as a barrier.

“If we don’t get enough time to prepare the discharge, that certainly is the barrier... The sooner you know somebody’s going home, the better. Having an estimated discharge date. Because when you’ve been given short notice, then you have to scramble to get services out. If they need meds, it’s going to take turnaround time for pharmacy things.”
– *COMM004*

From the observations on the unit and from the care coordinator interviews, it was evident that this was often the case with chronic needs infants, as they needed to be connected with a variety of services in the community as well as equipment (e.g. oxygen tank, etc.). One of the community discharge team members pointed out that healthcare professionals should know in advance of the infant’s discharge if equipment will be required at home and expressed frustration over inability to understand why notifying the CDT is left to the last minute:

“It depends on like if the baby has equipment. Usually if there is going to be, I feel like those are the ones where they tend to know more in advance that they are sending these babies home. I think often like starting those discharge referrals earlier, like as soon as they know the baby is just like getting ready to go home, they need to send those down. Versus waiting until they have all their other ducks in a row to send the discharge referral. They just need more time to work on those, it sounds like.” – *COMM005*

Considering the process that the CCAC goes through to request one of their contractors to take on required services (See section on Community Resources in Chapter 3), it is understandable that the amount of time it can take to get a contractor on board is unpredictable thus making it difficult to put resources together if the infant is going home within hours.

Unaware of community resources

Care coordinators brought up the issue of healthcare professionals in the hospital not being fully aware of what kinds of services are available in the community. This lack of awareness can lead to hospital-based healthcare professionals hanging on to infants who do not require their level of care longer.

“I think maybe the medical team isn’t always aware of what kind of follow-up we can provide in the community. Like if it’s just a baby who’s feeding well but we’re just watching them for weight checks, well, we can do that at home. They don’t need to be sitting in a hospital bed. Like there’s dieticians who can see them at home. There’s myself who can weigh them at home. The family physicians can weigh them. We can have referrals for feeding support at home that I don’t think all the medical staff necessarily know. And so they hold onto them a little longer to make sure they’re growing.” – *COMM005*

“I think there’s a lack of understanding of what is and isn’t available in the community. So there’s a lot of continuous teaching. Sometimes we’ll get referrals, and we’ll say no, that’s not appropriate, that’s not for us, that goes here. Or why didn’t you tell us, we could have done this, this and this.” – *COMM001*

This theme also concurs with what the hospital-based healthcare professionals detailed in chapter four. One care coordinator expressed frustration over having to deal with referrals that were not quite possible to facilitate in the community:

“And it depends where you’re coming from. Because they’re saying we want people there like all night, somebody all night providing care. And we’ll say, well, they don’t really...there’s nothing for a nurse to do. You just want the nurse to be sitting there watching. We’re not going to put in a nurse. It’s not sustainable to put somebody in to watch somebody all night. So how can we... If they need a feed, yes, we can put somebody in for that. Or if they need some special nursing care. But we’re not just going to put a nurse in there because you just kind of would like a nurse in there. It’s got to have a purpose or a role. Maybe respite so the parents can sleep through the night. But not... We wouldn’t provide that 7 nights a week.” – *COMM004*

When asked if any initiatives were undertaken to overcome this challenge, participants indicated that some educational initiatives were undertaken:

“But we’re promoting it, we’re pushing it every chance we get. Like whenever we do rounds with the medical...” – *COMM006*

No Understanding of the Community Process

In addition to a general lack of awareness of the community services available for neonatal patients, care coordinators indicated a lack of understanding the community discharge process and procedures. They alluded to this also being another reason for why they are notified late in the discharge planning process instead of right at the start:

“So oxygen. Sometimes they don’t understand that setting up oxygen in the community is a 48 hour process. You need... If you want it covered, you need like an oximetry report, you need to fill out this form that needs to be done by the same person who did the oximetry. You need to send that to a vendor. The vendor needs to find an RT that can do a set-up here at the hospital and then back at home. And the delivery guy who’s dropping off the oxygen isn’t an RT. He’s just the dropping off guy. So like it’s just like there’s a lot of things people don’t understand and they just assume, “Well, I sent you the consult 2 days ago, you said 48 hours.” Yeah, but I don’t have a script for the oxygen Like I need to give guidance to someone.” – *COMM003*

One care coordinator provides an example regarding funding and some of the barriers that they might run into while trying to get this set-up for the family to illustrate that because healthcare professionals do not understand this process they often give CDT members short time periods to pull resources together:

“So like finances are a huge thing. And you can’t just call someone and be like, “I need \$3,000.” Like it just doesn’t work like that. And foundations run out of money. Last year we saw that. Presidents Choice ran out of money in October...in September. So then what? So then that one place where you could turn to, you can’t turn to anymore. So then

what? Like it just doesn't fall from the trees, right. So yeah, the whole piece of people not really understanding." – *COMM003*

Frequent Staff Turnover

The frequent turnover of healthcare professionals on the NICU was another challenge to ToC identified by CDTs. Participants identified the frequent staff turnover, particularly of physicians, often left them confused about who they should consult when they needed medical advice when planning a discharge:

"Doctors, I don't always know which doctor it is though. That I find hard. I always have to ask someone who am I looking for? Because there's rotations and changes. And I'm not there all the time either." – *COMM001*

One CDT attributed the frequent staff turnover as a common problem when it came to building up their referrals:

"So I don't know the specifics but I know it's always been a slow process for us to kind of build up our referrals. We're not being utilized as we could be. And a lot of the times it's because the medical teams flip over so often that they don't know about us. And the same with the nursing staff. Like there's just so many that they don't all know about these programs." – *COMM005*

The team identified that their most method of outreaching to healthcare professionals to make them aware of their services is by presenting at teaching rounds and other meetings. As one CDT identified, the rotation of healthcare professionals occurs so often making it hard for them to catch all the healthcare professionals working on the unit especially with residents who frequent the unit often but only for short time periods.

Lack of Trust

An interesting point that was raised by COMM004 was the sense that hospital staffs are hesitant to handover an infant's care to the community out of fear of how they will manage:

“We always get the sense that there's a lack of trust in that point when you're handing over the care to the community - Well, we want to know how much service you're providing. Well, really I think when they come to the community, we'll look at them and how they're going in the home, and we'll up it and change it according to what we feel people need with healthcare professionals in the community. We don't want people to be harmed or in any danger. So we want to do the best for them too. But I think it's almost like you have to trust us to say, 'I'm handing this child to you now, and we're going to look after them. And if we're not happy or something, we'll send them back to you.'” – *COMM004*

This particular CDT attributes this hesitancy or fear to transfer the infant to the community to a sense of ownership of the infant's care as the NICU has been taking care of the infant for some time:

“They have some ownership in it. They've looked after this child all this time. They want to make sure they're okay. Yeah, I think there's just a... Like particularly I find here with respiratory patients, there is that...they are very concerned about their patients. I think they really get connected. And then these patients are going home, and they're worried that they won't receive the good level of care.” – *COMM004*

As a result of this fear, healthcare professionals tend to refer community services to patients that are not required or that are not feasible by the community:

“I think some of the barriers, perhaps if the hospital staff say, 'oh, this person needs 24 hour care in the community.' They don't need 24 hour care. It's they're [the parents] at home. Their parents are there. Do you know what I mean? It's not... They're not getting one-on-one 24 hour care in a hospital really. So I think there's a bit of a fear that somebody is going from an acute care into the community, there's a bit of a concern from the hospital staff, how are they going to manage? But actually when people get into the community, we find that they settle into the routine. When they're in their own home

environment, it's easier for them, I think. As long as they have the support in place obviously.” – *COMM004*

The fear that the healthcare professionals have when transitioning complex needs infants into the community is in one way understandable – as a healthcare professional you want to make sure the infant is receiving the best care and is not put at risk. It must also be understood that the patient cannot be kept in hospital for a long time:

“I mean when you look at it, in the community there are staff working independently in people’s homes. So sometimes things do go wrong. And so there is a level of risk for people living in their own home. But you can’t keep them in hospital forever.” – *COMM004*

Being an infant with complex needs that the patient and his/her family will have to deal with for the rest of his/her life, it is important that they learn how to deal with everyday life at home with the help of the community. One care coordinator highlights that this is not the case with just the community, but also with the other units in the hospital:

“There is a team that discharges straight I know from NICU because they don’t feel that the children can be appropriately cared for on the floor...Well, they said that in a meeting openly.” – *COMM004*

The environment of the NICU is such that the parents are not required to provide care for the infant as that is taken care of by the bedside nurse (e.g. feeding, diaper changing, etc.). On the other floors (e.g. cardiac or complex care units), because the nurse to patient ratio is smaller, the healthcare professionals depend on the parents of the infant to care for the infant. It is unfortunate that the NICUs do not have a step-down unit so that their complex care needs patients can have an intermediary location for care before being discharged home. In many cases, the other units/floors in the hospital can serve as that intermediary. This is especially

important for parents as it serves as a safe learning ground for them to learn how they are to care for their infant while help is just a call away versus having to practice at home alone. It also allows for healthcare professionals and the family to understand what services would be needed once at home (e.g. respite care, etc.):

“And to me, like then that puts so much pressure on that discharge process. Because if they could go to the floor and the parents could look after the child within the hospital environment, they can identify what those needs are and then they could have a safer transition home. But to come straight from this to home, it's a big jump.” – *COMM004*

The reason for deciding to skip transferring an infant to another unit/floor before transitioning to home is not understandable as indicated by this care coordinator:

“And that’s where it puts pressure on us and why they want so much service in there. Because they don’t feel that the nurses here can provide care but you can at home? That is a huge... To me, it doesn’t make sense.” – *COMM004*

It does help to understand why the community services are bombarded with service requests by hospital staff that are not required by the patient and/or that are not feasible (e.g. only able to provide five seven-hour shifts of respite care and not 24-hours of nursing as sometimes recommended by hospital professionals).

Parental Expectations

The care coordinators highlighted the importance of what information about community services once discharged home is passed on to the parents by hospital staff and what parents go out to find themselves. Providing information that is not what will actual happen at home, which may be done by hospital staff who are unaware of what is available in the community, leads to a

build-up of high parental expectations when the parents go home. Thus it is important to maintain the same message to parents by the hospital and community staff:

“Generally, as long as... It’s keeping the expectations realistic. So if they’re told like things like with IV meds, like sometimes the messaging from CHEO is like there will be a nurse coming to your house every 6 hours. And they’re not. We’ve set up a pump which is timed so it will be delivering that, and the nurse will come once a day to set the pump up. So it’s just kind of setting up the expectation so there’s the same messaging from hospital through to the community.” – *COMM004*

Creating false expectations leads to false hopes of parents who are left surprised when they find out the truth once home. This can lead to very upset parents with their anger often turned fully to the community health care professionals. Because the community healthcare professionals end up dealing with this, it again is crucial to be fully aware what can be provided to the patient once home before promising anything:

“So that hospital staff do know what is doable and not promise like that the nurse will be there.... I mean parents advocate, as they should do, hugely for their children. So you know, that’s an everyday sort of issue, is when parents... You know, some are reasonable and some are unreasonable. But generally, you know, parents do the best they can for their children. And I don’t... Yeah, most parents are doing their best. Some just don’t turn up, and yeah, are difficult. But by and large, no. You always get the odd person, don’t you?” – *COMM004*

Better communication amongst the hospital staff and the community health care team can help to prevent the creation of false expectations amongst parents of the infants being discharged home.

The importance of collaboration between the hospitals and the community care team is highlighted in this section. Issues were raised which can affect the planning of a ToC into the community and ultimately the experience of the patient’s family such as last-minute involvement in ToC planning and building false hopes. It is important to note that education or awareness

about the CDT and community services to hospital healthcare professionals may be the key to addressing some of the issues that were raised in this theme. Just as important as the collaboration with the NICU is the collaboration with the patients' families – a theme that I will explore next.

Family-Level Challenges

An important component that cannot be ignored in ToC planning is the family. Care coordinators in the community were asked to reflect and comment on their experiences with the families of the infants being discharged home from the NICU.

Communication

The responses obtained from the participants seemed to indicate that they do not have regular, set communication with the patient's family on a regular basis. Communication is kept to care coordinators providing updates to the parents on their infant's ToC plan or to obtain pertinent information from the parents, which is required for the ToC plan. Thus, even though parents are considered a part of the ToC communication, they mostly communicate with the care coordinators if they have been approached by the CDT. They can also contact their care coordinator via the unit if needed as well, however it is rare that that happens. Here is what two care coordinators said about communication with the parents:

“Yeah, just check in, touch base, offer a bit of support. Just let them know like you're working on the discharge. I think it's overwhelming for a lot of the parents. And then it's kind of like, okay, this is where I'm at, this is what I've done, and then okay, how is this going? Especially when we're looking for funding and things, or support in the community.” – *COMM001*

“So no, we tend to come down and if the family is there then we'll speak to them. If they're not there, then we don't usually need to phone them at home because we already know they're in close contact with the bedside nurses. So it would be rare that we would

phone a family from neonates at home, unless there was something extraordinary that we needed to find out.” – *COMM002*

One care coordinator highlighted that parents on the NICU are often bombarded with information, which presents as a challenge:

“And then they get thrown so much information from everybody, right. Like doing like a tracheostomy, I’ve noticed like... Like our goal is to get them out in 6 to 8 weeks. I almost have to take an hour a week to sit down with them and explain bits. Because if I do, of course, the first visit and throw everything at them, then they’re completely overwhelmed. And that’s just the discharge planning piece. Then they get the whole medical piece about their trach and blah-blah-blah, and all these different kind of therapies. And then there’s just being a parent and having no medical background, and being scared, and being... So yeah, it’s been challenging. And there’s definitely barriers – language barriers.” – *COMM003*

As mentioned above, being a parent with an infant on the NICU is stressful. Adding language barriers and/or no medical background makes it an even more complex situation for parents. This combination of “information overload” and anxiety/stress could be one reason why parents indicated not being aware of discharge plans (see Chapter 5) – they may be presented with an abundance of information that they are not able to fully absorb. Care coordinators also highlighted that even though post-discharge the infant is no longer their responsibility, they still have some parents contacting them once they have gone home. A care coordinator mentions that these calls post-discharge do happen and that it is okay for a while to act as a liaison between the family and the community care coordinator:

“Yeah, I think especially the ones you’ve followed for so long, they’ve come to know you so well, even though you’ve told them that they have like a district care coordinator and another contact person, they still contact me, yeah. And that’s okay for like a little bit. Like if I have to be that liaison just for that quick fix piece then I’m happy to do it. But they also have to understand they’re now discharged home. So how I may support them may be a little bit slower than a patient that’s here that I’m trying to get out.” – *COMM003*

Challenges Faced When Working with the Family

One of the challenges that care coordinators indicated as a challenge with the infant's family is the lack of preparedness of the parents when going home. One care coordinator had a lot to say about this challenge. She suggests that the unit's tendency to do all things for the parents leaves them unprepared and not knowing how to care for the complex needs infant at home:

“So yeah, I think CHEO being a pediatric hospital, we baby kind of our parents a lot. We do a lot of things for them that don't enable them to be able to do it alone in the community.” – *COMM003*

This care coordinator explains further that even though opportunity exists for healthcare professionals on the units to teach parents how to care for their infant and allow them practice in advance, it often does not happen until a day or two prior to discharge:

“Sometimes you have to tell the nurses, ‘You need to teach them. Like they're going to be going home shortly’. Yes, he has an enoxaparin injection but this is the perfect time to teach the parents to do it at bedside. So we find ourselves teaching parents like 24 hours before discharge when they've been on enoxaparin for a week.” – *COMM003*

She clarifies that the situation is different with each family. There will be parents who are proactive and they usually find a way to talk with the nurse and get trained way before discharge, and then there are others who are more silent and “go with the flow”:

“You have parents that are very, ‘I want to do this. Just teach me how.’ And there's other people, ‘Like if someone else can do it, have them do it because I ain't doing it.’” – *COMM003*

To further illustrate the importance of training parents in advance so that they are comfortable and know what needs to be done once at the home, one care coordinator provides an example:

“Like we do a lot of equipment ordering and supplies ordering and getting quotes from vendors for these families. And then we order all of their initial equipment. Well, in 30 days from now when their 30 days’ supply is done, like because... We may have explained to them how to do it but that was 30 days ago. They may not have the intuition or the knowledge on how to go forward and reorder, right.” – *COMM003*

Another challenge that was identified was the parents themselves. Every family is different. There are some parents who spend the majority of their time with their infant at hospital, and there are others who are unable to come for a variety of reasons. Parents in shock or denial of their infant’s situation can be a challenge to discharge planning in that they are less willing to take their infant home:

“And another barrier I found with children is sometimes the parents, I don't know if it's a child with special needs who is not involved or distant, and they don't come to hospital to visit or they don't answer phone calls. It's almost like they're in a bit of denial and they don't want to prepare for that discharge. And that can be a big barrier to getting those children...” – *COMM004*

A difference in the competency levels of the parents was also highlighted. Care coordinators pointed out that some parents were easier to teach and prepare for taking care of their infant once discharged home. Other parents had a harder time trying to understand what their infants required and learn how to provide care for their complex care needs infant. When parents are not ready to care for their infant at home, this can prolong discharge:

“Like some families have a harder time...it is a big step for parents to learn and to just wrap their head around the fact that they have to learn this. They were not necessarily expecting to go home with a baby with medical conditions. So some parents are quicker at picking it up than others. Some parents are more competent than picking it up than others. Some parents are like just typical anxious first-time parents who have a hard time, you know, taking this sick baby home.... But that has been a barrier in discharging some patients, is their parents just weren't able to learn the care. So they ended up staying in hospital way longer than they technically needed to be because the parents have to be competent in caring for them.” – *COMM005*

Another challenge is dealing with families who are not happy with the providers who are providing care in their homes. One care coordinator explains that they do their best to try and accommodate the requests to change the providers and that in some cases it can be difficult:

“And you know, we can set up a care plan. We can have a nurse set up, and they can say, “I don’t like that nurse.” And then we’ll change the nurse because we’re in your home, we’re providing service. You’ve got to have somebody in your home that you like.... We really do our very best to make it work. But yeah, sometimes it doesn’t. And some people just don’t like anybody.” – *COMM004*

This serves as a barrier as when the family is not happy with the provider, it can take time to find another suitable provider that the family agrees with which in turn can prolong the discharge date further.

Barriers Faced by the Family at Home

The most common barrier that was listed as a barrier for the family once home was respite care or lack of a support system. This is especially the case for families who are new immigrants to the country and do not have extended family with them, as was the case with one of the infants observed during this study (INF2). Round-the-clock care is needed for infants with complex care needs. When in the NICU, it is easier for the parents as there are many healthcare providers there to provide care. Once home, however, the care of the infant is solely the responsibility of the family. In dual parent households, one parent ends up quitting their job to stay at home to provide for the infant while the other parent tries to pick up for the lost income. In other households, other children may be present making it harder and more stressful to care:

“And I mean it’s things like sometimes you just need somebody at home. Like you can look after the baby. But then when you consider it’s not just looking after the baby,

you've got to look after any other children that you might have. It's also, well, we have to eat. And it's meal prep and laundry and ordering medical supplies." – *COMM006*

In any case, level of care burden is high and it is understandable that it is important that respite care is available to provide these parents with some time to themselves. For families with extended family overseas, the CDT tries to help with bringing a family member over for a short period of time to help:

"Now, sometimes, you know... And our social workers will help with letters of support in order to help them to bring them from their country of origin so that they have some support. And that's often been very effective. You know, sometimes they've been lucky. Like you know, my sister's a nurse or you know. So that often makes... And I think even psychologically it makes a huge difference. I mean when you're sick or your child is sick, you want your mom, you know." – *COMM006*

Sometimes it's not just the support needed in the home, but also support networks in the community. Parents want to be able to take their infant out and having support systems which foster these needs makes a huge impact on the psychological needs of the family as well:

"Like I know I had one family and they were a little concerned about taking their child to a drop-in because they were afraid of other germs and things like that....like she made some amazing friends in that drop-in. And she said, "that's what saved me". And often like they kind of... They would go for walks, you know, and she would be there with all of her equipment – suction machine, portable suction, and everything. And I think their acceptance of her, they're saying wow, you are one amazing mom, like I mean that... You know, getting that kind of positive reinforcement, especially when you're feeling that tired, you know, it kind of gives you a boost. And some of those moms, they would bake, you know, muffins and they'd meet her and say, "Here, I've got some muffins for you." You know, they'd help out and those kind of things." – *COMM006*

This section presented the family-level challenges to the planning of a neonate's ToC in the point-of-view of the community healthcare professionals. The section presents some of the

challenges that the care coordinators face when working with the family such as dealing with different competency levels of the parents, and barriers that the family face once they are at home such as dealing with parents who are unhappy with their community care providers. It is interesting to note that the care coordinators list these barriers and also mention that communication with the parents is not something that happens on a regular basis or in a sense is not given much importance. After going through these barriers one can understand that the cause of these barriers is the poor communication between the care coordinators and the parents themselves. Having regular communication with the family members can definitely help to alleviate, if not all, at least some of the challenges that were identified in this section.

Summary of Results

Based on the results presented, it can be understood that the challenges presented above stem out from two larger problems, which are lack of knowledge of community services available and poor communication between healthcare professionals and the CDT. It should be noted that planning a ToC into the community and ensuring that an infant and his/her family is well connected with appropriate resources once out of hospital is not a small task. It is in fact one that requires intense planning, specialized knowledge of the care needs and community resources and thus takes time and effort to tailor a plan that suits each family's needs. This definitely is not something that can be placed solely on the plate of the CDT but should be a plan that is created in collaboration with the NICU healthcare professionals and the patient's family as well. The care coordinators interviewed expressed frustration that the ToC of neonates are last minute and they also expressed frustration with healthcare professionals hanging onto infants longer than needed because they are unaware of what community resources are available in the

community and for those who are aware they are unsure of the competencies of these service providers. These issues that were raised definitely point to some real opportunities for improvements in this area with a little effective communication. For instance, it is important to not only make the healthcare professionals aware of the community services available by presenting to them at their educational meetings, but it is also important to present to them some follow-up data on the cases that they had transferred from the NICU to the community. By seeing that the neonates that they have transferred out to community care are receiving the services and care that they need and thus are doing well, will help healthcare professionals to understand that many services exist in the community and that the professionals who provide this care are indeed competent enough to deal with neonates. In terms of being notified last minute, care coordinators did highlight the importance of the discharge rounds, which occur on the unit with the care facilitators once a week. Even though it is important, meeting just once a week to discuss ToC plans is not enough as the situations regarding the ToC of the neonates can change a lot during the one week. Thus, it would be beneficial to have these meetings daily or at least to have one representative from the CDT to meet with the care facilitator to get a daily update. By increasing the methods of communication it is possible to overcome these barriers.

The lack of awareness of some of the services provided by the CCAC such as the Pediatric Rapid Response Nurse (see Chapter 3 for a description of this role) and therefore lack of referral to these services by healthcare professionals was one of the issues that were brought up by the respondents. When comparing the NICUs across the three sites, it was noted that professionals were more unaware of these services at the TOH NICUs. Why this difference was noted could be due to the fact that the TOH NICUs are located in non-pediatric hospitals and also because the infants that are admitted to those NICUs are less likely to require CCAC

services upon discharge to the home. Even though the CCAC members mentioned hosting educational sessions to make those NICU healthcare professionals aware of the services, a service not used is eventually a service forgotten.

It should also be noted that the challenges with ToC neonates may be different for other community healthcare professionals such as the Ottawa Public Health, family physicians and/or community neonatologists. Issues due to REB did not allow for communication with other relevant community healthcare professionals, which is why this section is based solely on the experiences of the Champlain CCAC. The next chapter will discuss in detail the community experience vis-à-vis the healthcare professionals in terms of where there is a lack in the ToC of neonates and how the families experience a lack of a seamless transition.

CHAPTER 7

Discussion

There are a number of prominent and crosscutting themes that emerged from the interviews with the healthcare professionals, the family members, and the community care coordinators. These reveal both some similarities and differences when compared to the literature on the ToC of patients in the experiences of the healthcare professionals and the patient. A number of critical recommendations also emerged from the accounts of the participants' experiences. Despite some significant contributions, which will be highlighted, this study also exhibits some limitations (those that were inherent to the study's methodology and recruitment), which in turn highlight some promising areas for future research.

Cross Cutting Themes

There are a number of themes that were salient across the three chapters will be presented in this section. They have been grouped into four categories: processes, knowledge, attitudes, and regionalization of services. Each category organizes each themes as 'challenges and consequences for each key category (See Table 10).

Table 10. Crosscutting Themes

	Processes	Knowledge	Attitudes	Regionalization of Services
Challenges	Poor communication	Lack of knowledge of what's available in the community and/or the CDT	- Lack of trust amongst healthcare professionals - Frequent turnover of healthcare professionals	Organization of NICUs
Consequences	- Involvement in ToC planning - Being unaware of Toc plans - Last-minute notification of ToC	Underuse of community resources	- Advising parents against fellow healthcare professionals and creating false hopes for parents - Keeping infants longer than needed (over-hospitalization)	- ToC of infants outside of Ottawa area - Difference in parental responsibilities
Promising Practices	Discharge Rounds	Written material		
Key Cross-Cutting Tensions	- Tensions between parental and healthcare professionals' perspectives - Tension between institutional and community care			

Processes

Poor Communication

Poor communication was one of the major challenge and persistent themes across the three chapters. Participants highlighted the complex communication field that existed between professionals as well as between the professionals and the patient's family. They also pointed to that as one of the main causes of many of the other consequences that are faced during a neonate's ToC. This is very similar to the literature that was found regarding communication in the ToC of patients. Poor communication was listed as one of the top reasons for unsuccessful ToCs from the hospital (Dept. of Health, 2003; Shepperd et al., 2013, Bull et al., 1997). The consequences that arose from poor communication include involvement in ToC planning, being unaware of ToC plans, and last-minute notification of ToC. Involvement in ToC planning and being unaware of ToC plans is supported in the literature (Waibel et al., 2012; Reinhard et al., 2008; Bull et al., 1997). These consequences will be summarized in the next sections.

In addition to poor communication being a top reason for unsuccessful transitions of care from the hospital, it is important to note the possible causes for the problems with transitions of care communication. The interviews with the healthcare professionals and from the observations it is understandable that the lack of contact opportunities between healthcare professionals, which is part is due to time restraints and conflicting schedules, does play a key role. This is a good example of a macro level issue (system level with regards to scheduling and professional demands) affecting the meso level (fewer opportunities for contact between HCPs) and in turn the micro level (receive different information from the HCPs and ultimately leading to confusion and stress). This finding is supported by Goldman et al. (2016) who reported that problems with communication and discharge can be linked back to insufficient contact among professionals.

Involvement in ToC Planning

All three respondent groups brought up the amount of involvement in a neonate's ToC planning quite frequently. The responses, however, were quite mixed with them acknowledging that they felt involved in neonates' ToC planning but at the same time felt that they were not included enough.

For instance, the parents interviewed indicated that they felt they were included in their infant's care team, but there were times when they felt left out during critical times, such as during morning rounds. Parents indicated being at their infant's bedside when the healthcare team came around in the morning to discuss their infant's care as a group. At times they were invited to join the discussion and ask questions as necessary. This inclusion to participate in the morning rounds seemed more ad hoc than truly integrated into the process. They also indicated times when their presence was not acknowledged and they often felt like they had to "eavesdrop" to hear what is being said about their infant. In the case of healthcare professionals (often the non-medical and non-nursing staff) and the community care coordinators, they indicated that the majority of the time they felt that they were a part of the care team but at times they were not informed of meetings or any changes to care plans which presented as a challenge. In this case, the healthcare professionals and care coordinators indicated that there is no way for them to learn of any changes and thus get left out of the ToC planning and are left unaware of their neonate's ToC plans.

My previous study also demonstrated that inadequate communication between healthcare professionals contributed to the non-seamlessness of ToC (Manogaran, 2011). In addition to these results, the findings from the study by Bull et al. (1997) that inadequate communication is a fundamental source of discontinuity in ToC. This finding is also supported by studies by King et al. (2013), and Shepperd et al. (2013) who all reported that healthcare professionals acknowledged that open communication was important to efficient and effective ToC and that being left out of the ToC

communication resulted in them not only feeling left out of the ToC planning process but also hindering the creation of a seamless ToC.

Healthcare professionals and care coordinators also felt left out of the ToC planning stage resulting in their being unaware of ToC plans. The parents interviewed expressed frustration over approaching healthcare professionals and/or care coordinators asking for updates regarding their infant's ToC plan and receiving conflicting or varying information from the different professionals. For instance, parents indicated approaching healthcare professionals, such as their occupational therapist or social worker, inquiring about the potential discharge date and obtaining different dates from the different professionals (see chapter 5). The care coordinators and healthcare professionals agreed with the parents that it was common to obtain different information from the healthcare professionals on the unit.

Waibel et al. (2012) highlighted that patients and/or their family members expected their healthcare professionals to have the most up-to-date information regarding their ToC. Reinhard et al. (2008) reported that caregivers had difficulty obtaining information from healthcare providers and stated the importance of healthcare providers being more responsive to patient and caregivers' information needs. In addition to these findings, my study brings out the point that the lack of including the allied healthcare professionals in the ToC planning process further adds to the non-seamlessness of the ToCs on the NICU.

Last-Minute Notification of ToC

This was another salient theme across the three respondent groups. The healthcare professionals and care coordinators indicated that this last minute notification complicated their ToC process. This issue of last-minute notification of a ToC also contradicts internal policy documents. The process that healthcare professionals go through to make sure the patient is set up with what they

need once they are transferred out is immense. For instance, a pharmacist would need to ensure that all the patients medications are available and accessible at the pharmacy close to the patient's home and a care coordinator would need to ensure that services such as an oxygen tank are affordable by the family (if not then funding prospects need to be investigated) and that these services are ready to go once the infant enters the home. Being told last minute, and by last minute healthcare professionals and care coordinators stressed that could mean a couple of hours before the transfer, means that the processes have to be sped up and that other tasks (i.e. setting up services for other patients) have to be dropped in order to fulfill these orders. Often, some of these services are provided after the infant has been transferred, as the time to get them organized is not enough.

In the case of the parents, they also stressed the hassle that they had to go through in terms of being told last minute (the day before or sometimes even the day of) that their infant is being transferred. These hassles included not being ready to take the infant home (e.g. Parents did not take time off from work or did not purchase a car seat) as well as not being mentally ready to take their infant home (so second-guessing if they are competent enough to care for their neonate). Helder et al. (2012) support this finding of the hassle parents undergo due to last-minute notification of discharge by stressing that keeping parents in the loop and well-informed of the infant's discharge plans meant less stress and anxiety for the parents. Being told earlier would help parents to make themselves prepared in terms of the logistics of taking their infant home as well to prepare themselves mentally for their responsibilities and changes to their everyday life.

This finding on last-minute notifications of discharge is something new and is not present in the current literature. I stress again the importance of this finding as when the parents were interviewed, this is the one barrier that they all stated when it came to their ToC experience.

Interestingly, when healthcare professionals (mostly medical and nursing staff) were asked about parents being notified last minute of their infant's discharge, they often responded with a confusion as to why this is the case because in their point-of-view they do notify the parents of what milestones need to be complete before the infant goes home (e.g. the infant has to pass seven days on the NICU without a spell before they can go home) and yet parents are shocked and react this way when they are told their infant is ready for discharge. This opposing view of the issue suggests that the method(s) used to communicate this information to the parents is definitely not effective. It is understandable, and was mentioned by healthcare professionals during their interviews, that the parents are already anxious and are often bombarded with information. Thus it is very likely that this information regarding when their infant will be ready for discharge can pass right over them very easily and thus an effective way of communicating this information to the parents is definitely of high need.

The study by Broedsgaard and Wagner (2005) also identified the need for information to parents in the NICU be repeated and supported by the availability of written informational materials. Bain et al. (2003) and Hurst (2006) both reported that written information to support verbal instruction for parents was lacking on all aspects of care. These studies support the findings in this dissertation that verbal communication is not enough when it comes to relaying information to the parents of the neonates. Having written material to support their verbal instructions gives parents something to refer to when they want to remind themselves of what they were told by their infant's healthcare providers. The internal policy document also supports this fact by suggesting that whiteboards be used to relay information regarding the potential discharge date.

Promising Practices

Importance of Discharge Rounds.

A main finding that was consistently brought up by the hospital healthcare professionals and the community care coordinators was the importance of the discharge rounds. These rounds occur every Tuesday mornings on the NICU at CHEO and are open to any healthcare professional who would like to get up-to-date information on infants ready for discharge. All the healthcare professionals stated that this discharge round was very useful and served as a platform for them to obtain information on discharge in one sitting. They stated that it also allowed for them to ask questions regarding the ToC plan of an infant directly to the respective healthcare professional if he/she was present. Community care coordinators stated that attending discharge rounds helped them to identify any potential infants who would require their services and who were not yet flagged by the hospital staff. When asked what helped to facilitate IPC on the unit, all healthcare professionals brought up the discharge round as a facilitator.

This promising practice is supported by Halm et al. (2003) who demonstrated that the introduction of interdisciplinary rounds resulted in a greater participation by all disciplines in achieving patient and family outcomes, increased early recognition of patients at risk, and improved communication among members of the healthcare team. Baker and Wellman (2005) also support this finding by reporting in their study that having the different healthcare professionals take part in the discharge process as positive outcomes given the responsibility of each interdisciplinary team member to have knowledge of what can be provided for the patient respective to their own field.

Knowledge

Lack of Knowledge of What's Available in the Community and/or the CDT

Care coordinators expressed frustration over the general lack of knowledge of healthcare professionals of the CDT's process to discharge into the community as well as what services are available for neonates in the community. This can also be viewed as a cause of last-minute notifications of ToC. Care coordinators expressed that it was frustrating when these last-minute notifications happened because it really adds stress when trying to hook neonates up with the services that they need in the community. There are actually certain processes and measures that need to be followed by the care coordinators and it goes without saying that this does take time. In this sense, communicating the role of the CDT, their processes and what's available in the community to healthcare professionals may help to alleviate these issues. Not addressing this issue can lead to other issues such as uncertainty or the underuse of community resources.

This finding of healthcare professionals' lack of knowledge of community resources is another new finding that was not prominent in the literature. Although I was able to find literature on the parents' or families' lack of knowledge of community resources, the theme of healthcare professionals' lack of knowledge of community resources available was relatively silent.

Underuse of Community Resources

It is not only important to make healthcare professionals aware of the services available in the community but also to highlight data about the neonates who they have transferred out into the community – a consequence of lacking knowledge of available community healthcare resources. Seeing what these infants were connected with and how they are being cared for in the community will help healthcare professionals learn of what resources are available (i.e. Rapid Response Nurse and Ottawa Public Health Nurses), how, and in which circumstances to use the different services. Having an awareness of what services are available and understanding of the competencies of the service providers in the community can help to deal with issues surrounding lack of trust of other

healthcare professionals in terms of their ability to take care of the neonates – a theme which will be discussed in the next section.

Attitudes

It was interesting to hear how the lack of trust amongst healthcare professionals (amongst the units and in the community) can play a role in the ToC of a neonate. Some of the consequences that arose from this lack of trust included healthcare professionals keeping infants longer than required on their units, advising parents against fellow healthcare professionals and thus giving false hopes to parents. These issues will be addressed in this section.

Frequent Turnover of Healthcare Professionals

The frequent turnover of healthcare professionals was brought up as a challenge, which fostered this lack of trust amongst healthcare professionals. The turnover time can range from two weeks to one month for the different healthcare professionals. In this case, healthcare professionals (especially physicians) are returning to work after some length of time and need to be updated on the specific cases. Thus it is possible that it can take some time before the healthcare professionals are up-to-date with the situation on the unit and if they are approached by the parents or other healthcare professionals and/or care coordinators, it is very possible that they will seem unsure of what the current state is and therefore unable to attend to their inquiries.

The frequent turnover of physicians also plays a role in the ToC plan of infants, sometimes resulting in last-minute notification of a ToC of infants to healthcare professionals and/or their parents. Physicians have their own sense or idea of care for patients. Thus, it is very possible that the care plans for the neonates can change to some degree when a new healthcare professional is in charge. For example, a physician may have decided that an infant needs a certain test done before the neonate can leave the unit, however, another physician who has just started their rotation and has thus

taken over the care of the neonates, may decide that the test can be done at another care facility and thus the infant can be transferred immediately.

The frequent turnover of physicians was reported in my previous study (Manogaran, 2011). The finding from my previous study supports that this frequent turnover does in fact hinder the ToC process due to the different attitudes of the healthcare professionals turning over and thus a lack of trust. This connection was not found in the literature and thus is an important finding in this study.

Advising Parents Against Fellow Healthcare Professionals and False Hopes

The healthcare professionals on the floor and in the community identified another consequence of lack of trust. They mentioned that there was not only a lack of trust in their competencies and ability to take care of a neonate, but also lack of trust in their word about what can and cannot be provided for an infant. For instance, one healthcare professional mentioned the issue of after telling a care team that they can only take an infant onto the floor on a certain day (after a spot has been cleared), healthcare professionals on the NICU do not trust that and so advise parents that if they are more vocal they will definitely get what it is that they want. In other words, they are giving parents the false hope that whatever it is that they desire for their infant is possible and it's the healthcare professionals on the floor who are not cooperating. This makes it a challenge for the non-NICU healthcare professionals, as they are the ones who end up dealing with upset parents. An example is of Case II in this study whose parents were told that they would be seen by the occupational therapist as soon as the infant is transferred to the floor and once that is done the infant can go home. In reality, however, the infant was a chronic infant who needed a lot of work done before she could be sent home. This false hope given to the parents in combination with the last-minute notification of their infant's transfer to the floor's occupational therapist created an issue where the parents were very upset and literally took their anger out on the occupational therapist and the other healthcare professionals on the floor (See Chapter 5 for more details). Healthcare

professionals also made it clear that similar situations also occurred amongst staff within the same unit. In one example, parents were told that the infant had to be transferred to the floor instead of to a hospital near their home, which was what was originally planned. The parents were not happy with this change, but went along with it until they were advised by another staff member to be more vocal and that that would help them to get what it is they desired. In reality, the change in ToC plans occurred because the infant's situation had changed as such. Situations like this can be avoided if the healthcare professionals can learn to understand and trust one another when it comes to the ToC of patients. The situation of each floor/unit is independent and only those respective healthcare professionals know what the processes and guidelines are that need to be followed. It is thus important for all healthcare professionals to respect this and thus trust that their fellow healthcare professionals are doing the maximum and the best that they can for their patients.

Keeping Infants Longer than Needed (Over-hospitalization)

Over-hospitalization was a common issue that was brought up by healthcare professionals on the floors and the care coordinators. They brought up the issue that because the healthcare professionals on the NICU did not trust their expertise and competencies to care for the neonates, the healthcare professionals on the NICU tended to hand on to their patients longer even though the neonate no longer required tertiary level care. For example, an infant who only needs to feed and grow does not need to be monitored and weighed by a neonatologist, as this is something that can be done in the community by a family physician or a Pediatric Rapid Response Nurse. Thus, in this case, hanging on to a feeding and growing infant takes away tertiary level neonatal care resources which can be used for an infant who is in need of this level of care. This theme highlights nicely how issues in one level affect the other levels. Here the issue that exists is present in the meso professional level with healthcare professionals in the hospital lacking knowledge of the community resources available to neonates and as a result a lack of trust causes neonates being held on the NICU

longer than needed. This of course causes increased costs to the macro system level. More importantly, it causes confusion and uncertainty for the micro family level.

The study by Vekov (2011) reported over-hospitalization as a result of patients not trusting lower sectors of health care. Not much literature was found to support the finding that healthcare professionals were hanging on to patients longer due to lack of trust of the community providers.

Regionalization of Services

Organization of NICUs as a Challenge

The healthcare professionals interviewed as well as the care coordinators brought the issue of how the NICUs are organized act as a barrier. The organization of the NICUs can be looked at in two dimensions, which are the actual system of how the five NICUs are organized in Ottawa and also at the individual unit's processes. The way that the five NICUs in Ottawa are organized is not supportive when wanting to send the infants to a step-down unit before going home. Lack of bed space and in some cases the different organizational practice act as barriers to transferring neonates to secondary level NICUs (See Chapter 4). The symptoms of this challenge include difficulty in transferring infants outside of Ottawa and a different in parental responsibilities across the sites.

ToC of Infants Outside of Ottawa

This is one theme, which was brought up by the healthcare professionals, the parents and the care coordinators. Transferring infants outside of the Ottawa are means transferring them to areas where services may or may not be available. For instance, a certain medication may not be available in liquid form at the pharmacy in the infant's hometown or there may not be respite care nurses located within close proximity of the infant's hometown. In these cases, healthcare professionals

have to work with the community providers to negotiate a plan such as having the closest available respite care nurse drive to the infant's home to provide care or working with the available community care providers to train them to provide the required care for the infant. In some other cases, parents have indicated making decisions to move to Ottawa or to other areas where the required services are available. This definitely can be very stressful for the families but is a decision that has to be considered. These findings are supported by the study by McWilliam and Sangster (1994) who found differences in the way that patients experience ToC rural versus urban settings.

Difference in Parental Responsibilities as a Challenge

Healthcare professionals, the family and the care coordinators highlighted this issue as a challenge to ToC. Specifically, healthcare professionals and care coordinators pointed out that on the NICU, the infant is cared for by the bedside nurse and thus the parents can take a back seat approach in caring for their infants. In fact, some parents are told to relax and take it easy while their infants on the NICU. Once the infant is transferred to another hospital or unit, most often the second site depends on the parents to take a bigger role and provide basic care for their infants. Where this becomes a barrier is when infants are transferred to another site and parents are not used to providing care. Thus this becomes a barrier to the healthcare professionals, as they have to provide care and train the parents at the same time – something that is difficult for them to do considering the amount of time and resources that they have. The same applies for when parents go into the community directly from the NICU. Since parents do not have the chance to practice caring for their infant, they are more unlikely to be ready to care for the infant once in the home. This results in anxious parents who are not ready to take their baby home and thus acts as a barrier. Something that was recommended by the three respondent groups was for the NICU to empower and encourage parents to practice caring for their infant in their unit (where the infant has one-on-one care with a nurse and has

his/her own pod). This allows parents to get used to caring for their infant in a safe environment (where help is close by) and gets them prepared to care for their infant at home.

The above section highlighted the main findings from this dissertation organized by way of cause and consequences of the causes reported. These findings presented the more concrete issues that arose when planning a neonate's ToC. There are, however, overarching inherent tensions that exist between all the key players in a ToC. The section below will highlight these key-crosscutting tensions.

Key Cross-Cutting Tensions

Tensions between Parental and Healthcare Professionals Perspectives

An interesting dynamic that exists on the NICU is that between the parents of the neonates and their healthcare professionals. Even though they are experiencing the same ToC, the way in which this process is experienced varies greatly between healthcare professionals and parents creating a sort of juxtaposition between the two.

For parents, this ToC is for their infant. It is a personal experience and the start of a journey with their newborn infant that they will most likely be travelling for the rest of their lives. Unlike parents of healthy infants, these parents are much stressed and anxious about the infant's care (Zanardo et al., 2003). This stress can lead to them doubting their own competencies when it comes to taking care of their infant (Smith et al., 2009). Parents are not just dealing a process that they have to deal with to get their infant home, but in combination with that they are riding an emotional rollercoaster and looking for something to steady to cling on to feel secure. As Kirk (2001) mentions, parents are not only dealing with a sick infant but also with the fact that they are on unfamiliar territory and have to rely on healthcare professionals for information. This can easily lead to feelings

of isolation (Hurst, 2006) and the need to feel that they are not alone in their experience. As was discussed in the results chapter of this study (Chapter 5), having proper discharge education (as much as parents felt enough) helped parents to feel confident in taking care of their infant once home (Rabelo et al., 2007). This discharge education, of course, can only happen with the help and cooperation of the healthcare professionals facilitating the ToC.

On the other hand, for healthcare professionals, ToC is just a routine that is a part of their everyday career. In that sense, healthcare professionals strip away the emotional aspects of a ToC and have reduced the ToC process to just a mundane task. In this everyday task, it does become possible that healthcare professionals can miss out on understanding the position of the parents. As Kirk (2001) mentions, healthcare professionals often misinterpret that parents wish to be involved in the nursing care of their infant. This lack of negotiation between the healthcare professionals and the parents can lead to parents who do not quite feel ready to take their infants home which adds on to more stress (Wong et al., 2011). Not understanding the position of the parents before planning a ToC definitely has an influence on the results of the ToC. Thus, healthcare professionals have an important role to play in ensuring not just that they have given all the information to the parents, but that the parents have understood the information and feel confident to take on caring for the infant. This is something that should not be forgotten due to the overarching notion that this is their job and that is needs to get done.

Tension between Institutional and Community Care

The transition from the hospital to the community is an important and more stressful aspect of a patient's ToC. Transferring a neonate to the community requires more work where the proper services and care required must be put in place. As the results in Chapter 6 highlight, connecting

patients to the resources in the community is in itself a big process, which requires time and much negotiation between the healthcare professionals in the hospital, the community care providers and the family (Wong et al., 2011).

The lack of seamlessness of transition is most likely present in this portion of an infant's ToC. Many challenges come into place depending on each individual family's situation such as funding, availability of resources in their community, etc. These challenges were highlighted in Chapter 6 of this dissertation.

Key Strengths of Thesis Research

This study brought forth several key contributions to the literature. Firstly, the issue of last-minute notification of an infant's ToC to parents and healthcare professionals. This is a significant issue, which serves as a consequence of poor communication. Another key finding is the lack of awareness of healthcare professionals of available community resources and thus uncertainty/underuse of community resources. The frequent turnover of healthcare professionals was also brought up as a key finding in that the different attitudes of the different healthcare professionals can impact the ToC plan of infants. Healthcare professionals hanging on to infants longer on the NICU was also reported. The consequences of this over hospitalization, which is due primarily to lack of trust of healthcare professionals in the community, results in unwanted use of resources and thus a higher cost to the system.

Another strength of this study was the inclusion of the community healthcare providers in the sample. This is something that was emergent in the design yet with only six interviews, it proved to be the most abundant chapter and provided the most valuable information as well as gaps that exist in the hospital-community interface. Being a population health dissertation, studying this link, which obviously based on the key findings is relatively silent in the literature, will help to examine and thus

enhance the experience of neonates in the community as this is where they will ultimately go to grow and become members of society.

This study followed the principles of institutional ethnography. Institutional ethnography, as Dorothy Smith proposed it, looks at power through a gender lens (Smith, 1990). As described in the methodology chapter in this dissertation (Chapter 2), it focuses on the importance of mediated-texts and how it shapes experiences. In the case of this research study, texts and policies related to the ToC of neonates were studied to see how they constrain the everyday experiences for parents and healthcare professionals. Also, by way of the institutional ethnography principles, the power dynamics that exist between healthcare professionals (inter and intra-organizational) and that which exists between parents and the healthcare professionals was also studied. As mentioned before, the power dynamic that exists between the healthcare professional and the patient's family is one that is hard to overcome and understand. Further, the power dynamic between parents (mother and father) was also studied and interestingly found that mothers were given more power by their families and healthcare professionals in the care of their infants compared to fathers.

A unique contribution of this study is the particular methodological approach that was used. The institutional ethnography approach allowed for a focus on the lived experience. It examined the 'relations of ruling' (in this case the structure and processes of the NICU transitions of care system) that are enacted through texts and how that is experienced by those navigating through this system (the parents). In addition to this, another of my contributions locally to the unit was the process map (see Figure 5). This process map highlights the possible pathways that the neonates on the NICU at CHEO can take before going home. It was a long complicated process to draw out (stemmed out of information received from interviews which are presented in Chapter 3 of the dissertation). Important feedback was received on this process map and the map was very important. Deliberative dialogue

sessions demonstrated that health care professionals had no idea what was happening on the unit. Participants indicated the importance of this process map to the unit to assist in the identification of crisis points during transfers for improvement with the biggest crisis points being located between the hospitals and the community (depicted here without an arrow connecting the two together).

Recommendations

The following section presents several recommendations identified by the researcher through information obtained from the interviews with the healthcare professionals, the family, and the community care coordinators. Recommendations, which were suggested by participants during the interviews, are also presented.

Proper Communication Methods

From the results it is obvious that communication was a major cause of many of the other challenges that were presented by the respondents. The recommendations respective to the family, healthcare professionals, and the care coordinators are presented next.

Communication with the Family

In terms of communicating with the parents, it is not only important to ensure that the most updated information is being presented to the parents but that the information is presented in a way that the parents will be able to absorb the details properly. For instance, when communicating to parents about the potential discharge date or what goals had to be attained before a discharge could be planned, it would be beneficial to not only verbally communicate this to the parents, but to also have it in written form for the parents to see on a daily basis such as on a white board near the infant's crib. Having the goals written on the whiteboard and updated on a daily basis (with new information or

checkmarks to indicate attainment of a goal) would help parents to keep on track and possibly predict themselves when a potential discharge or transfer might happen. Following such a method would also help for parents to feel updated on what's happening with their infant and to ask questions to the healthcare team as needed for clarification.

In addition to this, the parents did state that the frequent turnover of staff on the unit acted as a barrier to communication with healthcare professionals. The frequent turnover of staff left parents unsure of who they are to communicate with in terms of their baby and also left them unable to keep up with the change which, in some cases, was daily. In terms of this issue, the Care Facilitators on the unit try to overcome this by trying to schedule the same two nurses to a baby instead of the parents having to deal with a new nurse every day. This helped parents to feel comfortable with and maintain a relationship with familiar faces thus encouraging communication and collaboration of the parents with their baby's bedside nurse(s). This is a practice that is undertaken by the nursing team on the NICU and one that definitely should be highlighted to the rest of the team as a leading and promising practice.

Communication with Healthcare Professionals

In terms of communicating with healthcare professionals, the main problem was team members being left out on certain communication, which ended up creating a challenge when working on their part of the ToC. As mentioned in the results section (See Chapter 4), it is difficult for all healthcare professionals to be present for the morning rounds due to the demands of their job. Thus, having some form of a unified communication tool where infants' ToC information can be updated on a daily basis would be beneficial. For example, having the care facilitator or even resident update this electronically in the infant's chart will allow those healthcare professionals who were unable to attend morning rounds to be able to access an update simply by logging to the infant's

electronic medical chart. Of course an electronic chart would make it accessible to everyone regardless of where they are located; however, it can also be done at the chart which is located by the infant's bedside. As long as there is one location and everyone is aware that they can count on finding the most up-to-date information there.

Communication with Community Care Coordinators

It cannot be stressed enough how important it is to keep in communication with the care coordinators who will be planning the community aspect of an infant's ToC. There are two communication-related issues that the CDT experience which are 1) not being told of a potential infant that would require their services and 2) not being updated on the infant's ToC plans. First of all, it is important to alert the CDT right at the admission of a potential infant who would require CDT services upon discharge. I believe that currently the CDT is listed on the NICU discharge checklist, however, this checklist is often not referred to until a ToC has been confirmed which then would be too late to inform the CDT. Considering this, it is recommended to include the CDT in the unit's admission checklist. This way, healthcare professionals who are responsible for completing the admission will be reminded to think about whether the infant will require the CDT and then can therefore contact the CDT members and alert them about the infant. In terms of not being updated on the infant's ToC plans and thus resulting in last-minute notifications of a transfer, giving care coordinators access to the same unified documentation that was mentioned in the section above would help to relieve this issue. With the NICU being a very busy unit, proposing more frequent discharge planning meetings is not quite feasible considering the time restraints of the healthcare professionals. Thus, having such a method that is not only unified, but one which all care team members are aware of is very important and can help to alleviate this issue. With such a method, the care team members,

especially those that are not situated on the NICU, can access these details and update themselves when they do have time.

Education for Healthcare Professionals on Community Resources

Many of the challenges that the CDT face are a result of the healthcare professionals having a lack of knowledge of the community resources and services that are available for neonates once they are transitioned into the community. Having this knowledge may help healthcare professionals to decide on a good time in the patient's care to transfer an infant into the community. Having this knowledge is not enough. Healthcare professionals need to be shown that the community has the competency to care for the neonates. A recommendation to deal with these two issues is to educate the healthcare professional team. The NICU holds monthly multidisciplinary meetings where representatives from each healthcare occupation will be present to give a summary or update about their past month's activities (e.g. any adverse events, etc.). This would be an ideal location for a representative from the CDT to educate and remind healthcare professionals about their services and processes. It is also a good venue to present data or updates on infants who they helped to transition into the community from the NICU. This would help healthcare professionals to see firsthand that the infant is doing well in the community with the services that he/she requires. As currently the NICU has no method of evaluation of their discharges, it is also recommended to do follow-ups on the number of neonates who have been discharged from the NICU and then readmitted. These follow-ups can help to evaluate the discharge plans and to improve the process. It also serves as valid data for the healthcare professionals understand that the community does in fact have the competency to care for neonates.

Limitations

A couple of limitations of this study design existed. In terms of the study population two limitations existed. One limitation was the likelihood of finding an infant being transferred from the NICU directly to the home was very less. The majority of infants admitted to the NICU at this hospital are almost always transferred to another unit or another hospital. A very small proportion of the infants admitted are discharged directly to the home. Thus, there was an issue with trying to find an infant under that category during the study period. To deal with this issue of difficulty finding infants discharged directly home for future research, I would change the recruitment location from a tertiary NICU to a secondary/tertiary NICU and one that is connected with a maternity ward. This would broaden the sample to different types of infants including ones who are very acute (this go direct home after observation) to ones that require complex care (and thus have to be transferred to a tertiary level NICU). Recruiting neonates from a tertiary level NICU meant we were restricting the sample to infants with complex care needs since those were the type of patients that were most likely to be admitted to a tertiary level NICU. Another issue was trying to find equal numbers of acute and chronic cases of infants in each of the three categories. At one point, it was evident after having some difficulty in recruiting infants going to another floor that it was more likely that a chronic infant would be more likely transferred to the floor compared to an acute care infant. Similarly, it was more likely that an acute care infant would be transferred directly home from the NICU compared to a chronic care infant. Thus, to accommodate this issue the sampling criteria was changed to recruit either chronic or acute infants instead of both. The required modifications were sent to the respective REBs and approvals were obtained. In addition to this, the family consent form may have inadvertently excluded single parents from the sample as it does indicate that the study needed to recruit 12 babies and thus will have approximately 24 parents. The research assistant, however, was

told to recruit any infant that fit the study criteria regardless of the family situation and thus the study did have one single mother as part of the sample.

Another limitation was the issue of not knowing how long a patient's journey would last. In this study, the proposed methodology was to follow the patients right up until their discharge to their home. A chronic care patient, however, may be transferred between several units or hospitals and thus their length of stay prior to discharge may exceed the study timelines. There was an issue with being unable to contact the parents of a neonate in the study for interviews. I was unable to contact the parents of Case 2 for a pre and post-discharge interviews (After attempting to contact them for several months). However, the healthcare professionals interviews and observations for this baby were included in the data. The parents never stated that they wanted to drop out of the study. This inability to contact them could have been a result of many things such as the phone number noted on the consent form not being used anymore by the parents or being incorrect. In terms of cases that were recruited but ended up having a change in the transition of care site were removed from the study prior to the commencement of data collection. To address the issue of possible change in ToC site, I waited to interview the parents until the location was confirmed to be one of the hospitals that we had obtained REB for this study. This situation was dealt with by increasing the sample size so that it would make up for any participants lost in the study or for those whose stay exceeded the study period. For instance, the research proposal proposed six cases to be studied. Thus, this number of cases was doubled so that 12 cases were recruited to help deal with this issue. A similar situation did occur with one of the infants in the study. This infant and her family went through a remarkable journey in her ToC and thus because of the conflicts that arose interviewing the parents became almost impossible to do while in the hospital. The infant was in hospital from June to September 2015. Once the infant was discharged I tried multiple times to contact this family for an interview

(they had signed the consent form at the start of the study) but without luck. After trying to contact them for seven months, I decided to go ahead with the observations data that I had for the infant and the interviews with the infant's healthcare providers.

The multiple research ethics board (REB) applications were also a limitation to this study. Initially, this study was to include participation from five hospitals in Ottawa. It took almost a year to obtain REB approval from the CHEO and Ottawa Health Research Institute (OHRI) REBs. I was able to secure REB clearance from the University of Ottawa REB fairly quickly as since they have an agreement with the CHEO REB, they only conducted an administrative review thus saving some time. Due to the process and the time it took to obtain REB approval from the three REBs, it seemed unfeasible to obtain REB approval in a timely manner from the other REBs and thus unfortunately, was decided to drop recruitment from the remaining two hospitals (Montfort and Queensway-Carleton) to avoid delay in the start of the study. Unfortunately this decision resulted in the loss of potential participants because they were being transferred to the hospitals not a part of this study due to the length of time it would take to obtain REB approval.

Another limitation was being unable to interview other community healthcare professionals. This was a last-minute addition to the study and thus due to the REB process and limited time to complete the study, only members of the CCAC were interviewed since they had a cross appointment with CHEO and thus was covered under CHEO's REB approval. Even though the community aspect was a last minute addition, and only six care coordinators were interviewed, it turned out to be the longest chapter with an abundance of information regarding challenges that are present when transferring neonates into the community. Considering the amount of feedback received from the CCAC members it demonstrates the importance of exploring the issues faced by the community healthcare professionals and thus the importance of including other community healthcare

professionals in the sample such as family physicians, community paediatricians, Ottawa Public Health, etc.

Future Research Directions

The purpose of this research was to study the importance of the management of transitions on the NICU in the experiences of the healthcare professionals (system), the family, and the community care providers. This study assisted with not only understanding the importance of the management of ToC of neonates but also with identifying challenges in the ToC process which need to be further studies and improved in order to achieve a seamless ToC experience.

Inclusion of the Various Community Care Providers in the Sample

This study originally started off with including only the family and the hospital healthcare professionals in the sample. Towards the end of the study, however, the community care piece was added. Due to the time constraint and the REB process, our sample only included members of the CCAC. Thus, other community care providers such as family physicians, community pediatricians, and Ottawa Public Health were excluded. Even though the community piece was added in last, it was the longest results chapter with an abundance of information. This is definitely an area which has not been studied and definitely should be studied as the community care piece plays an important role for infants and their families once they are at home. Including all the possible community care providers that are involved the care of neonates would help to identify further challenges that these care providers and the family experience once out in the community.

Purposively Sample Families with Different SES Backgrounds

In this study, the infants were purposively sampled for acute or chronic and as a result it was noted that a difference did exist in the experience of parents with acute care infants versus those with chronic care infants. Similarly, it would be interesting to study if the different SES (socioeconomic status) of families had a role in defining the parents' ToC experience. In this study, I aimed to interview mothers and fathers separately to investigate any gender differences in the ways ToC are experienced. It was not as successful as I had hoped for as many of the parents wanted to be interviewed together and not separately. I did find in my study, however, that mothers seemed to take on a more leadership role and that healthcare professionals felt that they could relate more with the mothers compared to the fathers. Planning a study that would look into these issues in more depth would help to understand the variations in ToC experiences and possibly can inform healthcare professionals so that they are able to understand why certain experiences happen a certain way.

Assessing the Usefulness & Quality of the NICU Discharge Rounds

The usefulness of the NICU Discharge Rounds was mentioned by most of the healthcare professionals that I interviewed. There were, however, some healthcare professionals who felt that the weekly Discharge Rounds were just a repetition of the daily physician-led morning rounds. From my observations it was evident that physician-led morning rounds were merely discussions about each neonate on the unit between the medical team members and the non-medical team members present at the rounds watched and listened unless they made an attempt to have a say or were called upon to comment by the medical team. On the other hand, the discharge rounds which occurred every Tuesday was more open to hearing opinions from everyone on the team, however, whether the way the rounds is organized is efficient to serve its purpose does remain questionable. It would be

beneficial to the unit to have a study assessing the quality and usefulness of the discharge rounds and providing suggestions on how it can be effective in it's purpose.

Patient Needs or Hospital Regulations – Which Comes First?

A couple of times I came across the issue of patients being transferred to the next available site even though another site (which at that time did not have spots available) would have been more beneficial (due to availability of testing equipment, etc.). This mismatch in transfer (which was stated to be due to administrative pressure) has led to babies being transferred back and forth between sites for the purpose of certain testing, appointments, etc.

The Role of the Paediatric Rapid Response Nurse

A relatively new service provided by the Community Care Access Centre, the Paediatric Rapid Response Nurse (RRN) visits neonates and their families who within 24-48 hours of their discharge. The role of the RRN is medically assess the baby to make sure that the neonate is doing okay and that there are no red flags as well as goes over with the parents what they were taught on the NICU before going home to ensure they are comfortable and know how they are to care for their neonate. The RRN also writes a summary, which is provided to the physician who discharged the neonate for their review. The RRN visits the family up to 3 times within the first 30 days post-discharge. This service is definitely useful in that it helps to bridge that gap between the parents and the NICU healthcare professionals once discharged home. It gives both the parents and the healthcare professionals who discharged the neonate a sense of assurance that the neonate is doing well at home. This service can definitely help to speed up transitions to home deal with the situation of over-hospitalization as was discussed in the thesis on page 161. Studying the role and importance of the RRN can definitely help

to increase awareness of this important role and assist with promoting seamless transitions of care of neonates.

The Use of Reflective Practice Amongst Healthcare Professionals to Improve Transitions of Care Planning

The use of reflective practice to reflect on cases that have been transferred can prove to be useful to improving how healthcare professionals go about planning a transfer of care. During the interviews, many of the healthcare professionals mentioned that they are frustrated with dealing with the same issue repeatedly such as being notified last minute that an infant is going to be discharged (As a result they are left scrambling to get the infant connected with services at their next point of care). Another issue that was brought up was the underuse of community services and partially because of a lack of knowledge of what's available in the community as well as a lack of trust of the competency of community healthcare professionals. One way of dealing with this may be the introduction of reflective practice where cases that were transferred into the community are presented and reflected on in an interprofessional way so that healthcare professionals can understand critical points where breakdown occurs as well as gain trust in their community counterparts thus reducing over-hospitalization. Studying the benefit of this process and how the integration of such a practice can enhance transitions of care of neonates would definitely prove to be beneficial.

Who is Writing to the Chart

Who is writing to the chart and who is reading the chart is another aspect of the ToC of neonates that should be studied further. Healthcare professionals frequently raised the issue of charts not being read by healthcare professionals and/or not being read by healthcare professionals and the resulting problems that arise. There is, however, a promising practice in place by the community Rapid Response Nurse. Here, the Rapid Response Nurse completes a summary of her initial visit,

which is sent back to the discharging physician. Based on the interviews, however, it was evident that the discharging physician does not follow this practice in that they do not take the time (and may not have the time) to review the document. Another issue that was brought up was that that parents were being sent home with their infant's medical chart to pass to their primary care physician however when asked, parents were not aware of that step or the medical chart in some cases. Studying the importance proper charting and how the system can be improved so that healthcare professionals and parents understand the importance of it and follow the practice would be beneficial.

Conclusion

When examined closely, the current structure and organization of the NICU does provide several avenues for ToC communication (i.e. discharge rounds, morning rounds, etc.). Even though this is the case, the results showed that parents, healthcare professionals, and the community care coordinators felt that ToC communication was not efficient and needed improvement as important information was not being transferred resulting in further challenges. In the case of the parents, what the healthcare professionals think is the right method of communicating ToC information, has obviously been proved ineffective via this study. Revisiting simple communication methods as mentioned in the recommendations section above can help to alleviate some of these challenges due to poor communication.

More than just a process, this study has brought to light the juxtaposition that exists between parents and the healthcare professionals. For healthcare professionals planning the ToC of a neonate is nothing more than a daily routine. In that sense, it is possible for the healthcare professionals to unintentionally remove themselves from the emotional aspects of the ToC which parents experience. For parents, this ToC process is very important as it is their baby that is being transferred and thus their lives that are being transformed – thus aside from the systematic process parents also have to

deal at the same time with an emotional roller coaster which can definitely take unexpected turns. In this sense, the importance of healthcare professionals recognizing this situation for parents and implementing processes to not only make the ToC process clear but also to empower the parents will definitely prove helpful to improving the overall ToC experience.

This study has also highlighted the importance of studying the community care piece of an infant's ToC. As mentioned previously, being an emergent part of this study, the amount of feedback received from only six respondents proves that it is an area of ToC that is understudied. This study highlighted the importance of the hospital and community health care providers working together to plan an infant's ToC can help to create a seamless ToC for the patient, their family, and the healthcare team in the hospital and the community.

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Appendices

APPENDIX I – University of Ottawa REB Approval

Université d'Ottawa University of Ottawa

Bureau d'éthique et d'intégrité de la recherche Office of Research Ethics and Integrity

December 19th, 2014

Myuri Manogaran
Doctoral Student
Institute of Population Health
University of Ottawa
mmanogar@uottawa.ca

Thierry Daboval
Associate Professor/Clinical Research
Neonatology
CHEO Research Institute
tdaboval@cheo.on.ca

Co-Investigators: Ivy Bourgeault, University of Ottawa
Samantha Somers, CHEO

Re: U of O Ethics file no. A12-14-05 – “Managing the transitions of neonatal patients from the neonatal intensive care unit: The role of interprofessional collaboration”

Dear Ms. Manogaran, Dr. Daboval, Dr. Bourgeault and Ms. Somers,

Thank you for the protocol documents and Certificate of Approval from the CHEO REB (# 14/145X) for your project named above.

This is to confirm that, in accordance with the agreement between the University of Ottawa and CHEO REB, the University of Ottawa has authorized this board to act as Board of Record for the review and oversight of research involving human subjects conducted at or through the hospital.

We remind you of your obligation to:

- Follow all procedures of the CHEO REB including reporting and renewal procedures;
- Submit to the authority of the CHEO REB and that you are subject to CHEO REB requirements, including, without limitation, the requirement to modify or stop the research on demand of the CHEO REB.

If you have any questions, please contact our ethics office at 562-5387.

Sincerely yours,

Catherine Paquet
Director
Office of Research Ethics and Integrity

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Ottawa (Ontario) K1N 6N5 Canada Ottawa, Ontario K1N 6N5 Canada
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<http://www.research.uottawa.ca/ethics/>

APPENDIX II – CHEO REB Approval



RESEARCH INSTITUTE
INSTITUT DE RECHERCHE

CHEO Research Ethics Board Approval - Delegated Review

Principal Investigator: Dr. Thierry Daboval

REB Protocol No: 14/145X

Romeo File No: 20140402

Project Title: CHEOREB# 14/145X - Managing the transitions of neonatal patients from the neonatal intensive care unit: The role of interprofessional collaboration

Primary Affiliation: Clinical Research\Neonatology

Protocol Status: Active

Approval Date: December 16, 2014

Valid Until: December 15, 2015

Annual Renewal Submission Deadline: November 15, 2015

Documents Reviewed & Approved:

Document Name	Comments	Version Date
Other Document	Appendices_ToC Study_Version Nov 24 2014	2014/11/24
Protocol	Protocol_ToC Study_Version #2	2014/12/10
Consent Form	Parent Consent Form_ToC Study_Version 2	2014/12/10
Consent Form	HCP Consent Form_ToC Study_Version 2	2014/12/10

Of note, the Investigator is asked to ensure that all free text of collected documents is reviewed for identifying information (e.g., Mrs. X. was asked to give child Y), and this information is removed (de-identified).

This is to notify you that the Children's Hospital of Eastern Ontario Research Ethics Board has granted approval to the above named research study on the date noted above. Your project was reviewed under the delegated review stream, which is reserved for projects that involve no more than minimal risk to human subjects.

Final approval is granted for the above noted study, with the understanding that the investigator agrees to comply with the following requirements:

1. The investigator must conduct the study in compliance with the protocol and any additional conditions set out by the Board.
2. The investigator must not implement any deviation from, or changes to, the protocol without the approval of the REB, or when the change involves only logistical or administrative aspects of the study (e.g., change of telephone number or research staff).
3. The investigator must, prior to use, submit to the Board changes to the study documentation, e.g., changes to the informed consent letters, recruitment materials.
4. For all other research studies, investigators must promptly report to the REB all unexpected and untoward occurrences (including the loss or theft of study data and other such privacy breaches).
5. Investigators must submit an annual renewal report to the REB 30 days prior to the expiration date stated above.
6. Investigators must submit a final report at the conclusion of the study.
7. Investigators must provide the Board with French versions of the consent form, unless a waiver has been granted.

For complete procedures relating to REB procedures, please refer to the REB website at <http://www.cheori.org/en/researchethicsboard> or contact Natalie Anderson at ndanderson@cheo.on.ca or [613-737-7600 ext. 3350](tel:613-737-7600).

Regards,

Dr. Carole Gentile
Chair, Research Ethics Board
Présidente, Comité d'éthique de la recherche
401 Smyth Road, Ottawa, ON K1H 8L1
Tel: [613-737-7600 ext. 3624](tel:613-737-7600) | Fax/Téléc: [613-738-4202](tel:613-738-4202) | gentile@cheo.on.ca

APPENDIX III – OHRI-REB Approval



Ottawa Hospital
Research Institute
Institut de recherche
de l'hôpital d'Ottawa



**Ottawa Health Science Network Research Ethics Board/ Conseil d'éthique de la recherche du
Réseau de science de la santé d'Ottawa**

City Box #11 725 Portage Avenue, Ottawa, Ontario K1Y 4G9 613-798-5555 ext. 14903 Fax : 613-261-4311
<http://www.ohri.ca/ohri-reb>

April 1, 2015

Dr. Thierry Daboval
Neonatal Intensive Care Unit
Children's Hospital of Eastern Ontario
401 Smyth Road
Ottawa, ON K1H 8L1

Dear Dr. Daboval:

**Re: Protocol # 20150050-01H Managing the transitions of neonatal patients from the
Neonatal Intensive Care Unit: The role of Interprofessional
collaboration**

Thank you for the Protocol Amendment Report dated March 30, 2015. It is approved.

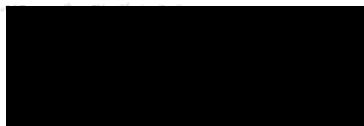
PLEASE NOTE: THE APPROVAL OF THIS PROTOCOL IS CONDITIONAL UPON A FULLY-SIGNED STUDY CONTRACT/AGREEMENT BETWEEN THE OTTAWA HOSPITAL RESEARCH INSTITUTE, THE PRINCIPAL INVESTIGATOR AND THE SPONSOR (OR AS OTHERWISE REQUIRED). YOU CANNOT START THE STUDY, OR BEGIN TO RECRUIT RESEARCH PARTICIPANTS INTO THE STUDY UNTIL THE STUDY CONTRACT/AGREEMENT HAS BEEN SIGNED BY ALL PARTIES, AND HAS BEEN RECEIVED BY THE OTTAWA HOSPITAL RESEARCH INSTITUTE'S CONTRACTS OFFICE. FOR FURTHER DETAILS, PLEASE CONTACT CHRISTINE LAFONTAINE, CONTRACTS ADMINISTRATOR AT CHRILAFONTAINE@OHRI.CA OR AT 613-798-5555 EXT. 19690.

APPROVAL IS ALSO CONDITIONAL UPON RECEIPT OF THE CHEO RESEARCH ETHICS BOARD APPROVAL LETTER FOR VERSION 4 OF THE PROTOCOL DATED MARCH 12, 2015 AND REVISED CONSENT FORMS.

Approval is for the following:

- Protocol Amendment Report dated March 30, 2015
- Revised English Parent Informed Consent Form (version 6) dated March 30, 2015
- Revised English Healthcare Provider Participant Informed Consent Form (version 5) dated March 30, 2015

OHSN-REB complies with the membership requirements and operates in compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans; the International Conference on Harmonization - Good Clinical Practice: Consolidated Guideline and the provisions of the Personal Health Information Protection Act 2004.



Raphael Saginur, M.D.
Chairperson
Ottawa Health Science Network Research Ethics Board
/sd

APPENDIX IV – Example of Data Accounting Log

	Case 1	Case 2	Case 3
HCPs Involved	MD, RN, PT, SW	MD, RN, OT, RD, SW, RT	
HCPs Interviewed	05/31/2014 – MD 06/03/2014 - SW	05/31/2014 – MD 06/03/2014 - SW	
Family Pre- discharge	03/06/2014	05/31/2014	
Family post- discharge		07/24/2014	
DOCUMENTS	Discharge handout	Family Intro Pkg Reminder cards Discharge handout	
OBS. 1	06/01/2014	05/31/2014	
OBS. 2	06/03/2014	06/12/2014	

APPENDIX V – Example of Contact Summary Form

APPENDIX VI – Health care Professionals Experiential Interview Guide

****Questions subject to change according to role of informant in discharge planning process**

Interprofessional Collaboration

“The continuous interaction of two or more professions, organized into a common effort to solve or explore common issues with the best possible participation of the child and family.”

Questions:

1. What does interprofessional collaboration (interdisciplinary team) mean to you?
2. What do you think are the key elements of your team?
 - Do you feel you are a part of the child’s care team?
3. In your opinion, is interprofessional collaboration occurring on the unit?
 - If yes, how?
 - If no, why not?
4. How do you communicate your ideas or suggestions regarding a child’s discharge plan to your team?
 - Who is your first contact regarding discharge planning?
 - Who else needs to be involved in discharge planning?
 - Is all the team needed involved in discharge planning most of the time?

- What could be done better?
5. How would you improve interprofessional collaboration on the N.I.C.U.?
6. What would you like done in the future regarding interprofessional collaboration?
- Meetings with the heads of each discipline? Etc.

APPENDIX VII – HCP Consent Form**HEALTH CARE PROVIDER PARTICIPANT INFORMED CONSENT FORM**

Title of Study: Managing the transitions of neonatal patients from the neonatal intensive care unit: The role of interprofessional collaboration

Principal Investigator (PI):

Dr. Thierry Daboval, MD, MSc., FRCPC
 Department of Pediatrics, Division of Neonatology
 The Children Hospital of Eastern Ontario
 401 Smyth Road
 Ottawa, ON K1H 8L1
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Co-Investigators:

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Dr. Ivy Bourgeault, PhD
 Telfer School of Management & The Institute of Population Health
 University of Ottawa
 1 Stewart St., Rm. 207
 Ottawa, ON K1N 6N5
 (613) 562-5800 ext. 8614

Participation in this study is voluntary. Please read this Health Care Provider Participant Informed Consent Form carefully before you decide if you would like to participate. Ask the study team as many questions as you like.

Why am I being given this form?

You are being asked to participate in this research study because you are a healthcare professional in the Neonatal Intensive Care Unit (NICU) at the Children's Hospital of Eastern Ontario (CHEO) and/or The Ottawa Hospital involved in the care of babies and their family who may be involved in this study.

Why is this study being done?

The primary purpose of the study is to identify and examine the factors associated with the collaboration between professionals that facilitate effective discharge planning. Specifically the study will look at the discharge planning of patients on the NICU at CHEO.

We estimate that 40 health care providers and a maximum of 24 parents and 12 infants will be enrolled in the study.

How is the study designed?

This is a qualitative study that will be conducted in four stages:

- **Stage one** involves a document analysis which will analyze documents that are passed to the family members of the cases being followed, between health care professionals, and flyers and posters around the unit. The physician's discharge notes and infant's medical record at CHEO and TOH will also be reviewed.
- **Stage two** involves participant observation. A maximum of 12 cases of infants identified as acute or chronic care patients will be observed from their admission to discharge. The three types of cases include infants who are discharged: a) from the CHEO NICU to another unit within CHEO, b) from the CHEO NICU to TOH, and c) from the CHEO or TOH NICU to home. These cases will be observed from admission until their discharge into the community or to home. During this stage, the interactions between healthcare professionals and with parents regarding discharge planning will be observed. Any emails sent to the investigator by healthcare professionals containing information on a case's discharge plan may also be included in the review. You will be notified if any email correspondences will be used.
- **Stage three** involves interviews of both the health care professionals and of the family members of each of the cases. The health care professionals involved in the cases being observed will be interviewed individually. These include health care professionals involved in the discharge planning of these cases from the NICU at CHEO, other units in CHEO and from TOH NICU. Healthcare professionals not a part of the cases' care may also be approached for interviews to ensure a fair representation of all the healthcare professions. A second interview may be conducted should additional information be required. As well, the parents or guardians being observed will be interviewed pre- and post-discharge for their views and opinions on their experiences in the NICU at CHEO and/or TOH.
- **Stage four** will involve an invited workshop with the research participants and relevant stakeholders (e.g. clinical managers, administration, etc.) to share and obtain feedback on the results collected. The purpose of the focus group in this study is knowledge exchange and to get feedback on the results obtained so far and to see if the participants feel the study is thorough or requires more attention to certain areas (e.g. are they able to provide further insight to a certain result?).

What is expected of me?

You are being invited to participate in the ongoing observations, one individual interview conducted with the researcher, and an arranged focus group.

We will observe the general workings of the NICU at CHEO and/or TOH unit and any meetings or rounds associated with the infant being observed. The researcher/delegate will approach you on a regular basis to obtain an update on any discharge planning communication that occurred between you and health care professionals who are participating in this study or the case's parents. You may be asked for copies of any educational documents that were passed regarding the discharge during this stage.

You will be asked to participate to an interview. We will be asking you to share your feelings and views about the discharge planning process especially the collaboration between healthcare professionals, and the exchange between healthcare professionals and parents. The interview will take approximately 30 minutes to one hour. We will contact you to set up the day and the time of the interview according to your preference. In some cases, you will be invited to participate to a second interview. The interviews will be audio-taped and transcribed. If you wish, you may opt out of the audio-recording and still participate in the interview. You will be asked to review a transcript from the taped interview for accuracy. Every effort will be made to de-identify the transcripts by assigning you a study number and using that number during your interview. The transcriber will be asked to sign a Confidentiality Agreement to ensure your de-identification and privacy.

An invited focus group with the research participants and key stakeholders to share and obtain feedback on the results collected. The focus group will last anywhere between 30 minutes to one hour. The focus group will start with an overview of the study and the study results by the researcher/delegate. The focus group will then take a round table format where the researcher/delegate will present a question and then go around the table allowing those who want to speak to offer their opinions. The questions to be asked during the focus group to promote discussion will be developed based on the results obtained from stages two and three. The focus groups will occur after all the observations and interviews have been completed with an expected date of November 2015. The focus groups will occur on the NICU at CHEO and TOH and will occur during regular work hours. Several focus groups at different times will be held to accommodate the various work schedules of the participants. Permission from the unit managers has been obtained to conduct these focus groups during regular work hours.

How long will I be involved in the study?

The entire study will last anywhere between 6 – 12 months. Your participation in the study will depend on your involvement with the infant being observed. Over this time, you will be approached for an interview regarding an infant's discharge from CHEO and/or TOH and will be invited to take part in a focus group as explain in the above section.

What are the potential risks I may experience?

We know of no harm that taking part in this study could cause you.

You might find the interview questions upsetting, distressing, or maybe tiring if they are lengthy. You might not like all of the questions that you are asked. You do not have to answer any questions that make you uncomfortable.

Sometimes people involved in discussions like these feel stress and anxiety. If this happens to you, we can stop the interview at any time. The interviewer will attempt to make you feel as comfortable as possible.

Can I expect to benefit from participating in this research study?

You will not receive any direct benefit from your participation in this study. Your participation may allow the researchers to identify barriers and facilitators in the current discharge planning process and suggest recommendations for change. This may benefit future patients, parents, healthcare professionals and educators. The results of this research will be available for review by all participants upon completion. There is no guarantee that the proposed research will result in any change specific to the policies or procedures around discharge planning in the NICU at CHEO or TOH.

Do I have to participate? What alternatives do I have? If I agree now, can I change my mind and withdraw later?

Your participation in this study is voluntary. The alternative to this study is not to participate.

You may decide not to be in this study, or to be in the study now, and then change your mind later without affecting the employment or other services to which you are entitled or are presently receiving at this institution.

If you withdraw your consent, the study team will no longer collect information from you for research purposes. Any information already provided by you prior to withdrawing will not be used in the study.

If you are not interested in participating in the observations, you may advise the Research team (contact details available on first page). The Research team will keep this information private/confidential and will not collect information from you.

How is my personal information being protected?

- All personal identifiable information (PII) will be kept confidential.
- Release of your PII information will only be allowed if it is legally required.
- As a participant, you will be assigned a coded study number that will be used throughout the study on all your study records.
- Documents collected at the CHEO or TOH will only contain the coded study number. The anonymized data will be stored on a central server password protected in RedCap at CHEO. *REDCap (Research Electronic Data Capture) is a secure, web-based application designed to support data capture for research studies.* A Master List provides the link between your identifying information and the coded study number. This list will only be available to Dr. Thierry Daboval and his staff through RedCap.
- The Master List and coded study records will be stored in a separate password-protected document on the CHEO server.
- For audit purposes only, your original study records may be reviewed under the supervision of Dr. Thierry Daboval or his staff by representatives from:

- the Ottawa Health Science Network Research Ethics Board (OHSN-REB),
 - The Ottawa Hospital Research Institute (OHRI),
 - the CHEO Research Institute Research Ethics Board (CHEO-RI REB),
 - The University of Ottawa Research Ethics Board.
- You will not be identified in any publications or presentations resulting from this study.
 - Research records will be kept for 10 years, as required by the OHSN-REB.
 - At the end of the storage time, all paper records will be shredded and all electronic records will be securely deleted.

Will I be informed about any new information that might affect my decision to continue participating?

You will be told in a timely fashion of any new findings during the study that could affect your willingness to continue in the study. You may be asked to sign a new consent form.

At your request, you can receive a copy of the study results at the end of the study. The results are expected in December 2015.

Do the investigators have any conflicts of interest?

There are no conflicts of interest to declare related to this study.

Who do I contact if I have any further questions?

If you have any questions about this study, please contact Dr. Thierry Daboval at (613) 737-7600 Ext. 2415 or Myuri Manogaran at mmanogar@uottawa.ca.

The CHEO Research Institute Research Ethics Board (CHEO REB) and the Ottawa Health Science Network Research Ethics Board (OHSN-REB) have reviewed this research study. The Research Ethics Board at the University of Ottawa has conducted an administrative review of this research study. The Ethics Boards considers the ethical aspects of all research studies involving human participants at CHEO, The Ottawa Hospital (TOH), and the University of Ottawa. If you have any questions about your rights as a study participant, you may contact the Chair of the Research Ethics Board at CHEO at (613) 737-7600 Ext. 3272 or the Chairperson of the Research Ethics Board at TOH at 613-798-5555, extension 16719, or the Protocol Officer for Ethics in Research at the University of Ottawa at (613) 562-5387.



CONSENT FORM

Managing the transitions of neonatal patients from the neonatal intensive care unit: The role of interprofessional collaboration

Consent to Participate in Research

- I understand that I am being asked to participate in a research study about the importance of managing transitions on a neonatal intensive care unit.
- This study was explained to me by _____.
- I have read, or have had it read to me, each page of this Participant Informed Consent Form.
- All of my questions have been answered to my satisfaction.
- If I decide later that I would like to withdraw my participation and/or consent from the study, I can do so at any time.
- I voluntarily agree to participate in all stages of this study as required.
- I will be given a copy of this signed Participant Informed Consent Form.

I agree to be audio taped during the interview and focus group. Yes ☐ No ☐ Initials ____

Participant's Printed Name

Participant's Signature

Date

Phone Number & Email: _____

Investigator or Delegate Statement

I have carefully explained the study to the study participant. To the best of my knowledge, the participant understands the nature, demands, risks and benefits involved in taking part in this study.

Investigator/Delegate's Printed Name

Investigator/Delegate's Signature

Date

Assistance Declaration

Was the participant assisted during the consent process? ☐ Yes ☐ No

☐ The person signing below acted as a translator for the participant/substitute decision-maker during the consent process. He/she attests that they have accurately translated the information for the participant/substitute decision-maker, and believe that the participant/substitute decision-maker has understood the information translated.

Name of Person Assisting (Print)

Signature

Date

APPENDIX VIII – Family Member Pre-discharge Interview Guide

1. Tell me about your experience on the unit so far.
2. Has anyone approached you so far regarding your child's discharge plan?
 - If yes, who?
 - When did they approach you?
 - What were you told?
 - Were you given any documents? (i.e. brochure, etc.)
3. Do you feel that you are well supported during your time here by the health professionals in charge of your baby's care?
4. How comfortable do you feel contributing to your baby's discharge plan?
 - a. Did you feel as if you were a part of the care team?
5. Were you encouraged to participate/contribute to your baby's discharge plan?
6. What is your overall view of the discharge process so far?

APPENDIX IX – Family Member Post-discharge Interview Guide

1. What is your overall opinion of the discharge process you experienced so far?
2. How much do you feel you contributed to your baby's discharge plan?
 - Are you satisfied with that contribution?
3. Do you feel any improvements to the discharge process in general are necessary?
 - What would you recommend?

If you have any questions or concerns about this study, please contact:

Ms. Myuri Manogaran

#204 - 1 Stewart Street, Ottawa, ON, K1N 7M9, Canada

This study has been reviewed and approved by the Research Ethics Boards at the University of Ottawa, the Children's Hospital of Eastern Ontario and the Ottawa Health Science Network. For questions regarding participants rights and ethical conduct of research, contact the University of Ottawa Research Office at (705) 748-1011 ext. 7050.

APPENDIX XI – Parent Consent Form



PARENT PARTICIPANT INFORMED CONSENT FORM

Title of Study: Managing the transitions of neonatal patients from the neonatal intensive care unit: The role of interprofessional collaboration

Principal Investigator (PI):

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The Children Hospital of Eastern Ontario
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Telfer School of Management & The Institute of Population Health
University of Ottawa
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Ottawa, ON K1N 6N5
(613) 562-5800 ext. 8614

Participation in this study is voluntary. Please read this Parent Participant Informed Consent Form carefully before you decide if you would like to participate. Ask the study team as many questions as you like.

Why am I being given this form?

Since your infant has been admitted to the Neonatal Intensive Care Unit (NICU) at the Children's Hospital of Eastern Ontario (CHEO), you have been identified as a potential participant in this study.

Why is this study being done?

The primary purpose of the study is to look at the discharge planning of patients in the NICU at CHEO.

We estimate that a maximum of 24 parents of 12 infants and 40 health care providers will be enrolled in the study.

How is the study designed?

This is a study that will be conducted in four stages:

- **Stage one** involves a document analysis which will analyze documents that are passed to you, between health care professionals, and flyers and posters around the unit. Your child's medical record and physician discharge notes at CHEO and The Ottawa Hospital (TOH) should your infant be transferred to TOH, will also be reviewed.
- **Stage two** involves participant observation. The purpose of this observation is to take note of the process that infants go through during their transition to home. A maximum of 12 cases of acute or chronic care patients, will be observed from their admission until their discharge to home. The three types of cases include infants who are discharged: a) from the CHEO NICU to another unit within CHEO, b) from the CHEO NICU to TOH NICU, and c) from the CHEO and/or TOH NICU to home. During this stage, the interactions between you and the healthcare professionals taking care of your infant regarding discharge planning will be observed. You may be approached by the researcher/delegate during your visits with your child to ask if you have been in any communication with anyone regarding your infant's discharge or if you have received any documents. Any emails sent to the investigator by healthcare professionals containing information on your child's discharge plan may also be included in the review.
- **Stage three** involves interviews with you, the health care professionals taking care of your infant, and other healthcare professionals on the unit. You will be approached shortly after your infant has been admitted to the NICU at CHEO for a pre-discharge interview. Here you will be asked mainly about your experience so far on the unit. You will also be approached for a post-discharge interview if your infant is transferred to TOH NICU which will occur closer to the date of your infant's discharge to home. In this interview, you will be asked about your overall experience across the two hospitals. The health care professionals involved in the cases being observed will be interviewed individually. These include health care professionals involved in the discharge planning of these cases from the NICU at CHEO, other units in CHEO and the healthcare professionals involved from the TOH NICU.
- **Stage four** will involve an invited workshop with the research participants and relevant stakeholders (e.g. NICU clinic managers, administrative staff, etc.) to share and obtain feedback on the results collected. The purpose of the focus group in this study is knowledge exchange and to get feedback on the results obtained so far and to see if the participants feel the study is thorough or requires more attention to certain areas (e.g. are they able to provide further insight to a certain result?).

What is expected of me?

You are being asked for permission to observe your infant's care and your interaction with all health care professionals involved in the care of your infant from admission to CHEO and/or TOH, and until your infant's discharge to home. This includes transfers within CHEO units or to TOH NICU if it happens. You are also being asked to participate in two individual interviews conducted with the researcher/delegate; one pre-discharge from CHEO and another after your infant's discharge from TOH and to share details regarding any discharge-related communication (e.g. meetings, pamphlets, etc.) with the researcher during observations.

In the interviews you will be asked to share your views and opinions on whom you have been approached by to discuss your infant's discharge plans, what support you were given along the way, how comfortable you felt contributing to your infant's discharge plan, and your overall view of the discharge experience. The interviews will take approximately 30 minutes to one hour. The interviews will be conducted largely in person. If you are unable to meet in person a telephone interview can be arranged. We will contact you by phone to set up the date and time of the interview. The interviews will be audio-taped and transcribed. If you wish, you may opt out of the audio-recording and still participate in the interview. You will be asked to review a transcript from the taped interview for accuracy. Every effort will be made to de-identify the transcripts by assigning you a study number and using that number during your interview. The transcriber will be asked to sign a Confidentiality Agreement to ensure your de-identification and privacy.

You will also be asked to participate in a focus group with other parents who have participated in the research study. Here, the results from the study will be presented to and your feedback will be obtained. The focus group will last about an hour and will be audio-taped for transcription later.

How long will I be involved in the study?

The entire study will last approximately 3 months post discharge of your infant to home. Your participation in the study will depend on the amount of time your infant is in transition until they reach home, and when the interviews can be scheduled.

What are the potential risks I may experience?

You might find the interview questions upsetting, distressing, or maybe tiring if they are lengthy. You might not like all of the questions that you are asked. You do not have to answer any questions that make you uncomfortable.

Sometimes people involved in discussions like these feel stress and anxiety. If this happens to you, we can stop the interview at any time. The interviewer will attempt to make you feel as comfortable as possible. You will also have access to all services that can provide you with help, if you feel the need. All the contact information for the Principal Investigator, Dr. Thierry Daboval, and co-investigators, have been provided to you on this consent form should you need to contact us.

Can I expect to benefit from participating in this research study?

You and your infant will not receive any direct benefit from your participation in this study. Your participation may allow the researchers to improve the current discharge planning process. This may benefit future patients, parents, healthcare professionals and educators. The results of this research will be available for review by all participants upon completion. There is no guarantee that the

proposed research will result in any change specific to the policies or procedures around discharge planning in the NICU at CHEO and/or TOH.

Do I have to participate? If I agree now, can I change my mind and withdraw later?

Your participation in this study is voluntary.

You may decide not to be in this study, or to be in the study now, and then change your mind later without affecting the medical care or other services to which you or your infant are entitled or are presently receiving at this institution.

If you withdraw your and your infant's consent, the study team will no longer collect information from you for research purposes. Any information already provided by you or your infant's health care team prior to withdrawing will not be used in the study.

How is my personal information being protected?

- All of your infant's personal health information (PHI) and your personal identifying information (PII), such as your name, address, phone number and/or email, etc. will be kept confidential.
- Release of your infant's PHI/PII, or your PII will only be allowed if it is legally required.
- As a participant, you and your infant, will be assigned a coded study number that will be used throughout the study on all your study records.
- Documents collected at the CHEO or TOH will only contain the coded study number. The anonymized data will be stored on a central server password protected in RedCap at CHEO. *REDCap (Research Electronic Data Capture) is a secure, web-based application designed to support data capture for research studies.* A Master List provides the link between your and your infant's identifying information and the coded study number. This list will only be available to Dr. Thierry Daboval and his research team/staff through RedCap.
- The Master List and coded study records will be stored in a separate password-protected document on the CHEO server.
- For audit purposes only, all original study records and your baby's medical record at TOH and/or CHEO may be reviewed under the supervision of Dr. Thierry Daboval or his staff by representatives from:
 - the Ottawa Health Science Network Research Ethics Board (OHSN-REB),
 - The Ottawa Hospital Research Institute (OHRI),
 - the CHEO Research Institute Research Ethics Board (CHEO-RI REB),
 - The University of Ottawa Research Ethics Board.
- You and your infant will not be identified in any publications or presentations resulting from this study.
- Research records will be kept for 10 years, as required by the OHSN-REB.
- At the end of the storage time, all paper records will be shredded and all electronic records will be securely deleted.

Will I be informed about any new information that might affect my decision to continue participating?

You will be told in a timely fashion of any new findings during the study that could affect your willingness to continue in the study. You may be asked to sign a new consent form.

At your request, you can receive a copy of the study results at the end of the study. The results are expected in December 2015.

Do the investigators have any conflicts of interest?

There are no conflicts of interest to declare related to this study.

Who do I contact if I have any further questions?

If you have any questions about this study, please contact Dr. Thierry Daboval at (613) 737-7600 Ext. 2415 or Myuri Manogaran at mmanogar@uottawa.ca.

The CHEO Research Institute Research Ethics Board and the Ottawa Health Science Network Research Ethics Board have reviewed this research study. The University of Ottawa Research Ethics Board has completed an administrative review of this study. The Ethics Boards considers the ethical aspects of all research studies involving human participants at CHEO The Ottawa Hospital (TOH), and the University of Ottawa.

If you have any questions about your rights as a study participant, you may contact the Chair of the Research Ethics Board at CHEO at (613) 737-7600 Ext. 3272 or the Chairperson of the Research Ethics Board at TOH at 613-798-5555, extension 16719, or the Protocol Officer for Ethics in Research at the University of Ottawa at (613) 562-5387.



CONSENT FORM

Managing the transitions of neonatal patients from the neonatal intensive care unit: The role of interprofessional collaboration

Consent to Participate in Research

- I understand that I and my infant are being asked to participate in a research study about the importance of managing transitions on a neonatal intensive care unit.
- I understand that my infant will be observed for the purpose of this study from admission to CHEO, through to the TOH NICU if transferred, until discharge to home.
- This study was explained to me by _____.
- I have read, or have had it read to me, each page of this Participant Informed Consent Form.
- All of my questions have been answered to my satisfaction.
- If I decide later that I would like to withdraw my or my infant's participation and/or consent from the study, I can do so at any time.
- I voluntarily agree to participate in all stages of this study as required.
- I voluntarily permit my infant to be observed in this study.
- I will be given a copy of this signed Participant Informed Consent Form.

I agree to be audio taped during the interview and focus group. Yes ☐ No ☐ Initials ____

Participant's Printed Name

Participant's Signature

Date

Phone Number/Email: _____

Investigator or Delegate Statement

I have carefully explained the study to the study participant. To the best of my knowledge, the participant understands the nature, demands, risks and benefits involved in taking part in this study.

Investigator/Delegate's Printed Name

Investigator/Delegate's Signature

Date

Assistance Declaration

Was the participant assisted during the consent process? ☐ Yes ☐ No

☐ The person signing below acted as a translator for the participant/substitute decision-maker during the consent process. He/she attests that they have accurately translated the information for the participant/substitute decision-maker, and believe that the participant/substitute decision-maker has understood the information translated.

Name of Person Assisting (Print)

Signature

Date

APPENDIX XII – CHEO Corporate Discharge Planning Policy for Inpatient Units



Corporate Discharge Planning Policy

Manual/Section: Administration Manual: Discharge Planning	Policy No. 046
Key Words: Community Discharge Team, Discharge Planning, Complex Discharge, Discharge Goals /Criteria, Individualized Discharge Care Plans, Community Care Access Center, OHSNI	

1. PURPOSE:

- 1.1 To facilitate the discharge planning process for all patients admitted to CHEO and to ensure a safe and seamless transition to home or other institution.
- 1.2 Clearly define the roles of each health care professional in the discharge planning process and guide the healthcare team in:
 - Early assessment of discharge needs
 - Individualized discharge care plans
 - Establishing predictable outcomes

2. POLICY:

- 2.1 To ensure that teams and families are well informed of the estimated date of discharge (EDD).
- 2.2 EDD will be established pre-admission or on the day of admission for predictable length of stay (LOS) and elective admissions. For complex or medically fragile and /or technology dependent patients, where LOS is less predictable, the EDD will be established with team input as early as possible or at least 3 weeks before the EDD. The EDD will be communicated with the health care team and family by documenting in the patient's electronic health record on admission, by using of the white board in the patient room and discussed with family and teams daily during patient rounds.
- 2.3 All patients' needs for discharge will be assessed prior to admission whenever possible in the clinic setting or within 24 hours of admission including but not limited to the following:
 - The patient's individualized discharge plan will be initiated on admission and documented in the Interdisciplinary Discharge Information Summary (IDIS) on e-clin doc.
 - Patient care needs towards discharge will be re-assessed regularly and the Interdisciplinary Discharge Information Summary will be updated accordingly. The health care team should decide the appropriate time for the review of needs according to the patient's condition.
 - For patients expected to be discharged with complex care needs at home and/or community health care services, a consult to the Community Discharge Team



will occur within 24-48 hours of admission (Appendix A).

2.4 Patient and parents/guardians will be active participants in the discharge planning process and appropriately prepared for discharge including but not limited to the following steps:

- Documentation on the CHEO approved Interdisciplinary Discharge Information Summary that the family has demonstrated ability to perform the skills required to safely care for their child at home.
- Patient/parents/guardians will receive a signed copy of the CHEO Interdisciplinary Discharge Information Summary at the time of discharge that may include the following information:
 - Diet
 - Medication
 - Special care needs at home
 - How to manage pain and discomfort
 - Activity restrictions, resuming activity/school
 - When and how to contact a health care provider
 - Recommended follow-up with primary care provider or pediatrician
 - Follow-up appointment with CHEO specialist

2.5 Patient discharges will be supported in as timely a manner as possible with the expectation that parents/caregivers are given sufficient advance notice to accommodate the earliest discharge time possible.

2.6 All patients who meet medical physiological and nursing criteria for discharge (i.e. no longer require acute care).but do not have either the equipment or resources in the community to care for the child and/or family refuses discharge, must have an Alternate Level of Care Form #1229(ALC) completed by the MD and sent to decision support by e-mailing internally to _ALC. See policy for Alternate Level of Care (ALC) Policy. The Clinical Managers must be aware of all ALC patients on the unit.

3. SCOPE:

This policy applies to all patients admitted to in-patient unit at CHEO and all health care providers caring for these patients during a given admission.

4. DEFINITIONS:

Complex patient discharges: generally require multiple services across different organizations and may have social/cultural issues or other circumstances such as services/home supports and equipment needs that necessitate intensive planning resources.

Community Discharge Team (CDT): The team that leads the most



Corporate Discharge Planning Policy for In-Patient Units

complex discharges/transfers from CHEO, by coordinating team communication, family teaching and organizing community services, resources, equipment and supplies for the patients at CHEO for a safe and smooth transition to home.

Discharge Planning: is a collaborative and interdisciplinary process that should begin prior to a planned admission or on admission and involves the patient/family, hospital and community to ensure the safe and timely transition of patients to the next sector of care (home, hospital or other center).

Discharge goals: guide the interdisciplinary team in terms of development of an individualized discharge care plan and are reviewed regularly. Goals are patient and family focused and should include the expected desirable medical status, patient/family competency with care, community resources and equipment in place and safe discharge environment. *Discharge criteria* refers to the desired final outcome at the time of discharge typically set by the MD but may involve input from the interdisciplinary team and should include stable medical condition of the patient (including stable vital signs and patient's disposition), safe discharge environment, established community resources and equipment, and patient/family competency with care.

Interdisciplinary Team: is all members of the health care team who have direct involvement and responsibility to meet the needs of the patient/family during a specific episode of hospitalization.

5. RESPONSIBILITY:

The Physician and Nurse together ultimately have the responsibility to ensure that the patient's discharge is safe and meets the discharge criteria. Each consulted member of the interdisciplinary health care team also has an important role to play in the safe and timely transition of patients from CHEO. Appendix C details the roles and responsibilities of the interdisciplinary team in the discharge planning process.

6. PROCEDURE:

See attached Corporate Interdisciplinary Discharge Planning Process Flow Map (Appendix B).

7. CROSS-REFERENCES:

- Interdisciplinary Discharge Information Sheet (IDIS-e-clin doc)
- Doctor Notification Letter (form #8016)
- Request for Consultation and Report (form #2043)
- Leave of Absence - Patients Policy #72
- Non-Urgent Long Distance Patient Air Transfer Policy #OTH-9



Corporate Discharge Planning Policy for In-Patient Units

8. REFERENCES

- Non-Urgent Land Ambulance Services Transfer Policy #OTH-8
- Alternate Level of Care (ALC) Policy # 078.
- Fact Sheet (form #P5676): Ottawa Health Services Network (OHSNI)
- Discharge Planning Process Guidelines, Vanderbilt University Children's Hospital
- Discharge Plan Policy, Vanderbilt University Children's Hospital, 2003
- Continuing Care Planning, Vanderbilt University Children's Hospital, 2003
- Discharge/Transfer Summary Guidelines Policy, Capital Health, Nova Scotia, 2002
- Domanski, M, Jackson, A., Miller, J, Jeffrey, C (2003) Towards the Development of a Pediatric Discharge Screening Tool, Journal of Child Health Care 7 (3), 163-169
- London, F (2004). How to Prepare Families for Discharge in the Limited Time Available. Pediatric Nursing, 30(3), 212-227.

9. ATTACHMENTS:

- Appendix A: Indicators for Referral to the Community Discharge Team (CDT) Team
- Appendix B: Corporate Interdisciplinary Discharge Planning Process Flow Map
- Appendix C: Summary – Roles and Responsibilities of the Interdisciplinary Team for Inpatient Discharges

10. DEVELOPED BY:

Continuing Care Coordinator in collaboration with the Interdisciplinary Discharge Planning Record working group (IDPR):
 Physicians: Pediatrics, Surgery, Oncology, Social Worker
 Pediatrics, Clinical Managers for NICU, 4E, 4W, 4N, APNs for 5E, Neurology, NICU, Discharge Planning Nurse
 PPL for: Dietitian, Physiotherapy, Occupational Therapy, Clinical Leaders, Pharmacists, Operation Directors, Corporate Patient Services, eHealth Coordinator, Director of Nursing Practice
 Updated by Manager, Care Transition, Ambulatory Care Manager (Oncology and Interlink Nurses), Clinical Manager 4N, 5E, Director CPS



Appendix A
Indicators for Referral to the Community
Discharge Team (CDT)



Indicators to initiate a referral Fax 613-745-1795

Children/youth requiring:

- Non-urgent air ambulance transfers
- Oncology related community services/support
- CCAC services to resume at discharge
- A transfer from CHEO to Rogers House for end of life care, pain management, respite or transition
- Professional home support &/or equipment/supplies for families with a child that may need:

N/G feeding	Home IV therapy
Home oxygen	New G-tube or G/J tube
New tracheostomy at discharge	invasive/non-invasive home ventilation
TPN	Home peritoneal dialysis
Suction or compressors	Monitoring (apnea, BP, saturation)
Ostomy/wound management	Injection education
Complex Orthopedic equipment not arranged pre-admission	
- Professional community support and/or respite, consult CDT before any discussion regarding placement alternative to the home environment.

Please Consult The Community Discharge Team closer to admission.

Do Not wait for the patient to be stable as this may cause delays.

How to Consult the Community Discharge Team (CDT)

- MD's/Care Facilitators/Charge Nurse/ Bedside Nurse or Social Worker anticipating patients to meet any of the indicators should consult the Community Discharge Team as soon as possible.
- Complete the Referral Form found on CHEO Net. (MD must sign if prescribed medication administration (IV or SC) or for prescribed treatment by a community professional (IV, wound care etc.)
- Fax referral to **613-745-1795** (this goes to a portal visible in real time to the CDT)

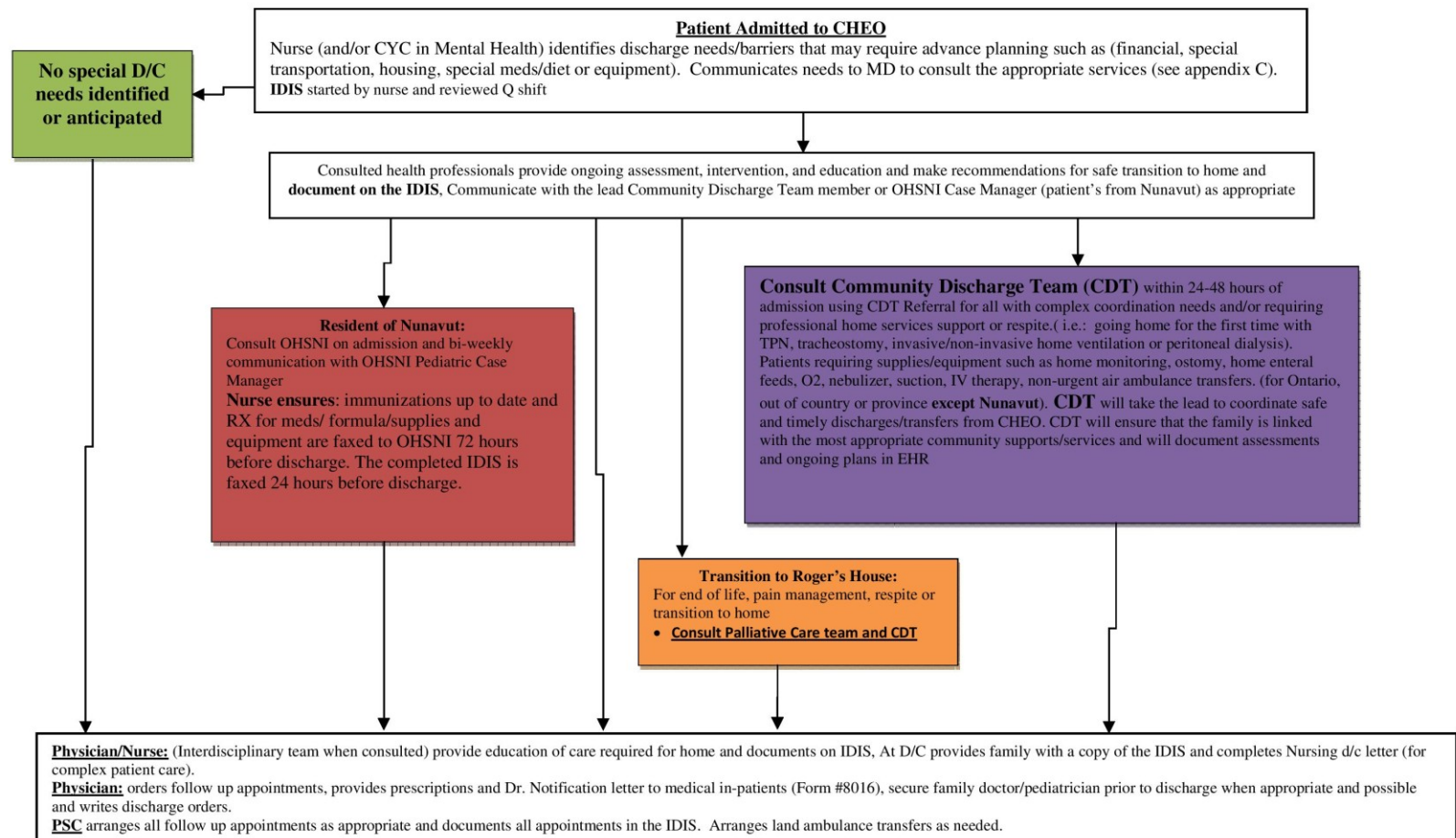
Rational for early consultation to the Community Discharge Team (CDT)

- Early assessment, planning, and implementation to meet family's need in the home.
- Promotion of team communication, mutual discharge goal setting and anticipating d/c dates.
- Coordinate timely family teaching, family presence and participation in the discharge process.
- Promotion of early communication with the community and early access to resources.
- Ensure timely/safe transition at home.
- Efficient use of hospital beds

Goal: To ensure community resources/home support/equipment are in place and that family is ready by the time the patient is medically stable for discharge

Appendix B
CHEO's Corporate Interdisciplinary Discharge Planning Process Flow Map and use of the Interdisciplinary Discharge Information Summary (IDIS)

For all patients admitted to CHEO except the Mental Health Units



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Appendix C
Roles and Responsibilities of the Interdisciplinary Team for
Inpatient Discharges

Communication with the interdisciplinary team is crucial for a smooth and timely discharge

Patient Service Clerk
• Completes information in the general information section and books follow-up appointments as ordered through central booking and documents on the IDIS. • Ensures that community physician and interpreter are booked for follow-up appointments as appropriate and documents in the IDIS. • Faxes prescriptions to community pharmacy (not IV meds) • Faxes documents to Baffin Program (OHSNI) 48 hrs. prior to discharge, as appropriate • Assists MD and Nurses in obtaining appropriate paperwork for referral process
RN/RPN (and/or CYC for in-patient Mental Health)
• Initiates the IDIS on admission and communicates any discharge needs/barriers that require further planning to the MD to ensure appropriate and timely consults to health professionals (barriers include: special transportation, exceptional medication, equipment, nutrition, technology dependency) • Reviews and updates the IDIS & Kardex every shift and promotes the discussion of D/C goals on rounds • Assists on the early identification of complex patient discharges and/or families known to CCAC to promote early consultation to the Community Discharge Team (CDT) or appropriate services/persons (i.e. OHSNI Case Manager) • Promotes discussion of discharge goals, expected discharge date on daily physician rounds with each patient and updates the white board in patient room • Initiates teaching/learning plan with families following principles of adult learning or child appropriate learnings. All teaching including use of CHEO loaner feeding pumps will be documented on the Interdisciplinary Discharge Information Sheet (IDIS) • Instructs the family regarding specific equipment and documents teaching on CHEO specific teaching checklists • Coordinates all patient discharges in collaboration with the health care team and communicates regularly with the Community Discharge Team (CDT) or OHSNI Case Manager and the team for more complex patient discharges • Reviews medication administration and indicates use and side effects. Provides parent friendly print out from Lexi-PALS (Patient Advisory Leaflet System) on CHEOnet and consults Pharmacy for complex medication plans (Appendix C) • Reviews and answers any questions related to the patient's care and safety and/or seeks the appropriate health professional to answer these questions prior to discharge • Completes the Interdisciplinary Discharge Information Sheet (IDIS) for all patients that will be requiring in-home nursing support (downtime should complete the Nursing Discharge Letter) • Reviews and has patient/family/guardian sign the IDIS at the time of discharge, or completes the Hospital-to-Hospital Transfer Form for any patient transfer to another hospital

- Ensures that the patient leaves with the legal guardian or designate identified by the guardian
- Notifies the interdisciplinary team of upcoming discharge date (specifically the Pharmacy – minimum 24 hour notice as that can help rectify any drug coverage or drug access issues in the community before discharge)

Clinical Manager/Care Facilitator/Charge Nurse (as appropriate)

- Provides support to the nurse around the discharge planning process and the use of the CHEO approved Interdisciplinary Discharge Information Sheet (IDIS). Supports a consistent nursing assignment to patients with long term complex care, learning and support needs to ensure continuity, ongoing and accurate assessment and evaluation of the family's readiness for discharge

Attending Physician or delegate (Fellow/Resident)

- Promotes discussion of discharge goals, expected discharge date on daily rounds with each patient and uses white board in patient room to communicate discharge plans/date with the family/patient
- Regularly updates and documents a medical plan of care in collaboration with the consulted surgical/medical specialists
- Timely consults to the appropriate specialist or team member to ensure safe discharges
- Consults with CHEO pharmacist during daily rounds on planned D/C drugs to be prescribed to ensure that drug coverage and/or community access to drugs is rectified before the patient is discharged
- Communicates, updates and documents the patient's stay and discharge criteria daily during surgical/medical patient rounds
- Communicates with the patient's primary care practitioner in the community prior to discharge or assists in securing a community health care provider prior to discharge as appropriate
- Provides the family with prescriptions for home medication and orders appropriate follow-up for the patients in the chart
- When appropriate completes the "Doctor Notification Letter" to the Community Physician for all discharges (form # 8016)
- Determines patient's readiness for discharge by writing a discharge order including all follow-up appointments and interventions required
- Preparation for discharge should be completed as early as possible
- Provides verbal information to the family and documents the instructions about specific activity restrictions, care at home and recommendations to return to school in the patient's chart (when applicable) and educates family on care needs at home, special activity restrictions and anticipatory guidance for emergencies
- Writes discharge orders as early as possible and dictates discharge summary that will be sent to community MD by Medical Records after discharge or prior to transfer to another facility

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In patient Interdisciplinary Team (if consulted)

Community Discharge Team (CDT) if consulted • Collaborates with the teams and families to assess, anticipate and coordinate complex patient discharge plans and makes recommendations for referrals to the appropriate community services • Key contact/ liaison for family, CHEO and community team in relation to complex discharges. • Facilitates problem solving for complex discharge plans, family engagement in the discharge process and coordinates teaching activities and access to community resources • Makes appropriate and timely referrals to community partners and vendors to ensure access to community support services and/or equipment prior to discharge • Shares information of what is available in the community with the CHEO team and family to ensure safe and sustainable discharge plans. Documents in the IDIS • Forwards appropriate reports and summary of recommendations to community partners working with client/family to ensure continuity of care (i.e. IDIS, protocols and MD discharge letter etc.). • Coordinates hospital to hospital transfers that require non-urgent ambulance transfers	
Social Worker Provides psychosocial/financial family assessment/support. Provides feedback to health care team, ensures timely access to funding and social services agencies. Communicates any concerns and plans to mitigate these concerns with the team and documents in the IDIS. Communicates with the CDT for complex discharges.	Mental Health Case Coordinator Collaborates with the team to recommend appropriate services in the community. Manages Mental Health Intake. Key contact/ liaison for family, CHEO and community team. Provides support to team for specific patient discharges, facilitates problem solving, and coordinates teaching activities and access to community resources. Forwards appropriate reports and summary of recommendations to community partners working with client/family to ensure continuity of care (i.e. IDIS, protocols and MD discharge letter etc.).
Psychologist Provides psychosocial support to families, children and youth and recommendations for success. Provides feedback and recommendations to the health care team at CHEO and the community partners. Documents discharge plans and recommendations in the IDIS.	Pharmacy Provides education for complex medications (high risk, multiple/uncommon meds or that involve complex administration directions). Ensures timely funding applications to government or private insurance plans to ensure drug coverage. Coordinates with Health Canada for approval of special drugs. Liaises with community pharmacy to ensure access at discharge for the drugs prescribed (i.e. oral formulation). Documents in the IDIS
Dietician Provides ongoing nutritional assessment and recommendations for specialized formula diet. Ensures community access and provides teaching and written instructions for special formula/diet. Completes paperwork for specialized formula funding. Documents teaching, plans and discharge recommendation in IDIS for the community. Communicates with the CDT for complex discharges.	Occupational Therapist (OT) Assesses and recommends specialized feeding/mobility/self-care equipment for D/C. Promotes/teaches patient safety and ADL. Documents teaching, plans and discharge recommendation in IDIS for the community. Communicates with the CDT for complex discharges.

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Vascular Access Team Provides education to parents for complex care of central line to be performed by the parents in the home environment. Liaises with CDT as appropriate. Documents Quality Assurance Forms for PICC lines. Documents teaching, plans and discharge recommendation in IDIS.	Physiotherapist (PT) Assesses, recommends and teaches improved mobility, child development, chest therapy and safe transferring (bed, w/c, car). Documents teaching, plans and discharge recommendation in IDIS. Communicates with the CDT for complex discharges.
Respiratory Therapist (RRT) Provides education on inhaled medication/use of inhaler for high risk and/or specialized education for CHEO loaner respiratory equipment. Applies to ADP for OSM and (VEP) ventilator equipment pool. Documents teaching, plans and discharge recommendation in IDIS for the community. Communicates with the CDT for complex discharges.	RN Case Managers Provides specialized teaching to the families (trach care, cleft palate, seizure, asthma, oncology specific teaching) and written resources. Documents teaching, plans and/or recommendations in the IDIS. Communicates with the CDT for complex discharges. Initiates pre-admission discharge planning when appropriate.
Speech Language Pathologist (SLP) Assesses and recommends strategies and/or equipment to optimize communication and family/community support post discharge. Documents teaching, plans and discharge recommendation in IDIS for the community. Communicates with the CDT for complex discharges.	Palliative Care Provides ongoing psychosocial support to families for end-of –life care and degenerative chronic illnesses. Documents teaching, plans and discharge recommendation in IDIS for the community. Communicates with the CDT for complex discharges.
Baffin Island Pediatric Case Manager (OHSNI) Coordinates all CHEO discharges for child/youth from Nunavut. Clears all patients for transportation. Applies for funding and organizes medication, supplies/equipment and professional supports. Coordinates interpreters as needed. Ensures that the patient's medical information is sent to the appropriate northern health care provider and nursing station for continuity of care	Interlink Nurses (Oncology/POGO) Works in collaboration with interdisciplinary team including CDT for complex D/C (i.e. neuro. oncology). Arranges oncology specific supports and services and specific oncology funding. Provides home and school visits to ease transition. Documents teaching, arrangements and discharge recommendation in IDIS and send a copy for the community provider when CDT is not involved.

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