FAMILY-MANAGED HOME CARE

FAMILY-MANAGED HOME CARE IN ONTARIO FOR FAMILIES WITH TECHNOLOGY-DEPENDENT CHILDREN

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LAY ABSTRACT

Family-Managed Home Care is a self-directed home care model parents of children with medical complexities that are technology dependent (CMC-technology dependent children) utilize to implement home care nursing services. The consistent presence of home care nurses is vital to preserve family functioning and ensure the safety of the CMC-technology dependent child. This study's purpose was to understand how parents of CMC-technology dependent children use and describe their experiences of coordinating nursing care under the Family-Managed Home Care model. Nine parents were interviewed. Findings indicated that in the process of managing the child's care (1) transitioning home is overwhelming, (2) parents take on the role of becoming their child's care manager, (3) parental control is a valuable aspect of using Family-Managed Home Care, and (4) enhanced support is needed for parents using this home care model. Findings can be used to improve support for families using the Family-Managed Home Care model.

ABSTRACT

Background: Advances in technology have led to an increasing number of CMC-technology dependent children being discharged from hospital to their home communities. Families with CMC-technology dependent children require home care nursing services established prior to discharge. The Family-Managed Home Care model is used by some families to acquire these nursing services.

Aim: The study purpose was to explore how families with CMC-technology dependent children describe their use of and experiences with using the Family-Managed Home Care model to coordinate nursing care.

Methods: Thorne's interpretive description method was used. Virtual, in-depth, semi-structured interviews were conducted with nine parents of CMC-technology dependent children. Data was analyzed using Braun and Clarke's reflexive thematic analysis.

Results: Parents of CMC-technology dependent children using the Family-Managed Home Care model became their child's care manager. The process of managing the child's care occurs in three interrelated and overlapping phases: (1) transitioning home, (2) building the home care team, and (3) partnering to provide care. Control was identified as a central concept that underpinned each step in the overarching process of managing the child's care. Parents value the control provided by the Family-Managed Home Care model as this alleviated some stress, anxiety, and uncertainty in caring for a CMC-technology dependent child at home.

Conclusion: Parents using this model of home care require enhanced support from LHINs and health care providers. Increasing health care provider knowledge of the Family-Managed Home Care model is needed to further support parents. Improved organization of discharges and policy changes are needed.

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TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

LIST OF ABBREVIATIONS

CCAC	Community Care Access Centres
CAPHC	Canadian Association of Pediatric Health Care Centres
CCCC	Children with Complex Chronic Conditions
CMC	Children with Medical Complexity
CNA	Canadian Nurses Association
FMHC	Family-Managed Home Care
LHIN	Local Health Integration Networks
NICU	Neonatal Intensive Care Unit
ODSP	Ontario Disability Service Program
ONA	Ontario Nurses Association
PCMCH	Provincial Council for Maternal and Child Health
PICU	Pediatric Intensive Care Unit

DECLARATION OF ACADEMIC ACHEIVEMENT

This master's thesis is an original report I conducted under the supervision of Drs. Michelle Butt, Susan Jack, and Nancy Carter. I developed the study protocol with feedback from my committee members. I completed the research ethics board submission with the assistance of Dr. Michelle Butt. I conducted the interviews and transcribed data recordings with the assistance of a transcriptionist where required. I led data analysis and the writing of this thesis with assistance and guidance from the supervisory committee.

CHAPTER ONE: INTRODUCTION

Advances in medical technology over the last 40 years have increased the survival rates of preterm infants and infants with chronic complex conditions (Amin et al., 2017; Amin et al., 2013; Bowles et al., 2016; Carter et al., 2013; Cohen et al., 2011; Edwards et al., 2004; Jardin & Wallace 1998; Noyes et al., 1998; Sick Kids, 2008; Wang & Barnard, 2003). Survival rates for preterm infants born at 23 weeks gestational age, for example, have increased from 0% in 2010 to 60% in 2017 (Canadian Neonatal Network, 2017). Subsequently, this has resulted in an increase in the number of ventilator-dependent children, who are classified under the broad umbrella term as *children with medical complexity (CMC).* Children with medical complexity in Ontario are amongst the highest users of the healthcare system, despite being a very small subset of the population – an Ontario health care study determined 0.67% of all children are children with medical complexity (CMC), of which 11.8% are also technology-dependent (Canadian Association of Pediatric Healthcare Centres [CAPHC], 2018; Cohen et al., 2012). Although small in number, children with medical complexity and/or technology-dependence account for one-third of child health provincial spending (CAPHC, 2018). These costs are not only associated with hospitalizations but also extend to the community health setting (CAPHC, 2018).

Children with medical complexity (CMC) share four defining characteristics: 1) the presence of one or more complex chronic conditions that are often multisystem and severe; 2) a functional limitation that is often significant and causes the child to be reliant on some form of technology; 3) high health care utilization, requiring specialized care and services from multiple providers in various settings; and 4) caregivers with high health care service needs (e.g., care coordination, home care services) which have significant financial and social impact on families (CAPHC, 2018). Within the definition of CMC there are subgroups of children with differing levels of complexity and subsequent care needs (CAPHC, 2018). One such CMC subgroup, termed CMC-technology dependent, includes children who are both medically fragile, complex, and dependent on technology to survive (CAPHC, 2018; Sick Kids, 2008). CMC-technology dependent are children who often have multiple, complex medical needs that can both be chronic and severe, and health systems may experience challenges in meeting these needs (Sick Kids, 2008).

CMC-technology dependent may rely on one or more of the following technologies: gastric tube feeding, supplemental oxygen, tracheostomy with or without mechanical ventilation, peritoneal dialysis, urinary catheters, colostomy bags and prolonged parenteral nutrition and/or intravenous drug therapy (Sick Kids, 2008). For example, a child with medical complexity who needs a tracheostomy with or without mechanical ventilation will also require gastric tube feedings. Several medical conditions necessitate a tracheostomy with subsequent mechanical ventilation, some of which include neuromuscular disorders, neurologic disorders, airway abnormalities (that may be combined with underlying chronic lung disease of prematurity or secondary to numerous respiratory pathologies), and congenital abnormalities affecting the pulmonary and respiratory systems (Edwards et al., 2004). One medical diagnosis affecting the respiratory system is bronchopulmonary dysplasia (BPD), the most common complication associated with prematurity (Thébaud et al., 2019). BPD occurs in preterm infants who require mechanical ventilation and oxygen therapy for acute respiratory distress that results in lung fibrosis and/or arrested lung development (Davidson & Berkelhamer, 2017; Merenstein & Gardner). The prevalence of BPD varies worldwide; data from major cohort studies demonstrate a BPD prevalence of 11-50%. This variation in prevalence is due to different gestational ages or birth weight criteria for a BPD diagnosis (Thébaud et al., 2019).

Preterm or term infants diagnosed with a medical condition that results in the need for some degree of technology-dependence require extensive stays in a Neonatal Intensive Care Unit (NICU) following birth and fall into the CMC-technology dependent category of children. In the NICU, they receive intensive supportive nursing care, such as constant monitoring of blood oxygen levels and vital signs; intravenous line insertions and maintenance; maintenance of a patent airway; assessment of feed tolerance; and coordination of care plans between multiple health care professionals. NICU nurses are also highly involved in family care, helping parents learn to care for their medically complex and technology-dependent infant until their child is stable enough to be discharged home. However, despite their “stability,” technology-dependent infants require constant monitoring and specialized care at home, due to their chronic medical needs and reliance on technology.

Table 1. Case Scenario: Caregiving Needs for a Medically Complex Infant at Home

Cleo (fictious name) was born premature at 24 weeks gestation and spent 10 months in the NICU. While in the NICU. Cleo was intubated and mechanically ventilated, requiring high amounts of oxygen therapy for many weeks and was subsequently diagnosed with severe bronchopulmonary dysplasia. She required a tracheostomy, ventilator and gastrostomy tube to go home. Prior to her discharge, Cleo’s parents were required to travel daily to the hospital to complete their training on how to manage these devices and Cleo’s care needs. Cleo’s parents live an hour away from the hospital and drive back and forth from hospital to home daily, while also caring for their two other children, ages 3 and 7 years. Cleo is now 8 months corrected gestational age. Cleo’s mother quit her job to provide care for Cleo and her two other children, while Cleo’s father continues to work. Cleo is now at home with her family and requires constant supervision, regular gastrostomy feeds, suctioning and oxygen monitoring. She has nurses that come into the home nightly to relieve Cleo’s parents from their care responsibilities so that they can sleep. She also has a respiratory therapist, occupational therapist and several hospital specialists following her care. They travel to the hospital 1-2 times per month for Cleo’s appointments. In one week, Cleo may have 5 different home care nurses, and sometimes, no nurses are available. On nights with no nursing care, Cleo’s parents take turns watching her and providing care throughout the night.

Changing ideologies in clinical practice regarding the appropriateness of long-term ventilation and changes in nursing care have contributed to the practice of CMC-technology dependent infants being safely discharged from a NICU into a community setting (Amin et al., 2017). Sufficient evidence has been established to support that medically stable, technology-dependent infants should be transitioned home as soon as possible, as it is inappropriate developmentally to keep them hospitalized longer than necessary (Edwards et al., 2004; Fields et al., 1991; Margolan et al., 2004). Furthermore, despite the pressure and stress it places on families, parents prefer to be at home with their child than remain in hospital (Carter et al., 2012; Fields et al., 1991; Murphy, 1997, Norwitz, 2019).

Establishing home care nursing for CMC-technology dependent infants and children is mandatory in order for families to be safely discharged from hospital. Parents and/or primary caregivers of CMC-technology dependent infants and children must also be adequately trained to provide ongoing assessment and care. Once discharged from the hospital, technology-dependent infants and children require a significant amount of specialized care in the home. The health care and nursing needs of technology-dependent infants and children in the home are complex, intensive, and diverse. There are variations in their characteristics of technology-dependence; their needs will depend on their diagnosis and condition, and are subject to change (Wang & Barnard, 2003). These needs include frequent airway and oxygen monitoring, suctioning, gastric tube feedings, medication administration, oxygen titration, and tracheostomy tube and dressing changes. Home care nursing for CMC-technology dependent infants and children facilitate a safe transition from hospital to home, alleviate the burden of care from parents and minimize hospital readmissions (Amin et al., 2017; Jardine et al., 1998; Maynard et al., 2019).

CMC-technology dependent infants and children require health care services from a multitude of providers, such as occupational and speech therapists, hospital-based specialists, physiotherapists, developmental or speciality pediatricians, and supportive services and programs. Despite being high health care users, CMC-technology dependent infants and children experience suboptimal care coordination and service delivery, including home care nursing (Boroughs & Dougherty, 2009; CAPHC, 2018; Dewan & Cohen, 2013; OACCAC, 2013; Sick Kids, 2008). Nurses with highly specialized clinical knowledge, skills and technical expertise to manage the required technology are the best fit to provide care for these infants and children at home, however, the literature describes a shortage of home care nurses with the appropriate skills to manage CMC-technology dependent infants' and children's care needs, leaving parents to care for their technology-dependent children without adequate support (Boroughs & Dougherty, 2009; Dewan & Cohen, 2013).

In Ontario, oversight of programs and services to address these families' needs fall to three different and non-integrated service ministries that parents of CMC-technology dependent children need to navigate: the Ministry of Education, the Ministry of Children, Community and Social Services and the Ministry of Health and Long-Term Care (CAPHC, 2018; Dewan & Cohen, 2013; OACCAC, 2013; Sick Kids, 2008). Families with CMC-technology dependent children can access home care nursing through their Local Health Integration Network (LHIN), funded by the Ministry of Health and Long-Term Care. Some families with CMC-technology dependent children in the NICU environment who are preparing for discharge are opting to develop their own home care nursing team using self-directed funding (Family-Managed Home Care, n.d.). This program, called Family-Managed Home Care, can be accessed using the LHINs and funds come from the Ontario government directly to families to develop and pay their home care nursing team. The Family-Managed Care Program, created in 2017, is designed to provide more control for health service delivery to eligible families who require home care services in the community, including technology-dependent infants and children (Family-Managed Home Care, n.d.). Families are expected to act as an employer and manage all employer responsibilities. This is an enormous task to ask of families with a technology-dependent infant and/or child, and while some guidance is provided by the LHIN, it is unclear what specific supports are provided to ensure families are successful under this care program. Furthermore, while the Family-Managed Home Care model provides parents of infants and children who require intensive home care with flexibility and resources to coordinate their child's nursing care, very little is known about the parents' experiences using this home care model and how they navigate the care coordination process.

CHAPTER TWO: LITERATURE REVIEW

Overview

This chapter will present a literature review addressing the following question: *How do families with technology-dependent children describe their use of and experiences with the Family-Managed Home Care Model in Ontario?* An overview of literature underpinning the research question will be addressed; this includes the defining characteristics of children with medical complexity and technology dependence (CMC-technology dependent), experiences of parenting a CMC-technology dependent child, a description of the nursing needs of CMC-technology dependent children, and an outline of current home care programs and policies in a Canadian health care context. An overview of the Family-Managed Home Care Model is also presented. This review will identify gaps in the literature and provide a critique of key articles generated from the search of the literature.

Search Strategy

A research librarian was consulted to review the chosen search strategies. The databases Web of Science, PubMed, and CINAHL were searched from January 1976 to June 2021, inclusive, with a combination of the following terms: *medically fragile, medically complex, complex care, technology-dependent, mechanical ventilation, infants, community health nursing, community nurse, community nursing, home care nurse, district nurse, education, nursing, transition, discharge, parents.* The reference lists of retrieved articles from the initial search were also assessed for relevant studies. Relevant studies were then retrieved and reviewed. The internet was searched for key grey literature and government documents through the search engine Google.

The criteria for inclusion in the literature review were: (a) English-language articles, (b) research articles pertaining to children with medical complexity (CMC) and/or technology-dependence; (c) articles on parent or caregiver experience of caring for children with medical complexity and/or technology-dependence, (d) research articles related to the training of parents and health care professionals in the care of CMC and/or technology-dependent children, and (e) grey literature that discussed the Family-Managed Home Care Model, home care practices in Ontario, and descriptions of CMC or technology-dependent children. Articles were excluded if they focused on: (a) adult populations, (b) health service structures, (c) general community nursing not specific to CMC, and (d) health care provider perspectives only. A wide inclusion criterion was accepted in order to provide a comprehensive background and overview of the aspects of home care for CMC and/or technology-dependent children and their families.

Search Results

The formal search generated twenty-five articles meeting the inclusion criteria. After reviewing the reference list of all articles, a combined total of forty-nine research articles and grey literature were included in the review of the literature. Study designs included qualitative, mixed methods, and metasyntheses, as well as integrative reviews, reviews of the literature, and editorials/informal literature summaries. Grey literature included Canadian government and organizational reports. The literature found is discussed in the sections that follow. Detailed critique of key articles related to caring for CMC-technology dependent children is presented near the end of the chapter.

The Number of Complex and/or Technology-Dependent Infants/Children

The number of children with medical complexities and/or technology-dependence in Canada is unknown, as Canada does not currently have a comprehensive national database to describe the prevalence of ventilator-assisted children (Rose et al., 2015). Internationally, however, prevalence rates estimate that 4.2-6.7/100 000 children <18 years old are ventilator-dependent (Goodwin et al., 2011; Racca et al., 2011).

Canadian-based surveys and studies provide varying numbers of ventilator-dependent children, and do not provide prevalence rates. Rose et al. (2015) conducted a survey of adults and children from 2012-2013 with a goal of profiling the number of ventilator service users. Out of the 4 334 ventilator-assisted individuals in this survey, data on age was provided for only 1998 individuals, of which 425 were < 18 years old (Rose et al., 2015). The Sick Kids Report of the Pediatric Complex Care Coordination Expert Panel (2008) focused its Ontario-based survey on children and youth with special health care needs (CYSHCN) and found over 2200 children in Ontario met their definition of medically fragile and/or technology-dependent. A retrospective cohort study by Cohen et al. (2012) identified that 15 771 (0.67%) of children fit their definition of children with medical complexity, and of those 15 771 children, 1863 (11.8%) were also technology dependent. Overall, there is mixed evidence on the prevalence rates of children with medical complexity and technology-dependence in Ontario, which is complicated by the use of varying terminology and definitions to define this specific population of children.

Defining Medically Complex and/or Technology Dependent Infants/Children

The terminology used to describe CMC and/or technology-dependent children in the literature is inconsistent, with no standardized formal definition (Cohen et al., 2011). This makes these children difficult to identify and creates varying service program eligibility criteria across districts and communities (CAPHC, 2018; OACCAC, 2013). Commonly used terms to describe this pediatric population include “medically fragile and/or technology-dependent,” “medically complex children,” and “children with medical complexity.” Although differences exist in terminology, there are some similarities in the varying descriptive definitions. For example, McPherson et al. (1998) use the term “children with special health care needs” (CSHCN) as an umbrella term for various subgroups. They define CSHCN as: “Children with special health care needs are those who have or are at increased risk for chronic physical, emotional, developmental or behavioural conditions and who also require health and related services of a type or amount beyond that required by children generally” (p. 138). Under this definition, CSHCN can be generically defined based on 1) the presence of a chronic condition (e.g., a child with diabetes); 2) the presence of a functional impairment (such as lung disease); and 3) the presence of an elevated service use (such as home care nursing).

Canadian literature is also inconsistent with its terminology and definitions for this population vary across the country (CAPHC, 2018). The Sick Kids Report of the Pediatric Complex Care Coordination Expert Panel (2008) appears to build upon McPherson et al.’s 1998 definition and terminology, but it is unclear in the report whether this founded the basis for their definition. This report uses a similar term, “children and youth with special health care needs” (CYSHCN), and further defines three subgroups under this umbrella term. These subgroups are children and youth who are medically fragile and/or technology dependent; children and youth with severe obesity; and children and youth with significant mental illness and complicating psychosocial factors. Dewan & Cohen (2013) use a similar term to the Sick Kids (2008) report, denoting “children with special health care needs” as an umbrella term with a subgroup identified as “children with medical complexity.” A more recent terminology proposed by the Canadian Association of Pediatric Health Centres (CAPHC) in 2018 is “children with medical complexity,” which can include technology-dependence (CMC and/or technology-dependent). CMC and/or technology dependent is a term accompanied by four defining characteristics of this population, as described in the introduction chapter of this thesis. These characteristics are: 1) the presence of one or more complex, multisystem and severe chronic conditions; 2) a significant functional limitation requiring technological support; 3) high health care utilization; and 4) caregivers identify high health care service needs that incur significant financial and social impact on families (CAPHC, 2018). These characteristics are almost identical to Dewan and Cohen's (2013) four defining characteristics of children with medical complexity. While most of the terminology used is from a medical perspective, another term and definition are proposed from a nursing perspective by Rehm (2013) in their integrative review of nurse researchers' contributions to understanding parenting children with complex chronic conditions (CCC). Rehm (2013) felt use of the term "medically fragile" implied weakness and negated children with CCC's resilience and strength, and thus proposed the following definition: "Children with complex chronic conditions (CCC) are those who require ongoing skilled monitoring and care from families or professional caregivers. They use complex supportive therapies, often including technology, to enhance health and well-being, and avert death or further disability" (p. 269).

For the purpose of the study presented in this thesis, the CAPHC (2018) definition will be used when referring to children with medical complexity and technology-dependence (CMC-technology dependent). This is the most recent definition that clearly summarizes and captures the complexity and high health care needs of this population of children. Additionally, the term "child and/or children" will be continually used throughout this thesis, as a child can be defined as a person 19 years or younger (WHO, 2013). Further to this point, infants who receive a tracheostomy while in the NICU often have extended hospital stays and may be initially discharged close to or after their first birthday. As such, infants who are close to or one year of age or greater are more appropriately categorized as children.

Unique Characteristics of Children with Medical Complexity (CMC)

Despite inconsistently described terminology for CMC-technology dependent children within the literature, what is consistently stated is the immense impact these children have on the health care system and the need for policy and process changes to improve service and care coordination for this population (Burke & Alverson, 2010; de Banate, Maypole & Sadof, 2019; CAPHC, 2018; McPherson et al., 1998; PCHCH, 2013; Rehm, 2013; Sick Kids, 2008; Stile & Antonelli, 2004;). CMC-technology dependent children are a unique population, and as such their care is delivered within multiple settings, including the hospital, community, home, and school (de Banate, Maypole & Sadof, 2019; CAPHC, 2018), with supports required from agencies in different sectors, including health, education and social services (where indicated).

CMC-technology dependent children face a variety of challenges. These children live everywhere in Canada, in urban and remote rural areas (CAPHC, 2018). However, the knowledge and expertise required to effectively manage their conditions and provide care are only found in specialized tertiary care centres; sometimes only one centre in Canada can provide the required care (CAPHC, 2018). Minor conditions that a relatively healthy child could manage, such as a simple cold, can be potentially catastrophic “tipping points” for these children (Sick Kids, 2008), and end in hospitalization. CMC-technology dependent children often require frequent hospitalizations, and are more likely to suffer from medical errors, caused in part by lack of communication between providers across the health care continuum (CAPHC, 2018). CMC-technology dependent children are at higher risk for adverse outcomes, due to their complex care requirements and frequent hospitalizations (Dewan & Cohen, 2013). CMC-technology dependent children also require significant services and supports, with high healthcare utilization. For example, children with medical complexity make up < 1% of pediatric patients but consume approximately one-third of child health provincial spending – about $419 million a year (CAPHC, 2018; Cohen et al., 2012; Dewan & Cohen, 2013; PCMCH, 2013). After discharge, almost one quarter of CMC will experience hospital readmission within 30 days and 78% will be admitted within two years (Dewan & Cohen, 2013). Despite the substantial amount of care CMC-technology dependent children receive, it is largely suboptimal (CAPHC, 2018; PCMCH, 2013; Sick Kids, 2008). Several Canadian reports and expert panel publications cite poor service coordination for families and children who are medically complex and/or technology dependent. They propose a variety of strategies to improve care coordination for this pediatric population, such as the identifying and implementing a key worker or care coordinator to facilitate service planning and care delivery and designing a system around the needs of CMC-technology dependent children and their families (CAPHC, 2018; Cohen et al., 2011; PCMCH, 2013; Sick Kids, 2008).

Parental Impact of Meeting the Needs of Technology Dependent Children

Social change and medical advances have redefined and reshaped parenthood for parents with CMC-technology dependent children (Kirk, Glendinning & Callery, 2005). Mothers, in particular, are responsible for addressing the majority of the caregiving activities in home care (Manhas & Mitchell, 2015; McCann, Bull & Winzenberg, 2015; Peter et al., 2007). This may be related to social norms and expectations where women are more likely to assume caregiving responsibilities and that in many circumstances, the income of males compared to females may be higher; as well as policies that limit the support provided by paid, external caregivers (Manhas & Mitchell, 2015).

Parents of technology-dependent children experience negative impacts on their health. They are at a higher risk of having depressive symptoms, and many experience anxiety and sleep deprivation related to caring for their child's technological devices and the uncertainty of their child's prognosis (Dewan & Cohen, 2013; Keilty et al., 2015; Kirk, 1998; Montagnino & Mauricio, 2004; Sick Kids, 2008; Wang & Barnard, 2003). McCann, Bull & Winzenberg (2015) conducted a systematic review examining sleep deprivation in parents caring for children with complex needs at home and found that 61% of parents of children dependent on technology experience regular sleep disruption, and more frequently when their child is unwell. Furthermore, sleep deprivation affects parents' ability to function and maintain employment, as well as causing strain on family relationships (McCann, Bull & Winzenberg, 2015). Evidence from this systematic review also suggests that parents do not receive adequate support to care for their children with complex needs overnight; this is a common theme throughout the literature (McCann, Bull & Winzenberg, 2015). Similar results were found in a prospective cohort study by Keilty et al. (2018), where family caregivers of children reliant on medical technology did not attain adequate sleep. Study participants experienced depression, excessive daytime sleepiness, and fatigue. Furthermore, outcomes were poor when family caregivers assumed responsibility for a child with extraordinary care needs in comparison to those with caregiving responsibility for healthy children, even when families with children with extraordinary care needs had assistance from home care nursing (Keilty et al., 2018).

Many studies reported that parents experience social isolation stemming from a variety of factors (Cockett, 2012; Kirk, 1998; Heaton et al, 2005; Wang & Barnard, 2008; Wang & Barnard, 2003). Social isolation can result from difficulty in finding appropriate community support networks, such as babysitters, and many parents are wary of leaving their child in the care of others (Kirk, 1998; Wang & Barnard, 2003). Heaton et al. (2005) described the significant amount of time it takes in a day for parents to administer adequate care routines and attention to various medical devices can contribute to the social exclusion of families with technology-dependent children.

Parents of technology-dependent children can also experience financial difficulty. Families use personal resources to make up for what is not covered by government agencies or insurance policies (Manhas & Mitchell, 2015). In many families, one parent stops working to care full-time for the child, which results in lost wages (Heaton et al., 2005; Kirk 1998). Travel expenses for appointments and changes in the home to accommodate a medically complex child are costly, and these financial burdens negatively impact the psychological health of parents, especially in parents of low socio-economic status (Heaton et al., 2005).

Parents as Primary Caregivers

Once discharged home from hospital to the community, families with technology-dependent children often experience multiple challenges related to care provision and coordination. Parents of technology-dependent infants and children are expected to take on a high level of medical care and be the primary care coordinators for their child (Dewan & Cohen, 2013). Parents experience tremendous emotional and physical burden related to having a technology-dependent child at home, with the increase in demands of their child's care placing them at risk for negative health outcomes (Dewan & Cohen, 2013; Sick Kids, 2008; Wang & Barnard, 2003). Not all of these families may be capable of handling these demands (or want to) without significant community support (Lindahl & Lindblad, 2013 Sick Kids, 2008). Ongoing monitoring and ready access to knowledgeable medical support is needed to manage these children safely in their communities (Sick Kids, 2008). This also highlights the need for effective home nursing care service delivery and the need for adequately trained nurses.

While each technology-dependent child and their family have unique circumstances, there are common lived experiences and overlapping themes recurring throughout the literature (Montagnino & Maruicio, 2004). One common theme is the *transformed meaning of home*. Having hospital equipment in the home inherently changes its meaning, as it is no longer a private refuge. The constant presence of multiple healthcare professionals in the home impacts the family's daily activities of living, social interactions, and leaves their actions open to public scrutiny (Kirk, Glendinning & Callery, 2005). A second common theme is the *altered meaning of parenthood* (Lindahl & Lindblad, 2013). Parents of technology-dependent children take on the dual role of nurse and parent (Kirk, Glendinning & Callery, 2005). For example, in a qualitative study by Kirk, Glendinning & Callery (2005), parents indicated they did not want their relationship with their child to be defined by the nursing activities they undertook. Parents in this study described a sense of resentment for the nursing role that underpins their parenting experience – nurses in the home were doing their job and therefore able to break from their responsibilities at the end of their shift, but parents live with this responsibility daily. Parents also felt their caregiving activities were laden with emotional significance (Kirk, Glendinning & Callery, 2005). Nurses and parents may perform the same caregiving activities, but they have drastically different meanings. Since parents are performing clinical procedures on their child, these procedures contain emotional significance, and parents noted this as creating a sharp distinction between their identities in parenting versus nursing (Kirk, Glendinning & Callery, 2005). This distinction between identities can increase the tension between parenting and caring, and the emotional burden of caring many parents of technology-dependent children experience (Cockett, 2012).

"Being home is good" is seen as the most desirable option for families with technology-dependent children, however, the literature implies that caring for a child with medical complexity impacts families' social, psychological, physical, and financial state that can result in significant moral dilemmas (Carnevale et al., 2006). Carnevale et al (2006) describe parents with technology-dependent children as "daily living with distress and enrichment" (p. 53). Their qualitative study in Quebec, Canada focused on families with technology-dependent children supported by a ventilator or positive pressure device at home. They examined the moral phenomena intrinsic in the 1) individual experiences of the ventilator-assisted child, siblings, and parents, and 2) everyday family life. Parents in this study described their experiences as stressful and overwhelming, and struggled with the emotional, physical, and psychological toll of caring for their technology-dependent child. They also described feeling like they had "no free choice" in the matter; that is, feeling like they could not let their child die. The authors suggest that critical care services such as those of the NICU should re-examine their approaches to this population and rethink approaches that may impose preventable burdens on the lives of these children and families. However, no specific recommendations to change these approaches were provided by the authors.

Parenting a medically fragile child is enriching but often burdensome as a result of limited professional support (Lindahl & Lindblad, 2013). A review of the evidence by Cockett (2012) found that one of the complications associated with discharging technology-dependent children home is the assumption by health care professionals that parents are willing to provide most of their child's care. Some parents disclosed in an interview that they were uncomfortable with the assumptions that were made about parental consent (Kirk, 2001), and most parents were unable to fully appreciate the implications of their child's discharge home (Cockett, 2012). It is important that clear, purposeful, and consistent communication occurs between the healthcare providers and parents prior to the discharge of a technology-dependent infant and/or child, as well as ensuring parents have understood the entirety of the message with respect to their child's medical condition (Bowles et al., 2016). Failing to confirm parents' understanding of their child's medical condition at an early phase in hospitalization may hinder their adaptation and stunt their ability to understand, anticipate and provide home healthcare for their infant/child at the time of discharge (Bowles et al., 2016). It is crucial for successful discharge that parents have a realistic understanding of what life at home with their technology-dependent child will be like. An integrative review of the literature about interactions between parents of technology-dependent children and care providers by Jachimeic et al. (2015) reported that parents wanted information related to their technology-dependent child's condition, symptoms, tests, treatments, medications, case management, available resources, insurance, and guidelines for care to share with family members and schools, and child-rearing tips. It was unclear in this review by Jachimeic et al. (2015), however, if parents requested this information prior to hospital discharge or after. These parents also reported that receiving practical information in a straightforward manner increased their confidence in their ability to care for their child and their sense of autonomy. However, they also felt their information needs were not always met, in the hospital or community, because providers did not have the appropriate knowledge.

The Other Side of Parenting CMC-Technology Dependent Children

Despite the oft-cited challenges associated with caring for a CMC-technology dependent child at home, many parents also report that it is an overall positive life experience. Relevant literature includes the theme of parents describing the positive aspects of having a child with complex needs and that having such a child in their family enriches the lives of the family overall (McCann, 2021). Wang and Barnard (2008) conducted a study based on the phenomenographic approach in which they identified and described the different ways caregivers understood their experience of caring for a ventilator-dependent child at home. Parents in this study describe their experience as “changing as a person.” Parents felt transformed as a result of caregiving at home, and this change was desirable and associated with positive attitudes towards life, increased empathy to others, and greater personal strength and resilience during hardship. Most parents in Carnevale et al.’s (2006) study also reported that despite the difficulties, the struggle of caring for a technology dependent child is worthwhile.

Mentro and Steward (2002) proposed an alternate perspective in examining the literature, in order to provide a more thorough understanding of the dynamics of caregiving for a medically fragile child. They utilized Sense-Making Methodology’s four central concepts (situation, gap, bridges, and outcomes) as a guiding framework to review literature related to caregiving of medically fragile children. Mentro and Steward (2002) found much of the literature frames caring for such children in a negative context, although many caregivers describe positive adaptations to the needs of the child. Mentro and Steward (2002) suggest focusing on the “burdens” is only capturing one snapshot in time, rather than the dynamic change that occurs when caring for these children. The authors noted several positive outcomes of caring for a medically fragile child, such as developmental growth of the caregivers. They also reported families felt they had increased self-esteem from mastering the various aspects of caregiving in this context. As well, Mentro and Steward (2002) found that families with strong support structures and shared values and beliefs had fewer conflicts with increased familial pride.

Nursing Care for the Technology Dependent Child in the Community

Specially trained nurses are needed in the home care setting because the health care and nursing needs of technology-dependent children in the home are specialized, complex, intensive, and the child's health status can quickly change (Wang & Barnard, 2003). Examples of these needs include frequent airway monitoring and suctioning, gastric tube feedings, medication administration, oxygen saturation monitoring and oxygen titration, and tracheostomy dressing and tube changes.

A shortage of nurses to provide care for CMC-technology dependent children in the community presents challenges prior to discharge from hospital. Lack of available community-based nursing services results in delayed discharge, which is a recurring theme in the literature with respect to technology-dependent children (Manhas & Mitchell, 2015; Maynard et al., 2019). Delayed discharges leave the infants and children at risk of harm from hospital-acquired infections, and the prolonged separation of the family unit results in significant parental distress (Noyes et al., 1999). Furthermore, this results in an enormous financial burden on hospitals, as well as an inappropriate use of hospital resources (Maynard et al., 2019).

The shortage of trained healthcare providers also poses challenges after technology-dependent children are discharged from hospital to their home communities (Boroughs & Dougherty, 2009; Manhas & Mitchell, 2015; Sick Kids, 2008). While Canadian literature of home care nursing and technology dependent children is limited, it is made clear that the lack of supportive home nursing care is a significant factor that could threaten the success of safely caring for technology-dependent infants and children at home (Sick Kids, 2008). One parent from Canada reported that "community nurse resources are so limited that even though their child qualifies for more hours through the CCAC, they can only secure 12 hours per week" (Sick

Kids, 2008, p. 28). When nurses are found, the family must invest significant time training these new staff, who often do not stay long, in part because they are not comfortable dealing with the child's complex needs (Sick Kids, 2008). Insufficient funding for paid caregivers, such as nurses, contributes to this issue and is a major barrier to transitioning home (Rose et al., 2015). Insufficient public funding for paid caregivers in Canada suggests that provincially determined maximum number of nursing hours families are entitled to are inadequate to meet the needs of mechanically-ventilated individuals at home (Rose et al., 2015). This trend is also documented in literature from the UK, Spain, and US, where parents reported that despite being allocated a certain number of nursing hours, it was not always provided (Gonzalez et al., 2017; Heaton et al, 2005; Kirk, 1998; Murphy, 1997). Another contributing factor to the nursing shortage in this particular home care context is the individual health conditions of CMC-technology dependent children. Their conditions can be rare and complex, making it difficult for community nurses and caregivers to develop and maintain the required knowledge, skill, expertise, and comfort to care safely and effectively for these children and manage their disorders (PCMCH, 2013; Sick kids, 2008).

Canadian literature about the community nurses' training to care for technology-dependent children is limited, although there are several studies from the UK and US that discuss training strategies (Wells et al., 2018; Whitney & O'Loughlin, 2012). Some of these studies, however, include a mix of professional (regulated) and nonprofessional (unregulated) care providers. For example, Whitney and O'Loughlin (2012) discuss the success of a training program in the UK called "Training High." This initiative was created out of an identified need to provide respite services for parents of children with medical complexity. This two-part program was delivered by nurses with the purpose of 1) providing generic skills training to unregulated care providers working in education, early years care, respite and leisure and play groups; and 2) providing protocol-based and competency-focused customized training to meet the needs of individual children. This training initiative was proven to be successful, as it allowed CMC to attend a range of leisure and respite opportunities that were otherwise not available to them. In the United States, Wells et al. (2018) outline an extensive remodel of their discharge process for tracheostomy patients from the Boston Children's Hospital. This quality improvement project created a Tracheostomy Subject Matter Expert Committee to standardize tracheostomy care, education, and the discharge process across the hospital. The target population were caregivers and parents of children with tracheostomies; it is unclear if community nurses were included in the caregiver category. At the start of the quality improvement initiative in 2014, the 7-day unplanned readmission rate for tracheostomy patients was 18.7%. After the initiative, this 7-day rate decreased to 6.67% in 2015 and 0% in 2016. The 30-day unplanned readmission rate decreased from 6.67% to 0% in 2016.

Rose et al. (2015) conducted a survey on home mechanical ventilation training for health care workers. Training and education for health care workers within institutional and community service providers participating in the survey (N=152) was provided by 61% of service providers, of which 41% offered training to health care workers outside their organizations. Topics of training for health care workers included the types of equipment utilized and their maintenance requirements, suctioning, tracheostomy care, and management of acute respiratory deterioration. However, specific course details, how training was delivered, or the duration of the training courses was not identified. This indicates that some form of mechanical ventilation training is being provided to health care workers by service providers, but not all service providers offer training, and there is a question of whether health care workers outside an organization are able to access appropriate mechanical ventilation training.

One Canadian study by Manhas and Mitchell (2015) specifically explored the roles and responsibilities of nurses included in the hospital-to-home transition of technology-dependent children. The authors followed methods described by Carnevale (2007), in which the sociological framework of Erving Goffman's Stigma Theory is used to help advance the understanding of medical problems as social problems (Carnevale, 2007). Manhas and Mitchell (2015) used a sociologically grounded theory orientation – trust – to reinterpret previous qualitative data for an ethical inquiry into a specific facet of data. The original qualitative case study involved interviewing 26 participants, 14 of which were nurses, about their roles and responsibilities in transitioning ventilator-dependent children under 5 years of age from hospital to home. The aim of Manhas and Mitchell's (2015) study was to elaborate on trust in the ethical inquiry of nurses' roles and responsibilities in the transition from hospital to complex pediatric home care. Lack of resources and support for home care nurses was cited as major barriers in the provision of care. Finding, securing, and retaining professional and non-professional caregivers was challenging for professionals and families, which created distrust between nurses and caregivers in supporting home care. Tensions between jurisdictional lines, such as urban-rural, medical versus family conflicts and professional versus personal distinctions, all seemed to have a "negative view of outsider" which further promoted a climate of distrust. Manhas and Mitchell (2015) recommended promoting trust between all parties along the transition continuum; while this will not solve the problem of finding and maintaining caregivers, it could lessen the manifestations and implications for conflict during transition.

The presence of health care professionals in the home can be both a barrier and a relief for parents as caregivers (Mentro & Steward, 2002). Barriers for caregivers include sporadic, unreliable, and unskilled care provision, indicated by lack of scheduled shifts, shift cancellations, staff turnover and a lack of licensed nursing care (Mentro & Steward, 2002). Poor quality or unreliable nursing care can subsequently increase family stress and result in care provision gaps, adverse outcomes or hospital readmission (Hummel & Cronin, 2004). Moreover, mothers with technology dependent children at home describe the lack of support from health care providers unhelpful in the caring of their child (Toly, Blanchette & Musil, 2019).

Another notable barrier for parents is related to the perception of experiential knowledge and what constitutes adequate care. Parents differentiate parenting from professional care through different knowledge types. Parents value the experiential knowledge that is derived from caring for their individual child (Kirk et al., 2005). This experiential knowledge allowed parents to note subtle changes in their child's condition that could indicate they were becoming ill. Parents perceived professionals lacked and did not value this experiential knowledge of caring for a specific child, which resulted in conflict between both parties (Jachimeic et al, 2015; Kirk, Glendinning & Callery, 2005). Parents also worried about the competence of their home care nurses (Jachimeic et al., 2015; Kirk, 1998; Murphy, 1997; Noyes et al., 1998) and reported difficulties in finding nurses that are appropriately educated to provide their child with the required and necessary care (Mendes, 2013). This creates challenging situations between health care professionals and parents. Parents are in a contradictory situation where they are expected to attain the skill and knowledge of a health care professional, effectively becoming experts in their child's care, yet defer and comply with the advice they receive from health care professionals (Kirk, 1998).

Other common tensions acting as barriers between parents and home care nurses includes role clarity and negotiation; conflicts over authority and control; differing child-rearing practices; judgements made by nurses to family members about their lifestyle choices; and how the presence of nurses affects family dynamics and relationships (Cockett, 2012; Kirk, 1998; Murphy, 1997; O'Brien & Wegner, 2002; Wang & Barnard, 2008).

Despite the challenges, however, several studies denoted that parents felt there were many positive benefits to having nurses in the home. Positive aspects of home care nursing relationships, as described by parents, are feelings of friendship, support, collaboration, and demonstrating genuine caring for the child (Coffman, 1997). Parents and non-parent caregivers expressed that the relationship between them and health care professionals was vital to the nature of the nurse-family relationship (Mentro & Steward, 2002). Nurses who were perceived as respectful towards the family, willing to collaborate and created normalcy led caregivers to consider the nurses "friends" in a professional capacity, also termed a "professional friendship," (Jachimeic et al., 2015; Lindahl & Lindblad, 2013; Mentro & Steward, 2002). Parents also described the presence of home care nurses as providing them freedom and support, allowing them to keep their family together in the home (Jachimeic et al., 2015). Overall, several studies found that parents felt the benefits of home care outweighed the challenges and limitations, and that the "best aspect" of home care was looking after their child (Mentro & Steward, 2002; Murphy, 1997). Furthermore, parents reported satisfaction in witnessing the emotional and social growth of their child at home (Wang & Barnard, 2003).

Critique of Research on Parents' Experiences Caring for CMC-Technology Dependent Children

Ten key studies discussed in this thesis were related to parents' experiences of caring for CMC-technology dependent children (Carnevale et al., 2006; Gonzalez et al., 2017; Heaton et al., 2005; Kirk et al., 2005; McCann et al., 2015; Mendes, 2013; Montagnino & Mauricio, 2004; Noyes et al., 1999; Toly et al., 2019; Wang & Barnard, 2008). The ten studies consisted of qualitative studies, a cross-sectional study, and a mixed methods systematic review. These studies were examined in depth and critically appraised using the Critical Appraisal Skills Programme (CASP) checklist criteria for qualitative research or systematic reviews (CASP, 2018), or The Joanna Briggs Institute checklist for an analytical cross-sectional study (Joanna Briggs Institute, 2017).

The CASP qualitative checklist (2018) assesses the validity of study results, appropriateness of the recruitment strategies, and the rigor of methodology. The CASP systematic review checklist (2018) examines criteria such as the inclusion of papers that address the research objective and have appropriate study designs, the rigor in quality assessment of included studies, and whether the review's results were clearly outlined. The Joanna Briggs Institute checklist for analytical cross-sectional studies (2017) analyzes a study's methodology by examining if the study had clearly defined inclusion criteria, the validity and reliability tools of measuring the exposure, whether confounding factors were identified and how these were addressed, and the use of appropriate statistical analysis.

Within this thesis, seven of the studies on parents' experiences of caring for CMC-technology dependent children used specific and nonspecific qualitative methods (Carnevale et al., 2006; Heaton et al., 2005; Kirk et al., 2005; Mendes, 2013; Noyes et al., 1999; Toly et al., 2019; Wang & Barnard, 2008) and were critiqued using the CASP qualitative checklist (2018); one cross-sectional study (Montagnino & Mauricio, 2004) was appraised using the Joanna Briggs Institute checklist for cross-sectional studies; and the CASP systematic review checklist (2018) was used to evaluate one review (McCann et al., 2015). Evaluation of the final study

(Gonzalez et al., 2017) was conducted utilizing both the CASP qualitative checklist and aspects of the Joanna Briggs Institute checklist for cross-sectional studies, as there was a semi-structured interview component with some qualitative data obtained. The methodological strengths and limitations of the ten studies appraised will be discussed in the upcoming sections.

Strengths

Most of the qualitative studies on parents' experiences of having a CMC-technology dependent child in this review used a rigorous methodology and analytical approach, congruent with their chosen research design (Carnevale et al., 2006; Heaton et al., 2005; Kirk et al., 2005; Mendes, 2013; Toly et al., 2019; Wang & Barnard, 2008). The sample recruited for each study "matched" the studies' objective and is consistent with the population of interest in this thesis (Carnevale et al., 2006; Heaton et al., 2005; Kirk et al., 2005; Mendes, 2013; Toly et al., 2019; Wang & Barnard, 2008). Sample sizes ranged from 7-103, which are appropriate for qualitative studies; those with smaller sample sizes had findings consistent with relevant literature (Mendes, 2013; Noyes et al., 1999). Rich, detailed descriptions from participants were included (Carnevale et al., 2006; Kirk, Glendinning & Callery, 2005; Mendes, 2013). Descriptions of participant (parent/caregiver) and child characteristics were stated, allowing the transferability of their findings to other contexts to be assessed (Carnevale et al., 2006; Kirk et al., 2005; Noyes et al., 1999; Mendes, 2013; Toly et al., 2019). Notably, Heaton et al.'s (2005) qualitative study examining time consequences of care regimes for technology-dependent children demonstrated rigor with the use of data triangulation and included an ethnically diverse sample of participants.

Reliable and valid measurement tools were used in both cross-sectional studies (e.g., the Pediatric Quality of Life questionnaire, Impact on Family Scale, the Family Crisis Oriented

Person Evaluation Scales) (Gonzalez et al., 2017; Montagnino & Mauricio, 2004). This is a strength and helps promote the validity of study findings.

McCann et al. (2015) was the only mixed method systematic review; it had a rigorous methodology and analytic approach. Most importantly, McCann et al. (2015) highlighted the inadequate overnight support provided to parents of children with complex needs, the reservations parents have about nurses' skill levels, and the shortage of appropriate caregivers.

Limitations

One limitation of the studies appraised is the variety of settings (countries) in which the studies were conducted. Although studies conducted in a variety of countries could be perceived as an asset as the studies were conducted in Spain, the United Kingdom, and Australia, it does limit the transferability of findings to a Canadian health care context (Gonzalez et al., 2017; Kirk et al., 2005; Mendes, 2013; Noyes et al., 1999; Toly et al., 2019; Wang & Barnard, 2008). Varying definitions and terminology for CMC and/or technology-dependent children may also limit the applicability of findings to other contexts. For example, if the children in the study were medically complex with wide variations between levels of technological support, generalizability to specifically ventilator-dependent children and families is limited (McCann et al., 2015; Noyes et al., 1999; Toly et al., 2019). Another limitation is that both Noyes et al. (1999) and Mendes (2013) had small sample sizes (N=7) and had limited or specific participant demographics, which affects the generalizability of study findings; the same applies to Toly et al. (2019) where participants were only female caregivers. The parent participants in Mendes' (2013) study were all from two-parent families with extra health coverage to support their caregiving needs; while this is similar to the parent demographics in the study presented in this thesis, it does limit the generalizability of findings to other types of families with CMC-technology dependent children.

Selection bias was evident in the studies conducted by Gonzalez et al. (2017) and Noyes et al. (1999). Participants in both studies were known to the researchers, and it was noted by Gonzalez et al. (2017) that sample participants were chosen from a previous study group by the physician in charge of the home mechanical ventilation follow-up team. Although selection bias was mitigated by keeping the proportion of subjects the same as that of the previous study, selection bias cannot be discarded. The external validity of this study is compromised because of selection bias in this manner.

Studies with qualitative components lacked details about the method of analysis (Gonzalez et al., 2017; Montagnino & Mauricio, 2004; Noyes et al., 1999). The inclusion of open-ended survey questionnaires limits the depth of collected data, as there is less opportunity to explore in-depth experiences of participants than if they were conducted in person (Noyes, 1999; Toly et al., 2019). Montagnino and Mauricio (2004) used mailed surveys as their primary method of data collection. Their study received a low response rate – of 50 mailed surveys, only 18 were mailed back with complete responses (a response rate of 36%). This limits the generalizability of findings.

The mixed methods systematic review by McCann et al. (2015) included children with a wide variety of complex needs, not just children who were tracheostomy and/or ventilator dependent. The diverse populations included in their systematic review makes cross study comparisons difficult.

Home Care in Canada

The goals of home and community care are primarily to assist people in maintaining or improving their quality of life and remaining as independent as possible, as well as providing support to informal or family caregivers (Government of Canada, 2016). Home and community care services include nursing, personal care, occupational therapy, speech therapy, social work, dietician services, homemaking, and respite care (Government of Canada, 2016). These services are not publicly funded through the Canada Health Act, but rather delivered by provincial, territorial, and municipal governments (Government of Canada, 2016).

Home care has traditionally been delivered to adults, seniors, and children with acute and/or chronic illnesses and disabilities by regulated (physicians and nurses) and unregulated (personal support workers) health care providers (Canada, 2006). Depending on the province, these service providers often are employed by or are contracted through home care agencies. This home care model fits under the "medical model" whereby the patient is dependent on expert knowledge and skills to assess and deliver the appropriate services and care (Canada, 2006). In Ontario, until the mid-1990s home care services were only accessible via physician referral, although the self-managed care model had been growing in popularity throughout Canada since the 1970s (Canada, 2006). The self-managed care model allows the individual to take a more active and central role in determining how, when and who delivers their care, while still having access to health care professionals. This model is derived from the Independent Living Movement of the 1970s, which states that people with disabilities should have the same civil rights, option, and control over their choices as those without disabilities (Canada, 2006).

A 2006 report to Health Canada, titled "Self-Managed Care Programs in Canada," describes publicly funded, self-managed home care programs at the federal, provincial, and territorial levels of Canada. It highlights that most self-care managed programs are directed to adults and seniors. The report identified 16 documented self-managed care programs, which was noted to likely be under representative of the number of self-managed care programs that actually exist. Only self-management programs providing funding for personal care and daily living needs were included, with programs that provided funding solely for education, respite care or education being excluded. As a result, many pediatric programs were omitted from this report, particularly those that would provide nursing care. One self-managed program in British Columbia developed in 1997 for parents with previously institutionalized children was cited in the report, however, it did not clarify the specificities of the children's medical conditions eligible for the program or if the program was specifically for families with medically complex children. Furthermore, the Self-Managed Care Programs in Canada report highlighted that it was difficult to access information about self-care managed programs, and that even front-line health care workers had a significant lack of knowledge about such programs. When health care workers did share self-managed program information, it was often found to be outdated or incorrect.

With the increasing numbers of CMC, there has been an increasing demand for home care services for CMC that has not been met with increased health care spending in this area, resulting in inadequate services for these children, including those who are technology-dependent (Dewan & Cohen, 2013). CMC have a high home care rate utilization, and those who are technology-dependent have a significantly higher home care rate than children not dependent on technology (PCMCH, 2013). Despite home care services being a vital aspect of health care for this pediatric population, in a review of the literature for this thesis, home care nursing was not often specifically mentioned as an area lacking in funding, training, or remuneration for nurses. Although, the literature repeatedly identified that community physicians are not adequately remunerated for their extended time providing services to CYSHCN (Dewan & Cohen, 2013; Sick Kids, 2008).

While there are various other health care professionals providing care to a technology-dependent child living in the community, home care nursing support is a requirement for families with technology-dependent children prior to discharge from a hospital. In Ontario, families have the option of home care nursing provided via community agencies or to access a self-directed funding model to create their home nursing team. While the self-directed model was created long after the publication of the Self-Managed Care Programs report (2006), the omission of pediatric programs from the report mirrors the dearth of information on current pediatric self-managed care programs in the published literature and available from online resources. Information found online during the conduct of this literature review was limited in detail and often led to webpage links that were outdated or inactive. This makes it extremely difficult for health care providers in hospital to guide parents in decision making regarding home care nursing services to facilitate a smooth transition from the hospital to home

Home Care Funding and Policies

Hospital and physician care is a universal entitlement under the Canada Health Act; however, home care is not covered under this Act; while provinces and territories may choose to cover some or all of home care costs, there is no legal obligation for them to do so (Peter et al., 2007; Rose et al., 2015). This means that home care coverage varies between provinces and territories, with no standardized method of funding for home care services or programs. Manhas and Mitchell (2015) explain that Canadian home care legislation and policies generally polarize family responsibilities from other forms of responsibility, such as professional, public, and social responsibility. Canadian home care legislation specifically outlines that: a) family serves as the first and primary caregiver; b) monetary compensation for family in this caregiving role is inappropriate; and c) public home care is a supplement, not a replacement, for familial care

(Manhas & Mitchell, 2015). However, some homes (and families) are unsuitable for home care, and the weight of home care responsibilities can be crushing to families as it is currently distributed (Manhas & Mitchell, 2015).

Individualized funding introduces a market dynamic anchored in consumer choice that leads to improved service quality, reduced inefficiency, lower costs, and better value for money than block-funded services (Canada, 2006). Individuals and families who receive such funding have high levels of satisfaction because they are empowered to direct their own lives, however, there are no Canadian studies examining the health status outcomes of self-managed program users (Canada, 2006, as cited in the Community Living Transition Steering Committee Final Report, 2002) and any current evidence was not found in this literature review. According to the Provincial Council for Maternal and Child Health (PCHCH) Action Plan (2013), Ontario families of children who are medically fragile and/or technology-dependent agree that for parents who are interested in taking a more active role in managing their child's health care delivery service, self-directed funding can make a positive difference and simultaneously save public dollars. At the time of the PCMCH report in 2013, pilot-testing of a Community Access Care Centre (CCAC) direct-funding model had been implemented for families with medically fragile and/or technology-dependent children. Results from the pilot evaluation indicated this direct-funding model had improved health outcomes and quality of life for families with CMC, while also providing independence and flexibility. The pilot project also resulted in reduced costs of direct service delivery and increased the amount of flexibility of service provided to the child (PCMCH, 2013). It is unclear if this pilot project led to the creation of the Family-Managed Home Care Model in 2017, but it does indicate some benefits this self-directed funding model could provide for families with technology-dependent children.

The Ontario Family-Managed Home Care Model

Families with CMC-technology dependent children can obtain home nursing care services through their local LHINs via nursing agencies, or, if eligible, can coordinate their own nursing services through a self-directed funding program called the Family-Managed Home Care model. The Family-Managed Home Care model, created in 2017, is designed to provide more control for health care service delivery to eligible families who require home care services in the community, including families of children with complex medical needs (Family-Managed Home Care, n.d.). Eligible families receive funding to purchase home care services or employ care providers. Families are responsible for knowing the different health care services available to them; when to obtain them; and recruiting, scheduling, and overseeing hired care providers in the home (Family-Managed Home Care, n.d.). Home care services that families with CMC-technology dependent children would purchase are primarily nursing services. Families using this model of care essentially become the employer and manage all employer responsibilities. This a significant responsibility, and while some guidance is provided by the LHIN, it is unclear what specific supports are provided to ensure families are successful under this program. A number of other fundamental details related to the operationalization and outcomes of the Family-Managed Home Care model are unknown. It is unclear how families access supporting information, how they form a nursing team or how parents perceive the quality of care they receive under this program; and there is no current literature that highlights this gap in knowledge (Rehm, 2013). It is unknown as to why families of children who are technology-dependent are choosing self-managed care programs, such as the Family-Managed Home Care model, as their choice of home care nursing service delivery. A formal evaluation of the Family-Managed Home Care model could not be found in the published or grey literature. Thus, overall, we have little understanding of the Family-Managed Home Care model and how it is utilized by families with technology-dependent children in Ontario. This gap warrants further exploration.

Chapter Summary

Parents of technology-dependent children prefer to care for their children at home, despite the social, financial, moral and health impacts this may have on them and their families. Insufficient home care funding, unavailable and/or unknown family resources and a lack of home care nurses creates challenges for families with technology-dependent children. Gaps in the literature indicate a paucity of Canadian literature regarding various home care practices and models, and differences between countries and health care systems make it difficult to assume how findings can be applied in a Canadian context. There is also very limited accurate demographic information about the population of technology-dependent children in Ontario, including how and what kind of home care services they receive. Specifically, little is known about the Family-Managed Home Care Model. It is unclear how parents find their nurse to create a home care nursing team, as well as what supports or guiding resources are available to them to successfully care for their technology-dependent child in the home. Given these large gaps in Canadian literature, further research is required in this area.

Research Question and Objectives

Based on the identified knowledge gap, the following research question was developed: *How do families with CMC-technology dependent children describe their use of and experiences with the Family-Managed Home Care model in Southwestern Ontario?*

The overall purpose of the study was to explore and then provide a comprehensive description of parents’ experiences of coordinating care for their technology-dependent child within the Family-Managed Home Care model. The specific study objectives included:

1. Describe how parents learned about and were introduced to the Family-Managed Home Care model;
2. Explore and identify the factors that influenced parents' decisions to choose the Family-Managed Home Care model;
3. Describe the different ways in which families coordinate the nursing services their child received under this model; and finally,
4. To examine the varying experiences that families have in partnering with nurses to provide care for their children.

The findings from this study will be used to address an important gap in the literature about the use of the Family-Managed Home Care model amongst families with CMC-technology dependent children; in this study's context, technology-dependent refers to a tracheostomy with or without mechanical ventilation. Study findings will also be used to identify recommendations for health care providers in the hospital setting to support and guide parents in decision-making regarding care in the community. Community health care providers may also benefit from recommendations regarding how to provide ongoing support to parents in the home.

CHAPTER THREE: METHODS

Chapter Overview

This chapter outlines the methods used to conduct this applied qualitative health research study and the rationale for selecting interpretive description as the methodological approach. A discussion of study scaffolding, context, sampling, recruitment strategies, data collection, data analysis and ethical considerations is included. Finally, the chapter will conclude with a discussion of strategies utilized to promote rigor and trustworthiness of this qualitative study.

Research Design and Rationale

Interpretive description, as described by Thorne (2016), was used to guide the research process. All study decisions related to sampling, data collection and analysis adhered to the principles of interpretive description. Interpretive description is an applied qualitative health research methodology developed within the discipline of nursing (Hunt, 2009; Thorne et al., 1997). Interpretive description methodology provides guidance to applied health researchers to generate specific knowledge that can be used to improve clinicians' understanding of health care challenges and provides clinically relevant information to inform or improve practice (Teodoro et al., 2019). Studies that use an interpretive description methodology have three attributes; they: (1) address real-world questions; (2) reflect an understanding of what we know and do not know based on all empirical evidence; and (3) acknowledge the conceptual and contextual realm within which the target audience is positioned to receive the answer to the question asked (Thorne, 2016).

An interpretive description research design was chosen to answer the research question, *How do families with CMC-technology dependent children describe their use of and experiences with the Family-Managed Home Care model in southwestern Ontario*. Interpretive description is an appropriate methodological approach to address this topic, as it is a real-world clinical question for which there is limited literature on the topic (Kalu, 2019; Thorne, 2016). There is a lack of literature about the Family-Managed Home Care model and how it is used by families with CMC-technology-dependent children. The study design and theoretical forestructure was guided by what is already in the empirical literature, the nursing lens in which the researcher viewed this topic, and what was unknown about the topic in question. This study sought to explore common patterns and variations within those patterns of how families experience a phenomenon, that is, families' experiences using the Family-Managed Home Care model. The research question is congruent with the purpose of interpretive description in that it will provide clinically relevant information to practice. Some families discharged from an NICU or pediatric intensive care unit (PICU) choose to coordinate their nursing care under the Family-Managed Home Care model, or switch to the model over traditional home care. Clinicians in the units from where these children are discharged, including nurses working in the NICU and PICU, have a limited understanding of how this model works for these families. The decision to center this research on how families utilize this model of care will serve to inform NICU and PICU clinicians to support and guide families in organizing their nursing care prior to discharge from the NICU and/or PICU.

Scaffolding

Scaffolding is a hallmark feature of an interpretive description study. Scaffolding a study sets up the initial position from which the researcher builds out their design plan; essentially, the researcher is foregrounding the study with important scholarly positioning that will influence the course of their study from beginning to end (Thorne, 2016). Scaffolding in an interpretive description study consists of three parts: (1) the researcher locates their theoretical allegiances; (2) the researcher locates themselves in a discipline; and (3) the researcher locates their personal relationship to the ideas they hold (Thorne, 2016). These three elements of scaffolding will be discussed below.

Theoretical Allegiance

Interpretive description locates itself outside of theoretical traditions associated with the social sciences in that it does not require that all studies be deliberately positioned within one or another formal theory (Thorne, 2016). Formal theories can, however, be incorporated into a study's scaffolding.

The theoretical underpinning of this study was based on Penchansky and Thomas' (1981) Concept of Access, which is presented as a general concept that summarizes a set of five specific dimensions describing the fit between the patient and the health care system; the better the fit, the better the access to a health care service (Saurman, 2015). The five dimensions are: (1) *availability*, the number of health care providers and other health care services; (2) *accessibility*, the geographic relationship between health care providers and care users; (3) *accommodation*, which describes how easily people can use health care based on the organization and content of the healthcare system; (4) *affordability*, the financial ability of the population to use the care the health care system provides and how patients perceive its value; and (5) *acceptability*, which represents the attitudes of the people using health care towards the providers and vice versa (Penchansky & Thomas, 1981, 1984; Ricketts & Goldsmith, 2005).

Access influences health care consumers in three ways: service use, consumer satisfaction, and system practice (Penchansky & Thomas, 1981; Saurman, 2015). Families of CMC and technology-dependent children, as health care consumers, use the Family-Managed Home Care model, which provides them with the service of home care nursing, and therefore the Concept of Access (Penchansky & Thomas, 1981) can be useful in understanding how and why families choose to utilize this model of home care, as well as assist in understanding the facilitators and barriers families experience when using this model.

It should be noted that the dimension of *affordability* does not have the same relevance in the Canadian context as it does in the United States. However, there is a unique aspect of the Family-Managed Care model that speaks to *affordability*, that is, families have a set amount of funding to manage. Furthermore, because medically complex children require such a high level of medical care, families often pay extra money out of pocket. Items such as medical supplies and developmental equipment are only partially covered by programs such as the Ontario Disability Service Program (ODSP).

Frenk (1992) expanded the work of Penchansky and Thomas by suggesting "fit" was a process of adjustment between the population and the health care delivery system (Ricketts & Goldsmith, 2005). Frenk noted that the terms "*access*," "*accessibility*," and "*availability*" were used interchangeably and not clearly defined, and therefore organized a series of "domains" for access. Frenk proposed *accessibility* as a term to be only used in the narrow domain to describe a population's ability to receive care once it is required and wanted. Frenk defined availability, accessibility, and resistance as important concepts to understanding his use of the term "*accessibility*" (Ricketts & Goldsmith, 2005). While these three terms characterize the health care system, *access* is reserved as a term used to describe the population's ability to obtain care if they need it and want it (Ricketts & Goldsmith, 2005). Essentially, to Frenk, *access* is the ability of a person to utilize health care given a need and/or desire to obtain it, whereas *accessibility* refers to the degree to which a person needing and seeking care actually receives care (Ricketts & Goldsmith, 2005).

The concept and terminology of the Concept of Access, as described by Penchansky & Thomas (1981, 1984) and Julio Frenk (1992) was used in this study to assist in understanding the participants' experiences of using a health care delivery service (i.e., home care under the Family-Managed Home Care model) during data analysis. The five dimensions in the Concept of Access (Julio Frenk, 1992; Penchansky & Thomas, 1981, 1984) also influenced the interpretation of the study findings that will be explained further in the discussion section of this thesis (see Chapter Five).

The Discipline of Nursing

The second part of scaffolding a study requires the researcher to situate themselves within their discipline and recognize the influence of their disciplinary orientation as a vital component of the research forestructure and grounding within the applied fields (Thorne, 2016). The epistemological positioning of the researcher is situated in the discipline of nursing, and this positioning provided another lens with which this study was viewed. According to Thorne (2016), qualitative nursing inquiry always involves a normative moral imperative, in that the research problem should be clinically relevant to nursing, and that the phenomenon in question requires improvement. As such, the researcher's motivation to conduct this work comes from the nursing lens that considers understanding families' experiences of Family-Managed Home Care vital to contributing to the relevant literature gap and improving support of families in this program by providing relevant knowledge to clinicians in positions to assist in this support.

Positionality Statement

The third aspect of scaffolding is personally reflecting on the ideas that a researcher holds (Thorne, 2016). The researcher is a central figure who influences the data collection, selection and interpretation (Finlay, 2002). By engaging in reflexivity, not only is the trustworthiness of the research enhanced but it also serves to make explicit the values, perceptions, and assumptions that the researcher holds about the topic under study; and thus, fulfills part of the scaffolding component as described by Thorne (2016). Accordingly, the following is the positionality statement of the researcher:

I am a neonatal intensive care (NICU) Registered Nurse. In the NICU, the practice of family-centered care is promoted, whereby a partnership approach between the nurses and family is taken when caring for the infant. In the NICU, a component of family-centered care is the practice of “primary nursing,” where an individual or small group of nurses take on one patient as their “primary.” In this sense, the nurse(s) are consistently assigned to this infant and family. My experience from primary nursing is that it fosters trust between the nurse and the family and allows the nurse to truly care for the family as a whole. Primary nursing is how I was introduced to home care nursing, specifically, the Family-Managed Home Care model. A previous primary NICU patient of mine required a tracheostomy and ventilator to transition home safely. The family initially went home using traditional home care, and later on switched to the Family-Managed Home Care model. This family contacted me to see if I would be interested in working for them under this model, because I already had the skill and knowledge to care for their child adequately and safely. I agreed to take on the role as “home care nurse” in this context. From a nursing standpoint, I value keeping families together (where appropriate) and supplying them with the tools to care for their child. In this case, that included becoming a “home care nurse," and allowing the parents to sleep through the night, thereby renewing their energy to care for a medically complex, technology-dependent child during the day. Through my lens as an NICU nurse, I consider this another aspect of family-centered care, simply practiced in a different setting.

My experience is unique in that I do not identify primarily as a home care nurse, and therefore do not share some of the worldviews one might expect from a home care nurse. As a result of my NICU background, I felt comfortable with the technology and nursing care I needed to provide. My relationship with the family reflected that of a “professional friendship” which had developed over the course of their child’s previous nine-month NICU stay. For this reason, I had no issues in negotiating care with the family, nor did I feel uncomfortable in their house. There was also, I believe, an element of relief for the parents whenever I was present in the home for a night shift. Their trust in me as a nurse and as a “professional friend” to their family was a responsibility I did not take lightly, and I valued the ability to provide care to their child.

This family had several nurses that made up their home care team, and I discovered through conversations with the parents and in report handovers to other nurses that not all of us identified primarily as home care nurses. I became interested in how this family chose to create a nursing care team that was adequately trained despite some having no prior experience with tracheostomies, ventilators, or even pediatric care. Some were friends of friends who happened to be nurses, some were NICU nurses, and some were primarily home care nurses. This phenomenon of forming a nursing team and their subsequent interactions in the family home under this model of care prompted my interest in this area of study, particularly a family’s motivation for choosing this model of home care. It is not an easy task to take on.

For many of my nursing years, bedside nursing in the NICU was all I knew. We transferred medically complex and technology-dependent children from hospital to the community and call it a successful discharge. This process is merely a snapshot of the discharge. My experience in the community with a technology-dependent child led me to believe that physically leaving the NICU did not equate a successful discharge, especially when the primary challenge for this family was obtaining consistent nursing care. I acknowledge that these challenges are highly complex and affected by many interacting health care systems. However, I believe consistent nursing care is as vital to the family in the home as it is in the NICU. I also believe understanding the motivations and experiences of families with technology-dependent children using the Family-Managed Home Care is important in improving how families are supported from hospital to community. Through my research, I hope to provide a detailed and comprehensive description of these families' experiences under the Family-Managed Home Care model in order to provide clinically relevant information for future practice and contribute to the significant gap in literature surrounding technology-dependent children.

Context

The context of this study was embedded in the Family-Managed Home Care model, as discussed in the literature review section of this thesis. The Family-Managed Home Care model is a self-directed model of care where families with CMC-technology dependent children receive funding primarily to coordinate home care nursing services. However, these families are then expected to act as the employer and follow all guidelines pertaining to the Employment Standards Act (Family-Managed Home Care, n.d.). This is a significant responsibility encompassing the phenomenon in question, that is, how such families use this model of home care.

Sampling and Recruitment

Sampling Strategies and Sample Size

A purposeful sample of families using Family-Managed Home Care to coordinate nursing services for their technology-dependent child was recruited. Purposeful sampling involves recruiting participants who are within the study setting, or context, and have specific knowledge or experience of the study phenomenon (Thorne, 2016). Participants were eligible if they met the following inclusion criteria: (1) approved by an Ontario Local Health Integration Network (LHIN) for Family-Managed Home Care; (2) had experience using the Family-Managed Home Care model currently, or for at least three months within the last three years (since its inception in 2017); (3) were using or had used the Family-Managed Home Care model to coordinate care and services for a medically complex child < 5 years of age and discharged home from a NICU or PICU; (4) had hired at least one service provider, coordinated through the Family-Managed Home Care, who is a Registered Nurse or a Registered Practical Nurse; and (5) at least one primary family caregiver is able to converse in English. This inclusion criteria ensured that study participants were able to provide insight to adequately answer the research question.

"Family" in the context of this study was defined as "the status of being in a parent and child relationship," which encompasses a family unit regardless of composition, that may be composed of a lone parent, blended families, families with parents in a "common law" relationship, or legal guardian(s) or an adult functioning as a parent to the infant (Ontario Human Rights Commission, n.d.). Multiple caregivers may exist in a home; therefore, the study design was flexible and allowed for interested family members who provide primary care to the technology-dependent child to participate.

Thorne (2016) does not recommend a specific sample size for an interpretive description study, but rather suggests the best way to justify a sample size is to generate a rationale that is consistent with the research questions. This study explored a unique phenomenon that is not experienced by many (i.e., the sample pool is small); the number of participants targeted was 15-

25. This sample size is consistent with previous interpretive description studies, where sample sizes ranged from 6 to 32 (Ames, Rennick & Baillargeon, 2011; Teodoro et al., 2018).

Braun and Clarke (2021) and Thorne (2016) agree that there will always be more to study, and there will always be potential for new meanings or understandings to be generated from the data. Recruitment ceased once data saturation was achieved. In the context of reflexive thematic analysis (Braun & Clarke, 2019), this means the researcher made an interpretive judgement related to the goals and purpose of analysis and determined that the data collected from the participants was sufficient in providing a rich description of participants' experiences thereby meeting this study's objectives (Braun & Clarke, 2021).

Recruitment Strategies

There were two primary recruitment strategies employed in this study: social media, and snowball sampling. A public Facebook page was created outlining study details (Appendix G) and included a recruitment poster (Appendix H). The Facebook page link was shared on Facebook and within relevant Facebook groups. A recruitment poster was shared on Twitter.

Snowball sampling was used by identifying a number of experts in the field who acted as gatekeepers. Gatekeepers or "co-researchers" are a component of purposeful sampling and allowed for gaining access to families using the Family-Managed Home Care model who met the inclusion criteria (Thorne, 2016). These experts included physicians, nurse practitioners, nurses, and social workers. Educators in a level III NICU were contacted by the researcher and study information and a recruitment poster were shared, which was then distributed to all members of the NICU interdisciplinary team. Gatekeepers within the researcher's professional network who had access to the desired participant population were contacted and provided with study information to then share with eligible families.

Snowball sampling was also used with family participants. After an interview, the researcher requested that participants share study information among their networks. This included some family participants sharing the recruitment poster within specific tracheostomy-community Facebook groups.

Potential participants contacted the researcher via email or phone. Eligibility for the study was confirmed and then relevant study details shared (i.e., purpose, data collection, benefits/risks). After participants had provided email agreement to participate, a mutually convenient time to meet and interview over the phone or on Zoom was arranged. All participants were provided with a $25 gift card to either Tim Horton's or Shoppers Drug Mart in recognition of their time given to participate.

Data Collection

The principles of interpretive description methodology guided data collection (Thorne, 2016). Thorne (2016) recommends employing data collection methods that allow researchers to get as close to the subjective experience of the participants as possible; further, it is important that the researcher utilize combinations of appropriate data collection approaches in order to achieve a better understanding of the participants' experience, without relying on the limits of any one single approach (Teodoro et al., 2018). As such, primary data from participants was generated through the completion of interviews, ecomaps, and a demographic questionnaire, and researcher observations were documented in field notes.

Interviews

Data collection occurred primarily through in-depth, semi-structured interviews with participants. As data collection occurred in the midst of the COVID-19 pandemic, participants were given the choice to interview over the phone or via Zoom with their camera on or off. All parents chose to have the interview over Zoom and were interviewed individually; where both parents from one family participated, the option to interview together was given. A semi-structured interview guide was utilized (see Appendix B). The interview guide was informed by existing literature to ensure the various dimensions of family experiences were explored, while allowing parents to describe their own unique experiences (Ames et al., 2011). This approach is congruent with interpretive description methodology, because it aims to develop a comprehensive understanding of the studied phenomenon (Campbell et al., 2019; Thorne, 2016). Interviews lasted 60-120 minutes in length and were recorded via Zoom for transcription purposes.

Ecomaps

Ecomaps served as a second method of data collection. An ecomap is a graphic representation of personal and social relationships and their connections with larger social networks (Rempel et al., 2007; Ray & Street, 2004). Ecomaps are commonly used as a clinical tool to depict the structure and strength of family or social relationships (Ray & Street, 2004). Although ecomaps are not widely used in research (Rempel et al., 2007), they are a useful data collection strategy in studies exploring social networks by incorporating all the supportive relationships identified by carers (Ray & Street, 2004).

The purpose of using an ecomap in this study was to identify the family structure and identify the composition of their Family-Managed home care team. Ecomap instructions and an example (Appendix C) were emailed to participants prior to the interview. Participants were asked to complete their ecomap prior to the interview. Ecomaps were used during the interview to illicit information that helped the researcher count the number of nurses in the home, and to understand the nature of the relationships among family members and nurses. Participants emailed their ecomap to the researcher or held it up to their camera during the interview for the researcher to visualize. Ecomaps provided the researcher with an understanding of the "big picture" of who was in the household and who provided care. Ecomaps also allowed for triangulation of data types.

Demographic Questionnaire

A PDF-fillable demographic form was emailed to participants prior to interviewing to be completed before or after the interview and emailed back to the researcher. Information collected included ages of parent participants and their children, medical reason for a tracheostomy, the length of time the children required their tracheostomy, educational level of parents, length of time using Family-Managed Home Care, amount of nursing hours entitled to and received, and whether families used personal funds to supplement caregiving services. This information was collected to fill a gap in the literature, as there is little available demographic information about this specific pediatric population (Carnevale et al., 2006). Demographic data collected can be found in Appendix D. Demographic data was entered into IBM® SPSS® version 26 software and summarized to produce descriptive statistics to accompany the qualitative data analysis.

Field Notes

Field notes were used to capture observations made by the researcher during interviews and the context in which they occurred, including noting participant reactions and nonverbal language, as well as annotations of emerging themes (Dymtryshyn et al., 2015; Teodoro et al., 2018; Thorne, 2016). This acted as a reflective diary to capture changes in ideas or personal responses to ongoing research (Teodoro et al., 2018). After interviews, field notes were used by the researcher to reflect upon thoughts from the interview in the form of reflexive journaling. Consistent with the recommendation of Birks, Chapman & Francis (2008), memos were also used as a method of engaging in-depth with the data. Memoing allowed the researcher to clarify their thoughts and perceptions on the research topic, explore meaning extracted from the data, and functioned as part of the audit trail (Birks, Chapman & Francis, 2008).

Data Analysis

Data was analyzed using reflexive thematic analysis, as described by Braun and Clarke (2019). Reflexive thematic analysis is a theoretically flexible approach to analyzing qualitative data that focuses on identifying patterns of meaning in qualitative data (Braun & Clarke, 2019). Reflexive thematic analysis is an appropriate method of analysis to utilize when the research question is related to people's experiences, views, and perceptions. Therefore, it was a relevant method of analysis to apply to this study. Data analysis was approached in an inductive manner, characteristic of interpretive description studies (Thorne, Kirkham & O'Flynn-Magee, 2004), whereby the coding and theme development were directed by the content of the data.

Analysis in this study followed the six phases of reflexive thematic analysis: 1) familiarization with the data; 2) coding; 3) generating initial themes; 4) reviewing themes, by checking potential themes against the dataset to ensure they tell a convincing story of the data and one that answers the research question; 5) defining and renaming themes, by developing a detailed analysis of each theme; and 6) writing up the final product by weaving together an analytic narrative and contextualizing the analysis in relation to existing literature. Although these phases are sequential, analysis remains a recursive process (Clarke & Braun, 2019).

Step 1: Familiarization with Data

The first step in reflective thematic analysis involves being immersed in the data (Braun & Clarke, 2019). The researcher listened to all audio-recorded interviews at least three times, and transcribed verbatim 5 of the 9 interviews while the remaining interviews were transcribed by a professional transcriptionist. Fields notes accompanying each recording were reviewed along with the transcript to ensure data was interpreted within the appropriate context. Notes and transcripts were shared in consultation with the researcher's supervisor throughout the analytic process for coding purposes in subsequent analytic phases.

Step 2: Coding

Coding is a process in which concise labels (codes) are generated that identify important characteristics of the data; the entire dataset was coded to be used in later analysis phases (Braun & Clarke, 2019). Each transcript was read and coded line by line with shorthand notes, words, and comments, noting where there were similarities and differences between interviews. This method is congruent with Braun and Clarke's (2012) recommendations on how to begin initial coding. The researcher and another member of the research team individually coded four transcripts, then met to discuss and review those codes. A coding list and diagram was created that was used in future coding and theme development.

Step 3: Generating Initial Themes

Once broader patterns of meaning from coding are identified, initial themes can be generated (Braun & Clarke, 2019). During this phase, codes were organized into potential themes. The researcher met regularly with a single research team member (supervisor) or multiple team members as required, to discuss and receive feedback related to initial theme development. Several thematic maps were drawn to visually map out patterns in the data (Clarke, 2018). Important codes in the dataset were highlighted as potential themes to be reviewed and refined in later analytic phases.

Step 4: Reviewing Themes

In this phase of analysis, themes were reviewed by the researcher and other members of the research team to check generated themes against the dataset to determine that they accurately described the studied phenomenon and answered the research question (Braun & Clarke, 2019). The researcher reviewed each theme at two levels: (1) the coded data under each theme to ensure that coded extracts formed a clear pattern, and (2) to check that each theme worked in relation to the entire data set. The researcher also ensured there was enough meaningful data to support all themes. A finalized thematic map was created.

Step 5: Defining Themes

Themes were named and defined, and a detailed analysis or "story" of each theme was developed in preparation to write a final report (Braun & Clarke, 2019).

Step 6: Producing the Report

The last phase of analysis involved preparing a final report of this master's thesis with the guidance of the researcher's supervisor and the research team (committee) members. The finalized report detailed an analytic narrative that addressed the initial research question. Consistent with both Braun and Clarke (2019) and Thorne (2016), thematic analysis was related to relevant literature. Findings from this study were situated within disciplinary knowledge in order to clearly position the implications developed (Thorne, 2016).

Rigor and Trustworthiness

Thorne (2016) describes and summarizes a number of evaluation criteria that are recognized across the qualitative research spectrum. The criteria of representative credibility, epistemological integrity, analytic logic, and other strategies were used to promote rigor and trustworthiness of this study.

Representative Credibility

Thorne (2016) cites representative credibility as an important component of interpretive description methodology, in which the study's theoretical claims are consistent with the phenomenon's sampling and methodological decisions. The use of ecomaps as a method of data triangulation was one method used to promote representative credibility. This strategy is also in alignment with Lincoln and Guba's (1985) concept of credibility to increase the trustworthiness of research (Krefting, 1991; Thorne, 2016).

Epistemological Integrity

Epistemological integrity implies there is a plausible line of reasoning from the assumptions about the nature of the knowledge through to the methodological rules that guide decision-making about the research process (Thorne, 2016). Epistemological integrity was demonstrated by providing an explicit description of the research methods that are congruent with the choice of interpretive description methodology as the best method in answering the research question. Field notes as an audit trail further demonstrated the application of this criteria as well as acting as a strategy to promote credibility (Krefting, 1991; Thorne, 2016).

Analytic Logic

Audit trails are supported by Thorne (2016) as demonstrating analytic logic. Field notes and memos functioned as parts of the audit trail and served as evidence to support the application of an inductive reasoning process in the concurrent data collection and analysis (Thorne, 2016).

Other Strategies to Promote Rigor

Coding and thematic checking occurred between the primary researcher and research supervisor to assess for any overlooked themes in the data. Research team (committee) members were engaged in data analysis as required. Braun and Clarke (2019) do not encourage a research team member or supervisor "checking" the accuracy of someone's coding, as the assumptions underpinning this type of "check" do not align with their reflexive thematic analysis approach. However, conceptually checking coding between the primary, novice researcher, and their experienced research supervisor, is appropriate to ensure data was coded correctly (Braun & Clarke, 2019). In this manner, the supervisor was able to assist the novice researcher in developing skills in coding and theme development.

Reflexivity was demonstrated by journaling the researcher's thoughts, experiences, and perceptions of the data from interviews. This assisted in informing future interviews and coding, as data collection and analysis occur simultaneously (Thorne, 2016). Reflexive journaling also served to enhance this study's credibility by providing a record of how the study was designed (Janesick, 2015).

Finally, to further enhance trustworthiness of this study, Kallio et al.'s (2016) five-phases of developing a qualitative semi-structured interview guide was utilized when creating the interview guide for this study (Kallio et al., 2016).

Ethical Issues

Institutional ethics approval was granted from the Hamilton Integrated Research Ethics Board (Project #12764). One of the families that wanted to participate in the study had an employer-employee relationship with the primary researcher. To address any conflict of interest, another graduate student conducted the interview of this family. Parent participants from this family emailed a scanned copy of their consent form, demographic form, and ecomap directly to the researcher. The interview was conducted using a link that only permitted the primary researcher's access to the audio and visual recording once the interview was complete.

Informed Consent

Informed consent was as an ongoing process that was emphasized at multiple points in the study. Informed consent was obtained via email prior to setting up an interview; verbally at the beginning of an interview; and/or via a signed consent that was scanned and emailed to the researcher prior to the interview. Even if a signed consent form was received, verbal consent was still obtained at the start of every interview. Where a scanned copy of consent was not obtained, participants signed their consent form on camera before starting the interview. A record log of the date and time consent was obtained was maintained. Refer to Appendix A for a copy of the consent form.

Confidentiality

A variety of security measures were taken to ensure participant confidentiality. As this study was conducted during the COVID-19 pandemic, all physical documents such as consent forms, interview field notes, and coded transcripts were kept in a locked cabinet in the researcher's home office. Copies of these documents were also kept on a password-protected laptop and backed up onto a password-protected external hard drive. Demographic data in IBM SPSS® version 26 was password protected and participant data anonymized.

Interviews recorded on Zoom were saved to the Zoom cloud; this is password protected. Zoom generated a rough transcript of each audio-visual recorded interview. Interviews not transcribed by the student researcher were sent to a transcriptionist, who signed a confidentiality agreement before receiving any interview recordings or documents. Recordings were sent to the transcriptionist via SecureDocs, an online, secure e-courier service that abides by PHIPA legislation. Rough transcriptions generated by Zoom were emailed to the transcriptionist in password-protected Word documents; the password was provided to the transcriptionist over the phone. Anonymized transcripts were shared with the research supervisor using DropBox and MacDrive and were password protected.

Identifying data was removed from interviews in the transcription process by the student researcher and the transcriptionist. Anonymized transcripts were used for data analysis and quotes from interviews were used in the final study product. While the risk to participation in this study is low, the study participants belong to a technology-dependent (i.e. the "trach") family community that is small, and there is a risk that participants would be able to be identified in the report of the study findings. Permission was obtained from each participant at the start of the interview to use direct quotes in the final study report. Care was taken to ensure possible family identifiers were removed from the presentation of study findings.

Honorariums

Caring for technology-dependent child is time-consuming, and by participating in this study, parent participants may have taken time away from caregiving which may be burdensome. In recognition of their time, an honorarium of either a $25 Shoppers Drug Mart or Tim Horton's gift card was emailed to study participants. The gift card was emailed to participants after obtaining consent and prior to starting the interview, to mitigate any concerns of coercion in order to obtain an interview.

Distress Protocol

Many families who have had a child in the NICU experience some element of post-traumatic stress disorder (PTSD; Lefkowitz et al., 2010) and discussing previous hospitalization and/or home care events may be difficult and cause mental anguish. Participants were given options to take a break in the interview if a particularly distressing topic was being discussed. Participants were reminded they could choose to decline to answer questions they were uncomfortable with. The student researcher strived to create an emotionally and physically safe space for parents to share their experiences by ensuring the interview occurred at a time that was convenient for them. Close attention was paid to the participants' emotional state during interviews and the researcher ensured their own agenda and motivations did not overshadow those of the parents (Munford et al., 2008).

CHAPTER FOUR: STUDY FINDINGS

Chapter Overview

This chapter will provide a detailed account of the study findings arising from the parent interviews. First, the demographic characteristics of parent participants and their children will be presented, along with the major elements derived from the completion of the ecomaps from parent participants. Second, the organizing structure of this study's findings will be presented, and the findings described in-depth. Direct quotes from parent participants are included throughout to support the study findings and labeled by their study ID number followed by a letter. The letter *A* denotes a mother participant and *B* a father participant.

Demographic Characteristics of Participants

A total of nine parent participants consented and participated in the study. Of these nine participants, six were couples from three separate families; the other three participants were mothers whose partners did not participate in the study. Eight interviews were conducted, as two participants (married) preferred to interview together. Most parent participants were mothers (67%: n = 6) while one-third were fathers (33%: n = 3). Most parent participants (78%: n = 7) were between 30-39 years of age. Eight parents had completed college, university, or graduate level university education. Six of the parent participants were currently working (67%: n=6), three were not working (33%: n = 3); three of the working parent participants were mothers. All parent participants were from two-parent families. See Table 2 for details of the parent demographics.

Table 2

Demographic Characteristics of Parent Participants

Characteristics	**n (%)**
Sex (%)	
Female	6 (67%)
Male	3 (33%)
Age of Parents (years)	
20-29	2 (22%)
30-39	7 (78%)
Highest Education Level Attained	
High School	1 (11.1%)
College or University (Undergraduate) Degree	7 (77.8%)
Graduate Degree	1 (11.1%)
Working	
Yes	6 (67%)
No	3 (33%)

There was a total of six children receiving nursing care under the Family-Managed Home Care model among the parent participants. The children's gestational ages at birth ranged from 23-38 weeks (mean = 28; *SD* = 5.9) and their diagnoses were varied. Most children required a tracheostomy and mechanical ventilation due to bronchopulmonary dysplasia (BPD) as a result of premature birth or for both BPD and stenosis of the airway. Most of the children were singletons (66.7%: n=4), while the other children were one of a twin or one of a triplet.

Table 3

CMC-Technology Dependent Children Demographic Characteristics

Characteristics	n (%)
Gestational Age at Birth (weeks)	
23	1 (16.7%)
25	2 (33.3%)
27	1 (16.7%)
34	1 (16.7%)
38	1 (16.7%)
Reason for Tracheostomy	
BPD	3 (50%)
BPD + stenosis of airway	1 (16.7%)
Congenital syndrome	2 (33.4%)

Parent participants had used the Family-Managed Home Care model anywhere from 9 to 30 months (mean = 16.8; *SD* = 7.3) at the time of the interview. These parents were entitled to nursing hours varying between 50-70 hours per week (mean = 57.6; *SD* = 6.6) and utilized the maximum hours eligible to receive nursing care. Parents spent a range of 2-10 hours per month coordinating care services for their child, including nursing care under the Family-Managed Home Care model. Eight of nine parents used their personal financial funds on nursing services, and of these parents, one used their funds on both nursing services and supplies. The total amount of personal funds parent participants had spent since the beginning of their Family-Managed Home Care use ranged from as little as $90.00 to as much as $17 000.

Table 4

Family-Managed Home Care Utilization

Utilization	Mean	SD
Length of Time with Family-Managed Home Care (months)	16.8	7.36
Number of Approved Nursing Hours (per week)	57.6	6.62
Hours Coordinating Care	6.3	3.50
Personal Funds (CAD)	7320	8270.92

Analysis of data arising from the ecomaps indicated that parents had two main sources of support, family members and nurses hired under the Family-Managed Home Care model. Eight of the nine parent participants had at least two family members, usually grandparents, fully trained on all aspects of tracheostomies and ventilators to provide any necessary medical care to the child. Although one parent participant did not have fully trained family members, a set of grandparents was partially trained and able to provide support to the family in other ways, such as watching the child with parents present in the home and assisting with medical care.

All parent participants illustrated strong, positive relationships with all home care nurses identified on their ecomaps. During discussions of the ecomaps and nurse-family relationships in the study interviews, parents noted they did not include nurses with whom they had tense or stressful relationships on their ecomaps; only nurses they felt had a good relationship with the family were included. It was evident from triangulating the data from the ecomaps and interviews that the findings presented in this thesis predominantly reflect very positive, supportive relationships that parents described as experiencing with their nurses; this small purposeful sample of parents also described having extensive informal support from family members.

Introduction of Organizing Structure of Study Findings

Family-Managed Home Care is a unique model of home care whereby parents of CMC-technology dependent children take on a health care management role, essentially becoming the care managers of their child (see Figure 1 for a visual representation of the phases). The process of managing the child's care occurs in three interrelated and often overlapping phases: (1) transitioning home, (2) building the home care team and, (3) partnering to provide care. These phases contain distinct steps and strategies parents employ while using Family-Managed Home Care. Within each phase of the process of managing a child's care under the Family-Managed Home Care model there are several subthemes; these will be noted with subheadings under the relevant phase. Although *partnering to provide care* has been identified as its own phase in the process of managing the child's care, elements of this partnership are heavily embedded in the *building the homecare team* process. Thus, this phase is presented in the discussion of *building the homecare team* and does not have its own subheading in the sections that follow; it is instead discussed in detail in phase two of *building the home care team*.

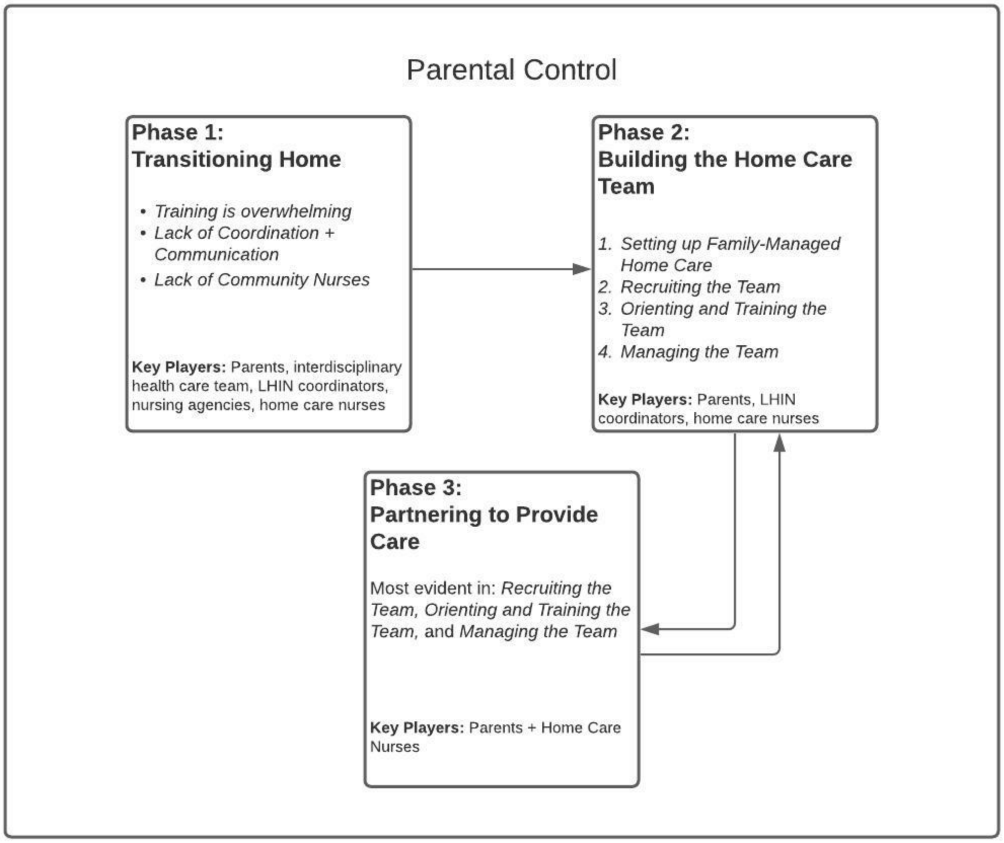
Within the Family-Managed Home Care model as a self-managed funding program, various supports provide a context to each of these phases that contribute to the success or difficulty parents of CMC-technology dependent children encounter when using the Family-Managed Home Care model; these are discussed in the section "The Context of Family-Managed Home Care" found later in this chapter. Finally, it was noted that *control* is a concept that is inextricably embedded within the overarching process, its phases, and the context of Family-

Managed Home Care Model. The concept of control is discussed where relevant in each section of this chapter.

Several outcomes of Family-Managed Home Care and parent recommendations were identified in the study. Family-Managed Home Care outcomes and parent recommendations are not included in Figure 1, as these were not identified phases of the overarching process of parents managing their child's care but will be discussed within the context of how they relate to the research question and objectives in the last section of this chapter.

Figure 1

Process of Managing a CMC-Technology Dependent Child's Care under the Family-Managed Home Care Model



The study findings, as they relate to the research questions and objectives are best described in a storytelling format, as the answers to the objectives overlap between phases. The overall narrative and its relationship to the research objectives are as follows:

(1) Managing the child's care is a process with interrelated and overlapping phases: *transitioning home, building the home care team,* and *partnering to provide care*. This addresses research objectives 1, 2, and 3.

(2) *Building the home care team* has four distinct steps and touches on aspects of objectives 3 and 4. *Partnering to provide care* is most apparent in three of these steps: *recruiting the team, orienting and training the team,* and *managing the team*.

(3) The *transitioning home* and *building the home care team* processes occur within the context of both formal and informal supports. The nature of these supports as acting as both a barrier and facilitator in utilizing Family-Managed Home Care relate to objective 3.

(4) The identification of "parental control" as a central organizing concept, that underpins each step in the process, refers to parent participants' desire to alleviate the stress, anxiety, and uncertainty of having a CMC-technology dependent child and home care nursing. Having control over their child's care, which Family-Managed Home Care gives parents, is one such rationale for parents' preference in using this model of home care (objective 2), and also describes some of the experiences families have in partnering with nurses (objective 4).

The Family-Managed Home Care outcomes identified in the data analysis related most to the overall experience of parent participants becoming their child's primary caregiver and care coordinator under the Family-Managed Home Care model; it includes subthemes such as the *altered meaning of parenthood*.

Finally, recommendations arose during study interviews where many parents provided the researchers with ideas and suggestions to improve the support systems within Family-Managed Home Care. These recommendations come from the overall parent participant experience with Family-Managed Home Care and partnering with nurses under this model.

Phase 1: Transitioning Home

The Training Process is Overwhelming

Within any NICU stay, there comes a turning point when the hospital care team communicates to the family that it is time to develop and begin to implement a discharge plan for the infant from the NICU to either another level of care or to their home in the community setting. Parents of CMC-technology dependent children require extensive support, information, and opportunities to learn new technical knowledge to prepare them for safely caring for their child at home. This process begins after the child receives their tracheostomy surgery. This training process is described by some parents as "overwhelming" and elicits high emotions such as anxiety. One mother described experiencing a dichotomy of emotions between feeling thankful and supported by the medical team in training to care for their child, to feeling angry that this was part of what she had to do to be a parent. Another mother expressed that the training affected her ability to parent her child at the beside; nurses were her child's primary caregivers, and she felt torn between trying to be present at the bedside in hospital to be a parent and having to leave multiple times during the week to complete training classes. As one mother explained:

> Taking that course at the beginning was extremely overwhelming because…obviously you're not their primary caregiver, they're in the NICU, they have nurses, but you're trying to be there for your child, spend time with them and care for them and just be a

> parent to them, but then you have to sneak away, go [to] these classrooms a couple times a week to do training… - 03A

Furthermore, the discharge teaching and learning had many parents struggling to feel like they had control of their child's care as a primary caregiver due to having to learn technical skills as a mandatory element of going home. However, most parent participants described the training process as necessary to take their child home, and that they would do whatever it took to do so.

Lack of Coordination and Communication

As parents are moving through their skills training, discharge planning is occurring simultaneously. Discharge coordination for a family with a CMC-technology dependent child is a complex process involving a number of health care professionals from different disciplines and departments in a hospital, such as nurses, respiratory therapists, occupational therapists, and physicians. The hospital team members are responsible for communicating with the hospital Local Health Integration Network (LHIN) coordinators, who then liaise with LHIN coordinators and community agencies. A key component of discharge is ensuring there is a sufficient number of qualified nurses in each family's home community to support them in providing care on night shifts once families are ready to be discharged. Disjointed care coordination and communication within this stage of the discharge process affected almost all of the parent participants' discharges and decisions in how they would receive home care nursing.

Many parent participants felt that there was a lack of communication between the interdisciplinary team members themselves, and between interdisciplinary team members and parents. Two parents noted that a lack of communication between interdisciplinary team members resulted in key pieces of discharge information being missed that ultimately resulted in a discharge delay for both families.

Parents also expressed there was a lack of efficient care coordination and organization of nursing services between the hospital and community which was compounded by the lack of communication. One family (parents 06A and 06B) described extensive advocacy efforts of the father to ensure a timely discharge with adequate nursing coverage at home. Eventually, this family switched to Family-Managed Home Care, however, prior to the decision to use Family-Managed Home Care both parents described a lot of back-and-forth communication between the hospital LHIN coordinator, community LHIN coordinator, agencies, and their hospital team, with parents given unclear answers on where they were in the discharge process. The family was told there were complications obtaining nurses in the community and stated that *"getting the answers and the updates was very challenging."* The father began calling nursing agencies in their community and surrounding area themselves, in an attempt to find nursing coverage. During this, the family learned that agencies could subcontract to other agencies to meet a client's needs. Once the family found there were agencies able to meet their care needs through the use of subcontracts, they coordinated a meeting with the discharge team and LHIN coordinators to resolve the situation. The following quote outlines the process participant 06B undertook in order to obtain home care nursing and, thus, securing a discharge date. As this father describes, there are political and policy-based factors that impact timely discharges, compounded by a difficulty in securing home care nurses.

> At that time I started calling…oh, I went higher up in the LHIN, as far as I could get...talking about our frustrations. I went and called a number of nursing agencies and met with them myself. And there's one in [city name] that could help us and then, so I took it back to a meeting. We had a big meeting at [hospital name] with his doctors, nurses, the LHIN, [agency name], complex care – it was a big room. And I just kind of threw it on the table and said, "Look, there's people that are able to do it. It's your contracts and your organization that's causing the struggles here. To me, I really don't care how you do it, as long as you get it done, and there's people that are able to do it."

> So, we kind of forced their hand and they did force [agency name] to use this nursing agency under a subcontractor agreement. And that did eventually get us home. – 06B

Another family (parents 01A and 01B) had a similar experience, where their discharge was consistently delayed due to a lack of trained nurses in their community. The father in this family also demonstrated advocacy behaviours by calling local agencies in an attempt to get answers and updates as to when they could be discharged and how nurse recruitment was happening. The family was able to use Family-Managed Home Care directly from discharge, however, they realized it would take one month before the paperwork would be completed and nurses hired. To avoid another month in hospital, they ultimately went home using a combination of agency nursing and privately hired nurses, covered by their insurance, to address their first month of nursing shifts at home. After one month, they were able to implement Family-Managed Home Care and the nurses they hired privately began working under the Family-Managed Home Care model.

Lack of Community Nurses

The subtheme of a lack of community nurses was prominent throughout the data, making it difficult for members of the interdisciplinary discharge team to coordinate community nursing services for families with CMC-technology dependent children. All parents in this study, at one point or another, experienced difficulty in receiving home care nursing or experienced delayed discharges from lack of community nurses prior to using Family-Managed Home Care. Home care nurses caring for CMC-technology dependent children are required to have adequate training about tracheostomies and the use of ventilators before being sent into homes. Nursing agencies servicing these families through the LHIN are obligated to have a certain number of nurses trained in order for families to be discharged home. However, with staffing difficulties, this often meant families' discharges were delayed.

The training program home care nurses can take to learn how to care for CMC-technology dependent children who live in the region of the families in this study is offered by a large children's hospital in southwestern Ontario. The timing of course offerings was another factor affecting the ability of nurses to be trained as hospital training sessions were only offered once per month, limiting the opportunities for nurses to be trained in a timely manner. As a result of this combination of a lack of community nurses and the extended period of time needed to train more, two parent participants advocated for Family-Managed Home Care to be put in place prior to their discharge. The other seven parents chose to use Family-Managed Home Care after being at home and receiving nursing care through nurse agencies contracted by their LHIN.

The seven parent participants who initially used agency nursing coordinated by the LHIN experienced challenges related to a lack of nurses in their community. Parents recounted times where they did not have nursing care at all for night shifts, and so they relied on each other and their trained support persons in covering missing nursing shifts. These same parents also outlined difficulties in working with agency nurses in their home who had not received adequate tracheostomy and ventilator training. One father (04B) expressed this as feeling like the agency *"didn't have enough nurses so they just threw bodies wherever they could."* Overall, he felt that the agency did not care about the quality of care that was provided to their child, only that the shift was covered. In some instances, shifts covered by inexperienced nurses resulted in unsafe situations for the child, and parents would ask not to have that nurse return to the home. In some cases, it was not possible to have a nurse whose parents felt to be unsafe removed from their care team, because it meant the family would subsequently be left with uncovered shifts that nurse was already booked to cover. Parents in this scenario were left with the option of having no nursing coverage for a night shift (i.e., they would have to cover the shift themselves) or have a nurse in the home they were uncomfortable with.

A lack of trained nurses resulted in inconsistencies in nursing care; one mother stated that in the 2.5 years they used nursing agencies, they had over 40 different nurses cycle through their home. Parent participants explained they preferred having consistent nurses in the home, as it was beneficial for both them and their child. Having the same nurses consistently care for a particular child meant parents did not have to recount their child's medical history, describe nightly care needs and routines, and orient new nurses to the home. Consistency in nursing care alleviates this time-consuming task for parents.

Overall, a combination of lack of available nurses and consistent nursing providers were the two main factors that primarily influenced families to adopt the use of the Family-Managed Home Care model. The timing of the parents' decisions to use Family-Managed Home Care highly varied across this sample. For example, some parents used Family-Managed Home Care immediately or within several months of being at home, whereas others had been home for 2-3 years before initiating use of Family-Managed Home Care. Using Family-Managed Home Care allowed parents control over who was coming into the home, the care coordination and the continuity of care, as well as control over *building the team.* This theme will be further explored in the next section of this chapter.

Phase 2: Building the Home Care Team

Within the overarching process of managing the child's care, the second phase of the process following transition home is *building the home care team*. This phase consists of four steps, again, which while presented in a linear fashion, may actually occur within an iterative loop. The four steps include *(1) setting up Family-Managed Home Care, (2) recruiting the team,* *(3) training the team,* and *(4) managing the team.* It is important to note that *setting up Family-Managed Home Care* and *recruiting the team* do overlap, but that *recruitment* is a distinct process in itself.

Setting Up Family-Managed Home Care

Before beginning the *"setting up"* step of Family-Managed Home Care, parent participants recognized their need for a better home care model to deliver home care services and had to learn about Family-Managed Home Care. As discussed in the previous section, the two reasons why parents shifted from agency nursing to nursing under Family-Managed Home Care were because of a lack of trained nurses and inconsistencies in nursing care. Families were introduced to Family-Managed Home Care through several sources including LHIN coordinators, hospital clinicians, and other families; these were the most common ways parents learned about this program. Once parents learned about Family-Managed Home Care, then the *"setting up"* process was initiated between parents and their LHIN coordinator. It was noted that parents were able to initiate Family-Managed Home Care before or after discharge from hospital.

Setting up Family-Managed Home Care requires parents to review educational paperwork and complete contract templates for use between the family and their LHIN, as well as the family and their hired nurses. This phase also involves how families manage their scheduling, payroll, and documentation. There are slight variations between families in how they manage these tasks, however, most follow similar formats. For example, most families use shared Google calendars to schedule nurses, and provide calendar access to their nursing team.

Using Family-Managed Home Care, parents are able to control how their nursing care is delivered and scheduled based on the unique needs of their child and family. This control is highly valued by all parent participants, as it provides them with predictability and direct communication with their nurses. As one mother explained:

> …having that control of who, when, what and where – when it comes to my child and their medical needs – has given me such a huge piece of mind that I'm not waiting to hear back from an agency… whether hours get filled up or not is up to me now and not someone else, and I couldn't stand that. – 05A

During theme development and data analysis, it was obvious that *parental control* was a concept embedded not only in the overarching process of managing the child's care, but also within each phase of this process. The foundation of parents' decision to use Family-Managed Home Care was also grounded in their desire for control over their family life, care for their child, and the desire to avoid unpredictability.

Recruiting the Team

The purpose of the *recruitment* step of *building the home care team* phase is to ensure families have enough nurses to meet their nursing shift needs and provide continuity of nursing care. Parent participants' goals in hiring home care nurses was to create their own primary home care team, with the same rotation of nurses providing care as well as being the right "fit" for the family. *Control* over home care team recruitment meant parents could have continuity of nursing care from nurses that they hired themselves, thereby increasing their trust and comfort with their nurses.

The *recruitment* process first involved finding nurses to hire under the Family-Managed Home Care model. Sources of recruitment occurred mostly through social media ads, where parents would post to Instagram or Facebook, which would be shared throughout their networks and interested nurses would contact the family. Word of mouth and personal recommendations of nurses from friends and family was another common source of recruitment. The families who had previously used agency nursing hired some of the nurses they trusted to work for them under

Family-Managed Home Care. Only one family (04A and 04B) also used job websites to post their nursing ads, as well as using personal recommendations and nurses from the agency to create their Family-Managed Home Care team. NICU staff also posted parents' ads in common unit spaces as part of parents' recruitment strategies.

The LHIN did not provide parents with interview guides to use when hiring their Family-Managed Home Care nurses. Parents created their own list of interview questions by relying on the advice from other families within the "trach community" as resources. One parent described asking members of the NICU health care team about questions to ask and, on their advice, the parent used the College of Nurses of Ontario's "Find a Nurse" feature as part of their background checks of all potential nurse hires.

As part of the recruitment process, families found it helpful to have potential nurse hires meet their child in the hospital prior to discharge or in the home during the recruitment interview. One parent also did a walk-through of their home with their nurses prior to the child's discharge.

Parents sought out nurses that were the right "fit" for their home, and all parent participants shared common ideas of what nurse characteristics were ideal. Interestingly, while parents did prefer nurses with previous tracheostomy, ventilator, and pediatric experience, many of the nurses working under the Family-Managed Home Care model came from diverse nursing backgrounds, including adult medical/surgical areas, emergency rooms, and NICU. Parents preferred nurses that were dependable, flexible, willing to learn and prepared to collaborate with parents to provide care. One family described turning away tracheostomy and ventilator-trained nurses because the nurses did not seem willing to collaborate with parents on how to deliver care, nor willing to receive constructive feedback. Another parent described a preference for hiring new graduate nurses because the nurses were eager to learn and more willing to collaborate with parents.

A nurses' willingness and ability to collaborate with parents in providing care in a partnership model was highly valued by parent participants. Parents desired to partner with nurses to provide care, or as one parent described it, working to *"create more of a dialogue than a dictatorship"* (Parent 05A). Although all parents desire *control* in their use of Family-Managed Home Care, parent participants were very clear in their interviews that when speaking about *control*, they did not mean they wanted the kind of control that comes with being in a position of power; however, they are by very nature in a power position as "care managers" under Family-Managed Home Care. Parent participants rarely described instances in which they took on a "dictatorship" role when working with their home care nurses. Rather, all parents extensively described maintaining and fostering open communication between them and their home care nursing team, allowing their nurses to be vulnerable and ask questions if they were unsure how to handle any given scenario. This appeared to promote a positive working partnership between parents and nurses as well as fostering a relationship of trust and comfort from the parents' perspective. Yet, even within the nurse-parent partnership, parents still seemed to preserve an element of control. When speaking about open communication, many parents provided the example of wanting to be woken up for "anything" (e.g., troubleshooting equipment, an event outside their child's normal day/night baseline status) and when nurses complied with this request, parents' abilities to trust the nurse increased. One father (04B) described himself and his wife as the primary caregivers for their CMC-technology dependent child, and in the case of an emergency, *"they're* [the nurses] *supposed to wake us up and we're supposed to fix it."* One mother (01A) described facilitating this trust and open communication by making nurses comfortable with communicating to parents in a way that "*there's no stress for either side, making it completely normal and comfortable to come knock on our door for the smallest things just because we'd rather be there than not.*" Even when parents partnered with nurses to provide care, they still maintained some level of control in the child's care.

Parents also viewed nurses demonstrating genuine caring for their child as a positive attribute, where nurses would engage with the child in a developmentally appropriate way that was meaningful to the child and family, and where nurses viewed the child as a person as compared to just seeing them as a patient. The following quote from one father describes how he could distinguish nurses that demonstrated genuine caring:

> …like if there was a care for him, like you could actually see they were invested in his overall well being, like, they had a care that he did well, rather than just, 'Tick all the boxes and get out at the exact time.' That meant a lot to us, too, if we could see that they actually wanted to see him do well. – 06B

Parents noted that how nurses gave report at the end of their shift was indicative of how good the "fit" of the nurse was for the family. Nurses who took their time providing a detailed handover and trying to engage with parents socially before and after the shift were valued by parents compared to nurses who would rush out the door with a brief report. One mother appreciated that her home care nurses would relay details of their shift like a story and include anecdotes about the child, *"…the taking your time doing report, the thoroughness of the things that they tell me, like they're telling me a story and as a parent, that's exactly what I need."* (05A). This made the mother feel included in the child's care, even though she was sleeping throughout the nurse's shift.

Orienting and Training the Team

Orienting and training the home care nursing team involves orientating nurses to the child's care needs and routines, ensuring they have the knowledge, skills and abilities to care for a CMC-technology dependent child, and establishing care responsibilities. Parents value the control they have in training their home care nurses under Family-Managed Home Care. Under agency nursing, parents are not responsible or aware of the training nurses undergo before entering their home. This created anxiety for some parent participants, especially as many had negative agency nursing experiences. Parents described occasions in which the nurses sent to their home from an agency had very little to no tracheostomy training and perceived the quality of care to be poor in some instances. One parent (02A) explained her frustration with a nurse who met the child's medical needs, but otherwise did not engage much with the child in a developmentally appropriate manner. Several other parents described instances where they would find nurses sleeping during their shift between care times. Although not all the experiences with nurses that families encountered through the agency were negative, once parent participants began using Family-Managed Home Care, their perception of quality of care increased as parents were responsible for the nurses' training and setting expectations with their home care nursing team. Family-Managed Home Care allows parents to control and customize the nurses' training and skill to their child's needs and care expectations.

Most nurses hired under Family-Managed Home Care attend a formal two-day course, one day in each tracheostomy and ventilator training at a tertiary children's hospital in southwestern Ontario. Some parents trained their home care nursing team themselves using their educational resources from their hospital training as guidance. One parent felt that training at home with the assistance of a community respiratory therapist increased the nurses' confidence and competence, as they were practicing their skills on an actual child.

Defining the roles and responsibilities of the nurses is another facet of *orienting and training the team,* with some variations between how families delegate tasks to their nurses.

Under Family-Managed Home Care, parents are responsible for outlining the care responsibilities for their home care nurses. All parents expected their nurses to provide basic care, such as tracheostomy suctioning, gastrostomy tube care and feedings, administering medication, and attending to their child's toileting needs. Parents expected nurses to be able to provide basic equipment troubleshooting and recognize when an alarm required parental attention. All but one parent had their home care nurses also be responsible for reconstituting or drawing up medications and cleaning or sterilizing dishes and syringes.

One noticeable difference in care responsibilities between each parent participants' home care nursing team was whether or not a nurse is trained to do regular tracheostomy changes. While nurses are trained for this skill at the formal training course, some families did not expect nurses to do regular tracheotomy changes. If nurses were present only for night shifts, they were not expected to provide care to the trach beyond routine suctioning, unless an emergency arose – in which case all parents requested their nurses to wake them up in such a scenario so that parents could help. However, families who had nurses routinely cover day shifts expected those nurses to be competent in providing full tracheostomy care, including regular and emergent tracheostomy changes.

Managing the Team

Managing the Team is a step in the process of *building the home care* team that encompasses the day-to-day maintenance of Family-Managed Home Care including ongoing payroll paperwork, managing sick calls and vacation, and ongoing training. It also involves redefining the nurse roles and responsibilities as the child grows, and the development of a "professional friendship" between nurses and families. In this step, parents also learn to adjust to the presence of nurses in the home.

Almost all parent participants had a bookkeeper, who was responsible for all aspects of payroll; a father of one family who did not have a bookkeeper managed the payroll himself, as he had a background in finance.

All parents had similar methods of covering sick calls. First, parents contact other members of their home care team to see if the shift can be covered. If this first method is unsuccessful, parents rely on themselves and their trained support persons to cover the shift.

Additionally, several families described providing ongoing training and “skills refreshers” where required. One mother explained that she kept a skills checklist of the nursing competencies she expected her team to perform, and every six months required them to complete it in order to identify learning opportunities to refresh their skills.

Managing the home care nursing team means parents have complete and total *control* over communication with their home care nurses. The ability to have direct communication with nurses was beneficial for parents as it removed the anxiety and stress of securing coverage for the nursing shift in time. In comparing the two models of care, one mother described the stress and uncertainty experienced in trying to secure nursing care and the control they attained in transitioning to Family-Managed Home Care:

> I remember clearly a Thursday afternoon and it's four o'clock, and you have no idea if a nurse is coming in and who it is, if they're trained or not or, and... are we gonna have to stay up? Do I need to try and get somebody, like a mom over so that I can nap for a few hours? That’s the worst! You need sleep when you have three babies and this one that's very dependent. So, having a full Google calendar schedule being, like, “These are my nurses, I can text them.” They can text me if there's something up, or if they're going to be a little bit later, whatever, instead of [me] sitting there like, ‘who's coming in, when and if?’ – 06A

All parent participants had communication plans worked out with their nurses to manage coverage of sick calls or last-minute schedule changes. Most parents would send out an email or text to all their nurses, and one parent described how their home care nursing team would communicate with each other via text first for last minute schedule changes. All parents described having little to no difficulty covering sick calls or last-minute schedule changes under Family-Managed Home Care, and in the rare instances where nurses were not able to cover a shift, parents again relied on their support systems – trained family members – to share the night shift.

The roles and responsibilities of the nurses change as children age and their medical needs change. Accordingly, parents then need to redefine the roles and responsibilities of the nurse. Particularly when nurses cover day shifts, parents expect them to not only meet the child's medical needs, but also their developmental needs; they expect there to be some interaction and play occurring that is appropriate for the child's age and developmental stage. For example, one mother requires their nurse to do basic cooking, as their child now eats orally, and also assist in toilet training. In this manner, the mother is negotiating parenting roles of the nurse. This mother described her "informal" approach to this type of negotiating, as she does not want the nurses to act fully as a parent but does expect them to keep their child safe and collaborate with parents to discuss strategies of how to manage the child's behaviour and developmental needs. In this manner, the mother is still in *control* of the child's care as a care manager and as a parent.

The qualities parents look for when finding the right "fit" of nurse in the *recruiting the home care team* phase contribute to the development and maintenance of the professional friendship. It was clear during parent participants interviews that parents had a strong professional friendship with their Family-Managed Home Care nursing team that was grounded in a deep sense of trust and comfort.

Comfort and trust were often used interchangeably when parents described the nurse-family relationship. For example, parents who were comfortable with nurses also trusted them; if they noticed the child was comfortable with the nurse, parents trusted the nurse. Parents also valued the competency of the nurse and their ability to alert parents to anything going wrong or if they had any questions. It was interesting to note that while mothers and fathers described trusting their home care nurses, all three father participants described trusting some nurses more than others, even among their own home care team under Family-Managed Home Care. The ability for parents to have *control* over hiring and training nurses also contributed to the development of trust in the professional friendship.

Adjusting to nursing presence in the home, or being comfortable with nurses in the home, was easier for some parents to adjust to than others. For some parents, having nurses in the home was never a cause for disturbance. For others, it took some time to adjust to having a routine nursing presence, as the presence of nurses impacted the privacy of the family's home. One parent (02A) described that having nurses in the home resulted in a loss of privacy, even if the family had good relationships with the nurses. Another parent (04B) described feeling neutral – they did not dislike having nurses present but would prefer them not to be there. This father further described it as not feeling "natural;" it is as if the presence of nurses was a constant reminder that their child had medical complexities and was not like other children. Some parents had no issues adjusting to the constant presence of nurses, others felt unease initially then became more comfortable over time as relationships developed. Even if parents described the presence of nursing in the home in a negative manner, they acknowledged that their presence was necessary to preserve family functioning and the safety of their child. The following quotes highlight the varying parent perspectives on having nurses in their home:

> …to be honest, you lose your home a little bit, and even if you do build good relations with them, you know, you still have someone coming in your home almost every day, every night. And I… appreciate them in the home, so it's just a lot of upkeep, you know, if there's one night where I don't want to do the dishes it just… sometimes you don't

> want to do them, but when you have someone constantly entering the home, it felt like, especially in the beginning when it was always night shifts just always constant…. I don't know, you're just never really… at your own comfortable state of being in your home alone. – 02A
>
> A lot of people say oh my gosh, you have strangers in your house every night and I'm like, no, I'm so comfortable with them being here. I sleep very well at night. [My husband] and I do not lose sleep. We sleep great because we're so comfortable with them. I would rather have them here than not. – 03A

One parent described the presence of nurses in the home as a form of loss of control.

> I wouldn't say it's a loss of privacy…our Family-Managed Home Care nurses are… we're so close with them. They're friends right, so not friends but they're very close with our family so I don't feel like a loss of privacy…I think it's just the lack of… we don't control his schedule, their schedule controls his schedule. I get up when the nurse leaves…it does bother me some mornings when he wakes up with the nurse. Like I prefer him to wake up with one of us…I sleep because they're here and I follow their schedule. – 04B

Parents expressed that working day shifts for nurses created a context that contributed to building trust and comfort in their relationship with them and the relationship between the nurse and the child.

The Context of Family-Managed Home Care

It is important to note that the context in which Family-Managed Home Care occurs includes the nature and type of supports for families with CMC-technology dependent children. Supports can be formal or informal and come from a variety of sources. These supports can act as both barriers and facilitators in using Family-Managed Home Care, particularly in the *transitioning home* and *building a home care team* phases. The following sections will further discuss the sources of formal and informal supports identified by parents in the study, and how they benefit and challenge parents using Family-Managed Home Care.

Formal Supports

Formal supports come from health, social care, and community-based agencies and services (Hupcey & Morse, 1995). For families with CMC-technology dependent children using Family-Managed Home Care, formal supports came from hospital clinicians, nurses, LHIN coordinators, and employers. Financial support is another source of formal support and was available to all parent participants.

Hospital clinicians

Parents credit nurses and physicians in the hospital for informing them of the Family-Managed Home Care and these clinicians were important sources of support when parent participants using Family-Managed Home Care at discharge were in the *recruiting the team* step of *building the home care team.* The training provided to parents in the discharge process is led by a team of respiratory therapists, and all parent participants felt adequately prepared and supported in providing technology-related care to their child outside of the hospital.

Formal supports from hospital clinicians were limited when it came to sharing information about Family-Managed Home Care. Although some nurses and physicians had knowledge of the Family-Managed Home Care model, often they could not provide parents with more information pertaining to this model of care other than stating it existed as an option to access home care nursing services. Delays in communication and updates regarding discharge coordination status, as discussed in the *transitioning home* section of this chapter, contributed to this barrier to using Family-Managed Home Care.

LHIN coordinators

LHIN coordinators, both in hospital and the community, were viewed as unsupportive by eight of the nine parent participants. However, one mother did have a positive experience with their community LHIN coordinator, who offered the option of Family-Managed Home Care when there was conflict between the family and their home care nursing agency under the LHIN contract. Otherwise, limited support from LHIN coordinators was experienced by all other parent participants, particularly when it came to timely communication and informational needs. Most parents stated that they were unaware that Family-Managed Home Care was an option to receive home care nursing services and felt that both agency care via the LHIN and Family-Managed Home Care should be presented during discharge discussions; one parent felt this information should be the LHIN's responsibility to present to families, as they are still overseeing management of the Family-Managed Home Care model.

Parents expressed difficulty in connecting with the hospital's LHIN coordinator for information regarding home care nursing options, including Family-Managed Home Care. Furthermore, several parent participants faced discouraging attitudes from their LHIN coordinators when they expressed interest in using Family-Managed Home Care. One mother described feeling as if her LHIN coordinator presented a biased opinion towards using the traditional agency model of home care and did not feel all her home care options were fairly presented:

> …she [LHIN coordinator] was trying to talk me out of this and to just go with the agency and not even really presenting it to me as an option, but I feel like that's your job. Your job is to help me get my child home and tell me about these options and she didn't want to. – 03A

Some parent participants explained that once they were given approval to use Family-Managed Home Care, the LHIN provided them with set-up information and paperwork but otherwise did not reach out or provide any further follow-up. Once families begin using the Family-Managed Home Care model, they are responsible for all aspects of managing a home care nursing team, including hiring, training nurses, and creating their own documentation system. Families indicated a need for information on what kind of information nurses should document, as well as being informed on nursing competencies and qualifications to look for during the hiring process. Overall, parents did not feel that the LHIN provided sufficient information to support them in setting up Family-Managed Home Care. As well, in conducting interviews with parent participants it was noted that some parents were given more or less informational support than others from the LHIN. Parents expressed wanting to know what to chart, how to track documentation, and best practice guidelines or competencies to guide them and their hired home care nurses. A lack of information from the LHIN led parents using the Family-Managed Home Care to feel like their family's best interest was not a priority. One father expressed frustration that there was not further direction provided once families were approved to use Family-Managed Home Care:

> My point is the LHIN doesn't care what happens after that nurse…after they give us the $10,000. Actually. They don't care if I hire nurses, they don't care if I have any nurses, they don't care what our nurse does in our house. There was no direction and that's my problem. 'Okay, that's great, you want to hire your own nurses? Our best practices are this binder. And here's a training module that any nurse gets through an agency.' Why can't that module be given to us to train our own nurses through best practices to take care of your child? And it seems so simple but never obviously happened. – 01B

Parents felt that when they advocated for their family and their child's need for a change in nursing services and their use of Family-Managed Home Care, the response from LHIN coordinators was interpreted as not caring about them or their child's needs. Another father described:

> It seemed like they didn't want us to do it. It didn't seem like they cared about us…. Dealing with the LHIN has almost been as bad as dealing with the agency, and it's super frustrating that there's an organization that their entire purpose is to advocate for proper healthcare for families, but they don't. They have a book of rules in front of them and if the rule's not there, they're not gonna help you with anything. – 04B

Financial Support

Financial support appeared to be a key form of formal support for parents. All parent participants had some form of private insurance that enabled them to pay for extra nursing shifts for respite care, pay for nurses' training, and to cover the cost of supplies. One mother stated that without their private insurance, the family would be paying $2000 out of pocket bi-weekly for their child's supplies. For another family (parents 04A and 04B), private insurance served as a support and facilitated their Family-Managed Home Care success by providing them the financial flexibility to cover training costs (e.g., attending tracheostomy and ventilator courses) associated with hiring new nurses, and supplement the extra cost of necessary supplies.

Employers

Two parents discussed the positive effects of a flexible employer on them as an employee and a parent. One father (01B) described his employer as providing him with flexibility to attend hospital training sessions for discharge, and work from home if a night nursing shift was uncovered and he and his wife had to stay awake throughout the night to care for their child. One mother (02A) also described the flexible working hours her employer provided for her, allowing both her and her husband to work while she managed all aspects of the Family-Managed Home Care model.

Informal Supports

Social supports, such as family and friends, are informal types of support and can have a positive influence on a person's quality of life and adjustments to stressful life events (Hupcey & Morse, 1995). Family and friends as informal social supports also promoted success in parents managing the Family-Managed Home Care model. Informal social support sources identified in this study that will be discussed in the following sections included family, friends, and a distinct social group comprised of the “trach community.”

Family

The most common kind of support provided by family members to parent participants was direct caregiving, as many had fully trained or partially trained family members (usually a grandparent). These family members were able to provide respite care for parents and assist parents in covering sick calls from home care nurses. One mother (03A) explained that her in-laws were fully (grandpa) and partially (grandma) trained in providing tracheostomy and ventilator care, and provided support five days of the week, every week. Another family (04A and 04B) had six fully trained family members (i.e., two sets of fully trained grandparents, a sister and brother-in-law) to provide care. These trained family members were available to provide all aspects of care as needed.

While family was ultimately a facilitating source of informal support, one mother (05A) described some difficulty in having the child’s grandparents trained to provide necessary care. The grandparents were part of the hospital discharge training with both parents, however, over time the parents felt that the grandparents were struggling with the emotional and physical demands of the care requirements. To mitigate this, the mother described how their family adapted to working with whatever kind of support the grandparents were able to provide, such as watching the child while the mother had a shower or was cooking, playing with the child, or indicating to the mother or father (who provide direct care) that the child required care attention.

Friends

One father (04B) described time with friends as an important aspect of their support system. A mother study participant (01A) described instrumental support provided by friends prior to the COVID-19 pandemic, where her friends would often drop off groceries or meals.

The "Trach Community"

The "trach community" was cited by all families as a source of beneficial support. This community is comprised of other "trach parents" who communicate with each other through a private Facebook group called "Trach Parents Canada." This "trach community" was a key source of social networking and informational support for parent participants. When parents found they were not receiving sufficient support or information from formal support sources, they described relying on the knowledge of the trach community for information about Family-Managed Home Care, other families' experiences with Family-Managed Home Care, and advice on how to set up their home care documentation and training for nurses. Parent participants noted that examples of charting and safety checklists are commonly shared among the trach community, and on occasion parents have shared members of their home care nursing team with other families who needed a qualified nurse.

Family-Managed Home Care Outcomes

The following section describes the outcomes for parents associated with receiving Family-Managed Home Care. The primary outcome was *altered meaning of parenthood.* This outcome was recognized as being separate from the overarching process of managing the child's care and the distinct phases of this process, as *altered meaning of parenthood* was a direct result of parent participants' experiences of being the parent and care manager of a CMC-technology dependent child.

Altered Meaning of Parenthood

Being the parent of a CMC-technology dependent child and using Family-Managed Home Care had significant impacts on how parents viewed themselves in their parenting role. The term *altered meaning of parenthood* is used throughout the literature in reference to this change in how parents view themselves.

The training parents underwent prior to hospital discharge altered the meaning of parenthood for some participants, and there was a variety of experiences outlined by parents in regard to this. Learning how to provide care for a child that is technology-dependent changed how families parented because of their child's tracheostomy and subsequent high care needs, as parents did not automatically know how to "parent" a child with high medical needs, and they required assistance and support from health care professionals. One mother (04A) described feeling neutral about the training process because they had a prenatal diagnosis where they knew the child would spend time in the NICU and possibly require a tracheostomy and ventilator; this mother also had a tracheostomy as a child and was familiar with the trach care and training already. During interviews, mothers were generally more open about the varying emotions they experienced during training whereas the father participants described that the training to go home was *"just something they had to do as parents."*

In interviews, parents would distinguish between "normal baby care" and the "medical care" when answering questions about the type of care they provide to their child. This was interesting to note as some parents also discussed how they would normalize the tracheostomy and ventilator care as part of their daily life. Some families with older CMC-technology children would begin to involve the child in the care of their tracheostomy to foster independence in caring for themselves. One mother (05A) expressed that it was at times difficult to normalize their child and they would “forget to just sit and enjoy” their child during playtime. Additionally, parents tended to distinguish themselves as “medical parents,” with one mother describing parents with a child without medical needs as “normie parents.”

Parents of CMC-technology dependent children become primary care coordinators and are the primary advocate for their child. Although all parents are advocates for their children, parents of CMC-technology dependent children take on a role beyond those of typical parents, that is, parents who do not have a child with technology dependence and high medical needs. Parents of CMC-technology dependent children coordinate and attend medical appointments, adjunct therapies, and take on all employer responsibilities of Family-Managed Home Care. Parents spent a significant amount of time advocating for their child both in and out of the hospital. Their advocacy efforts were mainly focused on receiving clear communication from health care providers, ensuring a timely discharge date, receiving sufficient nursing coverage in the home, receiving consistency in care from agency nurses, and advocating for the use of Family-Managed Home Care.

Altered meaning of parenthood also meant mothers and fathers in this study had to share the workload of tasks beyond those of typical parents. The manner in which the workload of Family-Managed Home Care is shared among parents varies among families. In the case of two parent participants (03A and 05A), the mothers were the primary care coordinators and took on all Family-Managed Home Care responsibilities. Both mothers declared their partners (fathers) were hands-on parents to their CMC-technology dependent child, although they did not partake in any Family-Managed Home Care responsibilities aside from being part of the decision-making process of which nurses would be hired. Other families, including the three families in this study where both mothers and fathers were interviewed, split the workload between parents as evenly as possible. Within these families, it was noted that workloads were split between mothers and fathers in a traditional gender role fashion; however, it is important to note that the three participating fathers have a career background in human resources or finance, and all three were responsible for the payroll and business side of Family-Managed Home Care. The mothers were then responsible for maintaining the nurses' schedules, acting as the primary coordinator for appointments and doing most of the hands-on care. These parent partners describe their division of work as playing to each other's strengths. Only one mother out of all parent participants was working in some capacity, and all father participants worked full time.

Parent Recommendations

A critical component of the data was that parent participants shared recommendations about how utilizing the Family-Managed Home Care model could be improved. Furthermore, they often described different ways in which support for parents of CMC-technology dependent children could be provided, and during which phase of implementation.

Table 5

Parent Recommendations

Recommendation	Phase of Implementation
Formal Resources Chart Templates Documentation Guidance Interview Questions Nurse Qualifications/Job Description	Transitioning Home Building the Home Care Team
Parent-Peer Mentoring Program	Transitioning Home
Increased Mental Health Support	Transitioning Home Building the Home Care Team
Health Management Education (Anticipatory Guidance)	Transitioning Home Building the Home Care Team Partnering to Provide Care

The first recommendation provided by most parents was improved formal supports. Parent participants specified they required resources of "standard operating procedures," and it was their strong recommendation that these resources be provided by the LHIN. Parents explicitly expressed needs for 1) templates of charts for nursing documentation purposes, and 2) written guidance as to what their home care nurses should document. Moreover, parents would benefit from being knowledgeable of what nursing competencies and qualifications they should seek out when hiring home care nurses. One parent (01B) suggested that all the initial steps and documents required for Family-Managed Home Care, as well as the best practices used by agencies and agency nurses, should be kept in a resource binder within the LHIN to be shared with families.

A second recommendation provided by two parents (02A and 04B) was to address the parents' need to have some understanding of what life would look like at home with their CMC-technology dependent child. Neither parents, however, could articulate what that type of information dissemination would be. Parent 02A described it as *"not wanting to scare them* [other trach parents]*,"* while parent 04B described it as, *"There was no 'this is what life is going to be like with a nurse in your home house,' or 'this is what it's gonna be like taking care of your child every single day' type thing."* Mitigating the uncertainty of what life will be like outside the hospital and at home for families with CMC-technology dependent children is important. Parent 04A offered a solution: a parent-peer mentoring program. This parent noted that an informal mentoring program was already occurring outside the hospital among parents in the "trach community." Furthermore, the parent also indicated that parents with CMC-technology dependent children who have extended hospital stays require an increase in mental health support. Not only are parents exposed to traumatic events their children experience, such as cardiac arrests and resuscitations, but they are also exposed to the events occurring around them while in hospital.

Finally, parents recommended that anticipatory guidance be provided for parents on how to manage role expectations and negotiations with nurses. It can be challenging for parents to act as employers and care managers while simultaneously parenting CMC-technology dependent children. CMC-technology dependent children’s care needs are dynamic and change as the child grows, requiring parents to renegotiate nursing roles and responsibilities. As well, parents are responsible for managing conflict between themselves and the home care nursing team. Nurses and other health disciplines and team members in the hospital assisting in the discharge process are in an ideal role to provide parents with guidance in conflict management and role negotiation, either at the bedside or having it built into the discharge training process.

CHAPTER FIVE: DISCUSSION

The research study presented in this thesis examined how families with technology-dependent children describe their use of and experiences with the Family-Managed Home Care Model in southwestern Ontario. Specifically, the research had several objectives, including to:

1. Describe how parents learned about and were introduced to the Family-Managed Home Care model;
2. Explore and identify the factors that influenced parents' decisions to choose the Family-Managed Home Care model;
3. Describe the different ways in which families coordinate the nursing services their child received under this model; and finally,
4. To examine the varying experiences that families have in partnering with nurses to provide care for their children.

Within this chapter is a discussion of the primary study findings, including interpretation of these findings within the context of the current literature. Next, application of the Concept of Access framework to understand parent participants' use of health care service under the Family-Managed Home Care model will be discussed. More specifically, the five dimensions of the Concept of Access and how they relate to the Family-Managed Home Care model and the study findings is provided. Finally, the chapter will conclude with a presentation of the study's strengths and limitations, and recommendations for clinical nursing research, practice, education, and policy.

Parents' Discovery of the Family-Managed Home Care Model

The first objective of this study was to describe how parents of CMC-technology dependent children learned about and were introduced to the Family-Managed Home Care model. Parent study participants learned about the Family-Managed Home Care model primarily from hospital clinicians, LHIN coordinators, and other families of CMC-technology dependent children. It is not surprising that hospital clinicians provide this key information about post-discharge care options to parents as many clinicians such as nurses, engage with parents on a daily basis at the bedside and help prepare parents and their child for discharge. This finding also points to the importance of nurses and other clinicians being knowledgeable about this model of care so they can provide comprehensive information to parents about home care options for their child. LHIN coordinators are an understandable source of information about Family-Managed Home Care as their role is to help families manage care in the community. Learning about Family-Managed Home Care from families who were already providing care for their CMC-technology dependent child in the community offered information that extended beyond care options. Informal support from the “trach community” was particularly beneficial for parent participants, as it allowed them access to Family-Managed Home Care resources other parents had created. Furthermore, this community provided parents with informational support on how to *set up Family-Managed Home Care* and advice on *recruitment* and documentation.

Influencing Factors in Parent Participants’ Use of Family-Managed Home Care

The second objective of this study was to identify and explore the factors that influenced parents’ decision to choose the Family-Managed Home Care model. There were several factors that affected this decision. The primary reason for using the Family-Managed Home Care model was because nursing agencies (coordinated via the LHIN) were unable to meet the family and child’s nursing needs. Nursing agencies often had difficulties with fulfilling families’ nightly nursing staffing needs. The inability to meet nursing care needs was affected by other factors that influenced parents’ decision to use Family-Managed Home Care including a lack of home care nurses, challenges in care coordination, and parents' desire to maintain control in their child's overall care.

Lack of Nurses

Nursing agencies were not able to meet parent participants' nursing needs and was thus a significant influencing factor in their decision to use Family-Managed Home Care. Furthermore, lack of nurses resulted in discharge delays for several parent participants. Factors that contributed to this inability to meet nursing care needs were mostly related to not having enough nurses in a family's LHIN region to be discharged in a timely and safe manner into the community under traditional agency nursing.

Challenges that families with CMC-technology dependent children encounter in the transitioning home process and through using agency nursing via the LHIN is affected by the general nursing shortage Ontario has been experiencing for some time. According to the Canadian Nurses Association, although the overall number of regulated nurses has increased at a rate greater than the population growth, the number working in nursing has actually decreased slightly since 2018; in 2019, nearly 40 000 nurses were not employed in health care (CNA, 2020). This nursing shortage also impacts the organizational process of planning the discharge of CMC-technology dependent children from hospital and is a major factor in the exacerbation of discharge delays. Vicki McKenna, president of the Ontario Nurses' Association, states that the home care nursing sector has been particularly affected by the nursing shortage because of working conditions, wages, benefits, and hours not being as robust as what is offered at hospitals (Mosleh, 2021). For example, a nurse working in an acute care hospital makes more than a nurse working in home care. It should also be noted that the salary for home care nurses directly employed under Family-Managed Home Care is significantly higher than the salary for home care nurses working for agencies. This may also further impact the ability of home care agencies to retain nurses. It was discovered during interviews that many parents' home care nursing teams were comprised of nurses who worked in hospital and in home care under the Family-Managed Home Care model, not in the traditional home and community care sectors. Some nurses even left their community agency jobs to join a family's home care team under the Family-Managed Home Care model. This may be because the salary in home care under Family-Managed Home Care is higher than that in traditional agencies.

Although there are incentives in place for nurses to work in home care, efforts are focused mainly on attracting new nurses rather than nurse retention. The Community Commitment Program for Nurses offers an incentive of $10 000 to eligible nurses in exchange for a 12-month commitment to an eligible employer, including home and community care agencies (Health Force Ontario, n.d.). However, to be eligible for this incentive, a nurse must not have been employed as a nurse in Ontario in the six months prior to being hired (Health Force Ontario, n.d.). This is a significant barrier to increasing the nursing workforce in home and community care, as the eligibility criteria is severely limiting; while this may attract nurses to work in home care, there is little effort to ensure nurse retention. Furthermore, recent government funding for the home care and community sectors is focused more on bolstering the health care system's capacity to provide virtual care. Ontario is investing $14.5 million to support the expansion of virtual care for Ontario Health Teams (the new terminology for Local Health Integration Networks) and frontline home and community care service providers (Government of Ontario, 2020). While virtual care is important, it has limitations in its usefulness for families of CMC-technology dependent children whose primary struggle is having nursing presence physically in the home. Essentially, this funding does not contribute to increasing nursing support in the home for parents of CMC-technology dependent children.

Under Family-Managed Home Care, parent participants hired nurses with a variety of backgrounds, including home care or community nurses, as well as medical-surgical nurses, intensive care unit nurses, and emergency room nurses. Parents using Family-Managed Home Care rarely struggled to retain staff or had uncovered shifts, likely due to the broad nursing background requirements when seeking recruitment of nurses.

Parents in this study who did initially get discharged under agency nursing care switched to Family-Managed Home Care due primarily to the inability of nursing care needs to be met in the home because of staffing issues, and in one family's case, conflict with a nurse manager. Thus, parents wanted to "control" the ability to have the appropriate nursing coverage at the times required and avoid the experience of a lack of nursing coverage and flexible scheduling which the Family-Managed Home Care model allowed them to achieve. Although parent participants in this study were satisfied with using Family-Managed Home Care to coordinate their nursing services, strategies to attract and retain nurses in community care include increasing salary and offering benefits to home care nurses working for agencies. Perhaps if parents did not experience staffing difficulties under traditional agency care, they would not have felt the need to use Family-Managed Home Care. Further, parents who may not have the ability to manage the Family-Managed Home Care model should not be left with unmet nursing care needs, and improving pay and benefits of home care nurses in traditional agencies may provide better experiences and safer care to other families with CMC-technology dependent children.

Parent participants' experiences with difficulties in finding adequate nursing coverage, that subsequently resulted in discharge delays, is consistent with experiences of other families with CMC-technology dependent children (Manhas & Mitchell, 2015; Margolan et al., 2004; Maynard et al., 2019). Several parents in this study initiated Family-Managed Home Care prior to hospital discharge to avoid discharge delays that would occur while waiting for an agency to hire and train nurses. Other parent participants that were initially discharged home under agency care later transitioned to using the Family-Managed Home Care model for reasons similar to those in existing literature, including that parents had concerns over the competency of some of the nursing staff sent into the home (Kirk, 1998; Mah et al., 2008) as well as having uncovered shifts. Mah et al. (2008) conducted a Canadian study of parents of technology-dependent children requiring home care nursing, who stated that they often found staff from community agencies lacked knowledge and understanding of their family needs, and that support from those agencies was perceived to be insufficient. Parent participants of this study expressed similar sentiments regarding their experiences with agency staff, and thus parental concerns over nurse competency were alleviated by using the Family-Managed Home Care model as parents were responsible for and in control of the training their home care nurses received.

Challenges in Care Coordination

Parent study participants' primary challenge with care coordination was typically related to what they perceived as unsatisfactory communication between interdisciplinary team members involved in their child's discharge, both in the acute care and community setting; this was another factor that influenced parents' decision to use the Family-Managed Home Care model. Parents felt they were not always receiving timely updates and two parents experienced communication breakdown between interdisciplinary team members that resulted in a discharge delay. This emphasizes the importance of open and frequent communication between the family and interdisciplinary team members. The issue of unsatisfactory communication and its impact on care coordination was not identified as an issue in literature, as the majority of communication challenges between parents and health care providers was regarding information related to the health status of their child and health teaching (Jachimeic et al., 2015). Other challenges parents faced during the transition home were mostly related to a lack of nursing support, or formal caregiving support. This is consistent with challenges reported by parents of ventilator-dependent children in a qualitative study by Noyes et al. (1999), where nursing support in their home communities after discharge widely varied; some parents reported being discharged home with no nursing support in the community, while others receive nightly nursing support.

It has been identified that service coordination for families of CMC-technology dependent children is poor (CAPHC, 2018; PCMCH, 2013; Sick Kids, 2008). This is due in part to CMC-technology dependent children requiring services across multiple settings, such as hospital, home, community, and school (de Banate, Maypole & Sadof, 2019; CAPHC, 2018). It is likely that communication difficulties affecting coordination of care identified in this study is more related to poor infrastructure of service coordination, or not having one main point of contact to coordinate communication between interdisciplinary team members rather than an interdisciplinary team members' inability to communicate.

Control

Control over their own lives and the ability to "control" that the healthcare needs of their child were met was a major factor for parents' utilization of the Family-Managed Home Care model. Rather than a central theme, the concept of control was deeply integrated into every phase, step, and in the overall process of managing their CMC-technology dependent child's care.

In the qualitative study presented in this thesis, control of a CMC-technology dependent child's care as an important factor in home care is similar to findings in other studies. Parent study participants did not want to work with home care nurses that were not willing to collaborate with them in providing care and recognize their parental role and expertise. Similarly, in a qualitative study by Mendes (2013) that explored seven parents' descriptions of ideal home care nursing for their technology-dependent children, one theme identified as important to parents was that nurses acknowledged parents' expertise about their child's care and respected parental decisions and control of the child's care. Parents in Mendes' (2013) study also did not want nurses working with them in their home whom they felt took away their parental control. Wang and Barnard (2008) in their qualitative study of parents of technology-dependent children, specifically those dependent on mechanical ventilation, discovered that parents found it difficult to have nurses in the home because it intruded on their ability to maintain parental control (Wang & Barnard, 2008). Although it is unavoidable for parents of CMC-technology dependent children to have nurses in the home, it may be that a self-directed model of care, like the Family-Managed Home Care model, is preferred because it allows parents total control over operationalization of their nursing services and thus the ability to maintain more parental control.

Having control over operationalization of their nursing services under the Family-Managed Home Care model was valuable to parent participants. This was a unique finding for this study, as there was no other literature found that focused on a self-directed model of home care. Parents are able to exert control in each step of *building the home care team.* When *recruiting the team,* parents were able to recruit and hire the nurses that would come into their home. Here, parents made unique choices on which nurses were the best fit to work in their home and had complete control over their "best fit" requirements. When it came to *orienting and* *training the team,* parents' previous concerns over nurses' knowledge, skills and competencies were alleviated as they were in control of training their nurses adequately. In this step of *orienting and training the team*, parents were also able to control what kind of care their child received and how it was delivered, as they had already ensured when *recruiting the team* that their nurses were willing to partner to provide care. Finally, when *managing the team,* parents were able to ensure their nursing needs were met. Parents controlled the ability to schedule their nurses to their exact needs, cover sick calls, and communicate effectively with their home care nursing team. In doing so, parents no longer experienced the unpredictability of unfilled shifts or anxiety over the nursing presence in their home.

How Parents Coordinate Nursing Care

New knowledge generated in this study to address study objective 3 of how parents coordinated nursing care was unique; these new findings are most likely because there was little to no evidence of similar models of home care documented in the literature. One part of the coordination of nursing care was recruitment of nurses for the home care team. Parent participants utilized various recruitment methods when looking to build their home care nursing team under the Family-Managed Home Care model, such as social media, word of mouth, job websites and assistance from hospital clinicians. Nurse recruitment methods employed by parents or agencies and institutions were not discussed in the literature, despite lack of nursing staffing in the community being a common challenge (Boroughs & Dougherty, 2009; Mah et al., 2008; Manhas & Mitchell, 2015; Maynard et al; Sick Kids, 2008). Finally, for parents who initially used agency nursing care, nurses that they felt were the right fit were hired on to continue working with the family and child under Family-Managed Home Care.

Parents desired and hired nurses whom they felt were a good "fit" for their home, and although this may vary based on each parent's personality and preferences, all parents consistently listed several key characteristics that they felt made a nurse a good “fit” for the home. Consistent with literature on exploring the nurse-parent partnership, these characteristics included dependability, flexibility, willingness to learn and collaborate and demonstrating genuine caring (Mendes, 2013; Mendes, 2016; Mentro & Steward, 2002; Nagaswaran & Golden, 2018).

Training under Family-Managed Home Care was organized and often conducted by parent study participants. Some parents conducted their own training with home care nurses, while others arranged for their home care nurses to attend a two-day course conducted by respiratory therapists at a children’s hospital. Some parents did a combination of both at-home training and training in the hospital course. One mother used community respiratory therapists to assist with nurses’ training, so they were able to practice skills on her child. Two parents continued to follow up on their home care nurses’ skills and had ongoing training plans for their nurses. This was perhaps a way for parents to maintain control over their nursing team’s skills and competency, and to ensure ongoing safety of their child and the care their child receives. This was also a unique finding, as there was no evidence found in the literature where parents were primarily responsible for the training of their home care nursing team.

Finally, methods for how parents managed their home care team were diverse but with some similarities. Most parents used technological platforms to schedule and communicate with their nurses; for example, sharing a Google calendar and using group chat messengers. All parent participants managed sick calls in a similar manner, whereby if another nurse was unable to cover a shift, parents used their trained support persons to help cover the shift. This reinforces the importance of informal support to parents’ success in using the Family-Managed Home Care model, as support persons were generally family members. Mah et al. (2008) also note the importance of familial support as mediating the parental stress, allowing parents to take breaks, and to have reliable alternate caregivers.

Parents' Experiences in Partnering to Provide Care

Partnering to Provide Care

Partnering to provide care was an important concept in the nurse-parent relationship and the focus of study objective 4. Collaboration and partnership are also key tenets of family-centered care (Kuo et al., 2012). Partnering to provide care was a process that began during the *recruiting the team* phase. The "take charge" skills of nurses that are valued in the hospital setting may lead to failure in the home, where protecting and fostering the abilities of family members is vital (Klug, 1993; Kuo et al., 2012; Liaschenko, 1994; Marvan-Hyam, 1986), as is honoring parental roles, choices, values and beliefs (Coffman, 1997; Kuo et al., 2012). This study's findings reflected the value parents place on working with nurses who recognize their parental role. Parent participants explained that even if a potential Family-Managed Home Care nurse had the required skills to care for a CMC-technology dependent child, if they were perceived as abrasive, a "know-it-all," or unwilling to collaborate, they would not be hired. Although parent participants did not want total control of their Family-Managed Home Care nurses and their actions, it appeared there was a delicate balance of nurse-parent collaboration, with control primarily held by parents; particularly as nurses in the Family-Managed Home Care model are directly employed by the parents. However, understanding the exact nature of this balance in this study is limited to the perspective of parents only in the creation of the nurse-family partnership.

Of particular interest to this study is the acknowledgment of parental control, one of the characteristics of the nurse-parent partnership identified by Mendes (2016) in their study using the Hybrid Model of Concept Development to examine partnership in nurses' work over an extended period of time in the home. Mendes (2016) described nurses acknowledging that parents are in control of their home, their family, and health care decisions for their child while parents acknowledged that nurses were in control of their safe practice. Although this current study examined parent perspectives only, it was evident during interviews with parents that they did not want to exert control directly over the nurse, but rather wanted to maintain control as parents while collaborating with nurses to provide care. Further, Mendes (2016) noted that parent descriptions of home care nurses who demonstrated flexibility and willingness to collaborate with parents enforced the notion that nurses who had these characteristics were honoring parents' wishes in how the child's care should be provided; the same was noted in this current study.

The Professional Friendship

The professional friendship develops when nurses are viewed as being respectful, collaborative, and providing normalcy to the family (Jachimeic et al., 2015; Lindahl & Lindblad, 2013; Mentro & Steward, 2002; Nagaswaran & Golden, 2018). Although there were varying degrees of professional friendships and boundaries, findings from this current study are similar to those reported in previous research, particularly about the requirements of what makes a nurse a good "fit" for the family (Lindahl & Lindblad, 2013; Mendes, 2013). The professional friendship is somewhat synonymous with the nurse-parent partnership, as the extended contact of home care nurses and families assists in the development of a relationship (Lindahl & Lindblad, 2011). Parent participants in this study commented that their home care nurses were more like family, or very good friends, yet also described maintaining professional boundaries. This is similar to how parents of CMC-technology dependent children in previous research described the relationships with their home care nurses (Jachimeic et al., 2015; Lindahl & Lindblad, 2013; Mendes, 2013; Mentro & Steward, 2002).

Each parent participant in this study had a unique personality, and as such who they perceive as a good nursing fit for the home may vary among parents. As previously mentioned, despite differences in personality and nurse preference, all parent participants listed the same characteristics of what makes a nurse a good “fit” for the home. Aside from characteristics such as dependability, flexibility, and willingness to collaborate, parent participants in this study frequently spoke about communication and trust as being part of their nurse-parent relationship. Communication and trust are important in the development and maintenance of the nurse-family relationship (Mendes, 2016; Nagaswaran & Golden, 2018), and that was evidenced in this study when parent participants spoke about how they felt the nurse-parent relationship developed. Parent participants described striving to maintain consistent and open communication with their home care nurses. As well, parents used the terms “trust” and “comfort” often when describing their relationship with their home care nurses, noting that trust and comfort developed over time as the nurse-parent partnership developed.

Professional friendship or nurse-parent partnership in the literature typically includes the challenges that can arise. These challenges mostly concern the difficulty in maintaining boundaries (Coffman, 1997; Mendes, 2013; Mendes, 2016; Nagaswaran & Golden, 2018). Navigating boundaries can be difficult and complicated for both nurses and parents (Nagawaran & Golden (2018). Nagawaran and Golden (2018) found that both parents and nurses struggled with physical, professional, and personal boundaries. Although the study presented in this thesis focused on the parent perspective only, the struggles with physical boundaries and adjusting to the presence of nurses in the home were similar to those described by caregivers in the study by Nagawaran and Golden (2018), where the authors described the relationship between parents/caregivers of CMC-technology dependent children. Conflict between parents and nurses is often also reported in the literature (Coffman, 1997; Mendes, 2013; Mendes, 2016; Nagaswaran & Golden, 2018). In contrast, however, it is interesting to note that parents in this study rarely discussed or described conflict with nurses, and in the one instance they did, it was not related to maintenance of boundaries. Previous literature implied that home care nurses were working for agencies, and therefore parents in these studies may have had to adjust to the nurses that were assigned to their home and had less of a choice in who they worked with (Coffman, 1997; Mendes, 2013; Mendes, 2016; Nagaswaran & Golden, 2018). This may have impacted the ability of parents in these studies to set boundaries because they may not have had a previous connection or interaction with those home care nurses. On the other hand, Family-Managed Home Care allows parents the ability to choose who their home care nurses are, and presumably there may be less conflict experienced by parent participants of this study because the expectations were set, and relationships fully developed at the time of interviews.

Application of a Conceptual Framework: Concept of Access

In Chapter Two, the Concept of Access (Penchansky & Thomas, 1981, 1984), expanded upon by Julio Frenk (1992), was introduced as the theoretical underpinning of this study. The Concept of Access is a conceptual framework for analyzing accessibility. It was used to assist the researcher in understanding the delivery of nursing services under Family-Managed Home Care and influenced the interpretation of data during the analysis phase. The Concept of Access outlines a set of five specific dimensions that describe the fit between the patient and the health care system; the better the fit, the better the access to a health care service (Saurman, 2015). These five dimensions are: (1) availability, (2) accessibility, (3) accommodation, (4) affordability, and (5) acceptability. Access, within the framework and in broad terms, is the ability of a person to utilize health care service given a need and/or want to obtain it, whereas accessibility is the degree to which the care is actually received (Frenk, 1992). Understanding and applying the dimensions of the Concept of Access during data analysis in this study was helpful in providing insight into how parents of CMC-technology dependent children utilize a health care service (i.e., the Family-Managed Home Care model). Parent participants experienced some challenges in obtaining nursing care prior to Family-Managed Home Care (access), and once they had their home care nursing team set using Family-Managed Home Care, received consistent and quality nursing care (accessibility). Each of the five dimensions of the Concept of Access will be discussed in relation to the study findings in the sections that follow.

Availability

The dimension of availability refers the number of health care providers and other health care services. Within the context of home care nursing, there is a lack of availability of home care nurses in the community, specifically those capable of providing specialized care to CMC-technology dependent children. The lack of community nurses was noticeable when parents were initially receiving nursing care via agencies, which led parents to seeking their own home care nurses under the Family-Managed Home Care model. Under this model of care, parents hire nurses from diverse nursing backgrounds, and train those who do not have tracheostomy or ventilator skills to become competent to provide safe care under these conditions, thereby increasing the availability of nurses with the required skills to care for a CMC-technology dependent child.

Accessibility

Accessibility, according to Penchansky (1982, 1984) refers to the geographic relationship between health care providers and care users. Geographical access to care is an important factor to be considered for CMC-technology dependent families, in particular when they use agency nursing contracted by the LHIN. Each family belongs to a specific LHIN in Ontario based on their home address, or geographical location. When families use agency nursing via their LHIN, they are relying on the agencies who are contracted by that specific LHIN to deliver their nursing services. Sometimes, as it was the circumstance of two of the parent participants in this study, agencies contracted by one LHIN are not able to meet a families' nursing needs and, thus, the LHIN must subcontract an agency outside the LHIN that can assist in meeting the family's nursing requirements. Family-Managed Home Care may offer families experiencing difficulty in receiving nursing care from LHIN nursing agencies the opportunity to hire nurses who are more easily able to get to their home, and to hire from a pool of diverse nursing backgrounds, not specifically home care nurses, as parent participants in this study did.

The interpretation of accessibility by Frenk (1992), or the degree to which a person requiring and seeking care actually received it, is also relevant to the discussion of families with CMC-technology dependent children using Family-Managed Home Care. When comparing parent participants' experiences between home care nursing under traditional home care to home care using the Family-Managed Home Care model, parents actually received more consistent nursing care from their home care nurses under Family-Managed Home Care than those who did not use that model of care.

Accommodation

Accommodation encompasses how easily people can use health care based on the organization and content of the health care system. The LHIN was described by parent study participants as a highly siloed organization. For example, one mother detailed how they changed LHIN coordinators when they chose to use Family-Managed Home Care because their original coordinator did not oversee that model of home care within the LHIN organization. This parent participant described that there was a different contact person for different parts of *setting up Family-Managed Home Care,* such as speaking with someone other than their coordinator to discuss questions related to the financial paperwork required. This can make it challenging for parents when trying to establish Family-Managed Home Care especially if they have questions and are directed to multiple people in order to receive sufficient information.

Accommodation challenges were evident in relation to discharge of the CMC-technology dependent child when *transitioning home.* The communication between the acute and community care sectors as well as having multidisciplinary team members involved in one CMC-technology dependent child's discharge presented challenges in care coordination. Particularly, it was unclear during parent interviews in the discussion of *transitioning home* if there was one person in charge of discharge coordination, as parents did not clarify this and spoke about multiple health care team members being responsible for their child's discharge. Once home in the community, parents became the main care coordinators for their child. The use of a key worker, who is a main point of contact between all multidisciplinary team members in the hospital and in the community, has been documented in the literature as an important strategy in bridging collaboration between acute and community settings while acting as the central organizer in discharge planning. Instituting the use of a key worker in this pediatric setting may benefit the accommodation of families of CMC-technology dependent children and assist parents in their advocacy efforts.

Affordability

Affordability as a dimension in the Concept of Access has a different meaning in the Canadian health care context – compared to the United States where the framework was originally developed. Affordability speaks to the financial ability of the population to use the care the health care system provides, and how patients perceive its value.

In Canada, hospital stays, medication, consults from specialists and surgeries are fully financially covered by the provincial government for Canadians. However, once CMC-technology dependent families leave the hospital, not everything required for the medical needs of the child is financially covered; in fact, most families discharged from a tertiary centre in southwestern Ontario are told to expect to pay $10 000-$15 000 annually out of pocket to cover medical supplies and other expenses not covered by the Ontario Disability Support Program (ODSP).

The affordability of Family-Managed Home Care for families may be dependent on the resources available to users of the model. For example, it is interesting to note that all parent participants in this study were from two-parent families, with at least one full-time working parent. All parent participants also had some form of private insurance that assisted with a variety of extra costs, including nursing care, and many had to use their own financial resources (e.g., money not from private insurance) in the use of the Family-Managed Home Care model.

Acceptability

Acceptability as a domain of the Concept of Access represents the attitudes of health care users towards providers and vice versa (Ricketts & Goldsmith, 2005). While this study only captured the attitudes of the health care users (i.e., parent participants), the inclusion of parents who have experience using traditional home care and Family-Managed Home Care provide insight into both health care model perspectives.

Parents very clearly had strong, positive relationships with their nurses under the Family-Managed Home Care model, with some parents describing similar relationships with a select number of agency nurses. Parent participants described that they generally trusted the nurses they hired themselves under Family-Managed Home Care as part of their home care nursing team more than nurses that frequently rotated through their home under traditional home care. Parents describe their relationships with the nurses as that of a "professional friendship;" this is similar to other CMC-technology dependent families' descriptions of the nurse-family relationships (Jachimiec et al., 2015; Lindahl & Lindblad, 2013; Mentro & Steward, 2002).

Parent participants spoke highly of the multidisciplinary team that assisted them in training during the *transition home.* However, all but one parent participant described negative perceptions of the LHIN coordinators and felt that they were unsupportive in their use of the Family-Managed Home Care model. Many of the parent participants' frustrations stemmed from feeling like the LHIN did not care about them or the quality of care that was being provided prior to families initiating Family-Managed Home Care.

Study Strengths and Limitations

Strengths

The study presented in this thesis had a number of strengths. It is one of the first studies to examine the experiences of families using the Family-Managed Home Care model. It adds new knowledge about the Family-Managed Home Care model, of which there was previously no research. Second, the qualitative study design was a strength, as it provided parents with the opportunity to freely describe their own unique experiences through in-depth interviews and qualitative analysis (Ames et al., 2011). This resulted in a rich description of parents' overall experiences with Family-Managed Home Care. Third, a use of field notes and ecomaps was a study design strength. Field notes added information about the study's context and also functioned as an audit trail, which demonstrated the application of epistemological integrity and enhanced study credibility (Krefting, 1991; Thorne, 2016). Ecomaps also served to strengthen the study by adding context to parent participants' supportive relationships and the nature of such relationships; they also served as a point of data triangulation. Fourth, was the diverse perspective of parent participants and the length of time they used Family-Managed Home Care. The perspective of fathers was captured in this study, which is often missed. The ability to have both parent perspectives within one family was also a positive contribution to the findings. As well, the length of time that parent participants used Family-Managed Home Care widely varied, and included several parents who had initially used traditional, agency-provided home care nursing before switching to Family-Managed Home Care. Finally, the use of a rigorous analysis strategy, as described by Braun and Clarke (2019) as well as the knowledge and participation of an experienced research team in the analysis further strengthens the rigor of this study.

Limitations

Despite the numerous study strengths, this study did also have some limitations. First, there was a lack of diversity among the parent participants. All parent participants were Caucasian, English-speaking, and from two-parent families. Parent participants were well educated with all but one parent having post-secondary education; this is not representative of the Ontario population, which, on average, has a much lower proportion of adults with post-secondary education. As well, all parent participants had extended health benefits. This may limit transferability of findings to similar populations. Second, during discussion of the ecomaps and the nature of the nurse-parent relationship with parent participants, it was noted that parents rarely included nurses with whom they did not have positive relationship on their ecomaps. This limits the ability to understand how parent navigate conflict with their nurses under Family-Managed Home Care and provides a one-sided perspective into the nurse-family relationship and partnership. Third, all parent participants in the study were discharged from the same children's hospital in southwestern Ontario, and therefore their experiences in *transitioning home* may be different from other parents of CMC-technology dependent children in other areas of Ontario. Finally, as Family-Managed Home Care is a model of home care specific to the province of Ontario, the transferability of findings is restricted to only other provinces who may provide a similar model of home care. Transferability is subsequently further limited and thus may not be directly relevant to countries other than Canada that do not have a similar health care structure or home care models.

Recommendations

Research

This study highlights several areas for future research. It is important to consider the perspective of nurses working within the Family-Managed Home Care model to better understand the nurse-family relationship, boundaries, and role development and negotiation. Future research exploring the nurse's perspective may help guide educational content for both nurses and families of CMC-technology dependent children; this content may be related to navigating family dynamics and boundary setting to ensure a positive therapeutic relationship with Family-Managed Home Care families. Difficult relationships between nurses and families were not a focus of this study, as many parents did not include nurses with whom they had tense or difficult relationships with on their ecomaps; this is a knowledge gap for further exploration.

Given the many parent recommendations that could be implemented by the LHIN, a formal program evaluation of Family-Managed Home Care is warranted. Evaluation can be a useful form of research by applying research methodology and standards to answer practical questions in a timely fashion (CIHR, 2012). Although Family-Managed Home Care has been running for some time and evaluations are generally reserved for programs judging the merit or value of a program at the end of a program's activities, an improvement-oriented evaluation approach may provide information to improve the Family-Managed Home Care model (CIHR, 2012). Findings from this type of evaluation should focus on parents' views of what is positive and challenging about using the Family-Managed Home Care model. Results from this type of evaluation will ultimately benefit Family-Managed Home Care users, parents of CMC-technology dependent children. In addition, this evaluation design tends to be less threatening to participants and is more likely to promote joint problem-solving (CIHR, 2012).

As the study presented in this thesis focused mostly on some challenges parents using the Family-Managed Home Care model experienced, it would be prudent to explore the perspective of the LHIN. What the LHIN as a health care service provider organization perceives as challenges in running the Family-Managed Home Care model would add new knowledge to the current literature and possibly provide further insight into why some of the limitations that parents perceive in working with the LHIN exist.

Finally, it would be important to assess health care providers' knowledge of the Family-Managed Home Care model. Health care providers in hospital are in the position of supporting families of CMC-technology children in transitioning home. Assessing health care providers' baseline knowledge of the Family-Managed Home Care model may assist in the development of knowledge translation strategies to improve awareness and understanding of this particular model of home care.

Practice

Communication and care coordination between hospital interdisciplinary team members and the community (i.e., LHIN coordinators, nursing agencies) was noted in this study as inefficient and insufficient at times in parents' transition to home. The implementation of a key worker within the health care system would be beneficial to improve communication and collaboration among parties involved in Family-Managed Home Care, while supporting care delivery and transition to home. Key workers are uncommon in the Canadian context, where "care coordination" is generally taken on informally by professionals or non-professionals at various organizations, mainly pediatric rehabilitation centres. However, key workers are included in the Complex Care for Kids Ontario model of care and their use recommended by the Canadian Association of Pediatric Health Care Centres (CAPHC, 2018; Drennan et al., n.d.; PCMCH, 2017). The key worker would act as a single point of contact for a family and assist in coordinating their care, both within the health care system and across systems such as education, social services, and financial (CAPHC, 2018; Drennan et al., n.d.; PCMCH, 2017). The main idea of the key worker role is to empower parents by providing them with support, resources, and information tailored to their unique needs (Drennan et al., n.d.). According to the Complex Care for Kids Ontario model (2017), the key worker is ideally a nurse practitioner, and their role includes working with other members of the care team to build relationships and strategic partnerships within their organization and with community partners. The Sick Kids Report of the Pediatric Complex Care Coordination Panel also designates the key worker role to the nursing profession, although they recommend registered nurses (Sick Kids, 2018). It is unclear from the literature where specifically a key worker could be situated within the health care system; however, it seems they could be situated in either a pediatric hospital, rehabilitation centre, or within a community organization while bridging care between the acute and community health care systems.

Communication between all members of the health care team and families, both in the community and acute care sector, could be improved by incorporating the use of comprehensive care plans and care maps into practice. Care plans are written medical documents that outline major medical issues and care needs for a specific child that is created in collaboration with the health care provider and family (Adams et al., 2013). In contrast, care maps are a one-page visual of the places, people and things needed to care for children with medical complexity, including CMC-technology dependent children, on a daily, weekly, and monthly basis (Adams et al., 2019). Care maps represent the family experience and the vast web of care required to care for children with medical complexity, and although care plans are developed by both the family and health care providers, only the family can create the care map (Adams et al., 2013; Adams et al., 2019).

Findings from Adam et al.'s (2013) qualitative study suggest that comprehensive care plans are useful components of care for CMC-technology dependent children, and that both parent and health care provider participants found the care plans helpful in navigating the complex care of CMC-technology dependent children. Combining care plans and care maps to be used as complimentary documents may be helpful in facilitating communication between the many health care providers involved in the care of CMC-technology dependent children. Implementing the use of care plans and care maps could be facilitated by the key worker or most responsible health care provider. As recommended by the Complex Care for Kids Ontario model (2017), the key worker or health care provider could be responsible for creating and maintaining the care plan and care map documents in collaboration with families. Care plans and maps can then be integrated into the child's electronic medical record, so hospital team members can all access these documents as required on visits or admission to hospital (Quigley et al., 2014). Hard copies of care plans and care maps can be placed in families' homes to be accessible to home care nurses, to be replaced when updated by parents. Despite the benefits of enhanced communication through the use of care plans and care maps, there are barriers to information sharing with the use of these communication tools. For example, there are issues in relation to the availability and use of a common platform, making accessing such documents difficult. Barriers such as these should be considered when finding the best way to incorporate care plans and care maps into clinical use (Quigley et al., 2014).

Implementation of a parent-peer mentorship program was recommended by one parent in this study, as there currently is an informal model of this happening in the "trach community." Neonatal and pediatric intensive care units may consider supporting a formal mentorship program for families. Parenting a CMC-technology dependent child is socially isolating for families, especially as there are few parents who can relate to similar challenges experienced by parents of CMC-technology dependent children (Cockett, 2012; Kirk, 1998; Heaton et al, 2005; Wang & Barnard, 2008; Wang & Barnard, 2003). Implementing a formal parent-peer mentorship program may help alleviate social isolation for families of CMC-technology dependent children.

Education

It was evident during parent interviews that hospital clinicians had very little knowledge of the Family-Managed Home Care and how it worked. Education regarding basic program details should be provided to health care clinicians in units where CMC-technology dependent children are discharged, such as the NICU or PICU. A basic knowledge and understanding of Family-Managed Home Care will provide health care clinicians with the ability to assist, guide, and support parents of CMC-technology dependent children in decision-making regarding care in the community after discharge. Additionally, this will allow hospital clinicians to support and empower parents with the skills required for successful discharge home, and to advocate for health care changes to ease the transition and adaptation of parents from caring for their child in the hospital to home.

A large tertiary children's hospital in the southwestern Ontario region offers tracheostomy and ventilator training courses to nurses working with CMC-technology dependent children. Lack of community nurses trained to care for such children was at times a barrier to timely discharge for families. Furthermore, as there are currently no training requirements for nurses under Family-Managed Home Care, parents are responsible for their training. Increasing the number of dates training courses are offered may increase the availability of home care nurses, as well as alleviate parents' task of training nurses to become skilled in tracheostomy and ventilator care.

Connected Care is a program funded by the Ministry of Health and Long-Term Care that is operated by the children's hospital, Sick Kids, in partnership with the Toronto Central LHIN. This program aims to enhance the experience with transitions and build confidence, competence and promote shared understanding among children with medical complexity, their families and health care providers. Connected Care partners across the continuum of care to coordinate services, improve health and safety, and promote the standards of pediatric practice. Their services include offering online pediatric education modules to community and home care providers as well as 24/7 access to a Sick Kids nurse-led consultation service to support provider skills in taking care of children with medical complexity. A similar program should be implemented in partnership with other communities surrounding major children's hospitals to further support home care nurses in caring for CMC-technology dependent children (Connected Care, n.d.).

Family-Managed Home Care is designed for users to have control over the hiring and managing of nursing care teams, and as such, parents in this study were effectively care coordinators or managers. It would be beneficial to provide education to parents with regards to managing conflict, negotiating, and renegotiating nurse roles and responsibilities in the home. This education could be provided in their discharge training classes or in partnership with the LHIN when implementing Family-Managed Home Care.

Policy

Findings in this study illustrate several gaps in policy. During a review of the literature, it was noted that specific eligibility requirements were not outlined in any Family-Managed Home Care document. However, several parent participants described asking for approval from their LHIN to implement Family-Managed Home Care and initially being informed they were not eligible, with no further details provided. Clear and specific eligibility guidelines should be made public to allow transparency of the assessment process, as well as assist hospital health care providers in planning discharge in conjunction with parents.

As mentioned in the *affordability* section of the discussion of the Concept of Access, it appears Family-Managed Home Care is a model of care designed for those capable of a high level of independence with financial flexibility and significant external support. It is unclear if single parents and/or parents with fewer resources would be able to utilize Family-Managed Home Care (i.e., are they eligible). To this point, findings from this study indicate that agency nursing care, coordinated through the LHIN, was not able to meet the nursing care needs of all families; a primary reason for their implementation of Family-Managed Home Care. It begs the question of what specific requirements a family must meet to be considered for Family-Managed Home Care – if a single-parent family or a lower socioeconomically status family was not having their nursing needs met via agency nursing care, would the LHIN support the use of Family-Managed Home Care? It was clear from parent participants that they perceived the quality of care from their home care nursing team under Family-Managed Home Care to be superior to what they received using agency nursing care. This is because, as per some parent participants, there were times when they had nurses not trained in tracheostomy and/or ventilator care sent into their homes, or they did not have nursing coverage at all. Although Family-Managed Home Care is obviously beneficial for families, does it create an unofficial “two-tiered” home care nursing system? Therefore, policies should be implemented to either support such families in the use of Family-Managed Home Care or resolve unmet needs via agency nursing care.

Findings of this current study demonstrate that parents do not feel supported by their LHIN and that there is a need for concrete guidelines to assist parents in establishing Family-Managed Home Care. The researcher learned that nursing agencies working with CMC-technology dependent nurses and their families have required training and charting guidelines established. However, once families transition to Family-Managed Home Care, there are no specific training requirements for the nurses they hire, or documentation requirements provided for them to use. As Family-Managed Home Care is a program within the LHIN, the organization and its employees are in a good position to assist and guide families with CMC-technology dependent children through the provision of guidelines. Recommendations for change in this area were offered by parents during interviews. These include the development of sample interview questions to inform the process families undergo in trying to hire nurses and guidance on conducting background checks of potential nurse hires. One father felt that because he and his wife did not have a medical background (beyond their required hospital training), they were not equipped to be making safety checklists or documents for nurses to use when charting. Under

Family-Managed Home Care, parents are responsible for making their own job postings and implementing individual recruitment strategies. Recommended job requirements for nurses as well as recruitment strategies should also be provided by the LHIN as part of the *setting up Family-Managed Home Care* process.

Conclusion

This study makes an important contribution to our understanding of the experiences of parents of CMC-technology dependent children in coordinating nursing care under the Family-Managed Home Care model. Study findings revealed that parents valued the control Family-Managed Home Care provided them and they utilized Family-Managed Home Care because nursing agencies were not able to meet their care needs. Parents felt there is a need for improved formal support, particularly from the LHIN in providing concrete guidelines and advice for hiring nurses when *setting up Family-Managed Home Care.* Knowledge of Family-Managed Home Care needs to be increased amongst hospital clinicians to further support and guide parents of CMC-technology dependent children in decision-making when preparing to transition home. Organizational and policy changes must occur to increase formal support to parents of CMC-technology dependent children using Family-Managed Home Care as well as to improve service coordination for this population.

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APPENDICIES

Appendix A

LETTER OF INFORMATION / CONSENT
Family-Managed Home Care in Ontario for Families with Technology-Dependent Children

Investigators:

Local Principal Investigator:	**Student Investigator:**
Dr. Michelle Butt	Andrea Fulton
School of Nursing, Faculty of Health Sciences	School of Nursing, Faculty of Health Sciences
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	Phone: Removed from thesis to maintain privacy

Purpose of the Study

We are doing this research as part of the student investigator's graduate school thesis. The purpose of this study is to explore and then provide a thorough description of parents' experiences of coordinating care for their technology-dependent child using the Family-Managed Home Care Model. We are interested in learning about parents' overall experiences using this model to obtain home care nursing services.

You are invited to take part in this study about the experience of families with technology-dependent children with the Family-Managed Home Care model. We are hoping to learn about how families discovered this model of home care, why families choose this model of home care, how families coordinate nursing services using this model, and explore the different experiences that parents have when partnering with home care nurses who provide care for their children.

Procedures involved in the Research

If you chose to participate, you will be asked to:

1. Draw a diagram of your household family members and nursing care team. This diagram is called an ecomap. We will provide detailed instructions of how to draw an ecomap.
2. Participate in a one-on-one interview with a member of the research team. Interviews will be completed over the phone or the video conferencing app Zoom. The interviews will take about 60 minutes. You can choose whether you would like to interview on the

computer via Zoom or on the phone. All interviews will be done at a time and date convenient for you. You may be asked for a short follow-up interview at a later date.

3. With your permission, we would like to record the interview (via telephone or Zoom).
4. We would like to your permission to use direct quotes from the interview in the study write up.

We will also ask about your experience using Family-Managed Home Care. Some questions include:

- **Describing your ecomap and the type of relationships between you (the parent) and your home care nursing team.**
- **How did you discover the Family-Managed Home Care model?**
- **How were you supported by the staff from where you were initially discharged from the hospital? What kind of supports did your LHIN give you when starting this model of home care?**
- **What has your overall experience been like using the Family-Managed Home care model?**

Potential Harms, Risks or Discomforts:

The risks involved in participating in this study are minimal. Participating in our study may mean you have to take time out of your day caring for your child or working. You may feel anxious or stressed about answering some questions or remembering your time in the neonatal or pediatric intensive care unit. You do not need to answer questions you do not want to answer or that make you feel uncomfortable. We can stop the interview for a break at any time you want. You can withdraw (stop taking part) in the interview and study at any time. Your personal information and name will be kept anonymous for study analysis and the final study product. Because the number of families with technology-dependent children is small, there is a chance you may still be able to identify yourself in the final study version. Below are the steps we are taking to protect your privacy.

- Handwritten notes from our interview will be stored in a locked drawer.
- Recordings of your interview will be kept on an encrypted USB flash drive (memory stick) and/or in a password-protected Zoom cloud.
- Your name will not be used or recorded during the transcription process (typing out our interview word for word) or during analysis (studying our interview to understand the important parts) or in the final study write up and/or publication
- You may choose to turn off your video camera during the interview, if participating via Zoom.
- The Zoom interviews will require a passcode to enter – this will be provided to you in your meeting information email.
- Upon starting the Zoom meeting, you will be placed into a virtual waiting room before being admitted to the meeting by the researcher.

This study will use the platform Zoom to collect data, which is an externally hosted cloud-based service. A link to their privacy policy is available here: https://zoom.us/privacy. While the

Hamilton Integrated Research Ethics Board has approved using the platform to collect data for this study, there is a small risk of privacy breach for data collected on external servers.

If you are concerned about this, we would be happy to make alternative arrangements for you to participate, perhaps via telephone. Please talk to either of the researchers if you have any concerns.

Potential Benefits

The research will not benefit you directly. We hope to learn more about your experience with the Family-Managed Care model to help other families with technology-dependent children have easy transitions from hospital to home. We hope that what is learned as a result of this study will help us to better understand how nurses and doctors in the neonatal and pediatric intensive care units can support parents with technology-dependent children. There is not a lot of information about technology-dependent children and what kind of home care nursing service they receive, or how much. We hope this study will contribute to understanding the home care nursing needs of technology-dependent children, and fill an important gap in the literature.

Payment or Reimbursement

If you choose to participate in this study, you will receive a $25 gift card to Shoppers Drug Mart **OR** Tim Horton’s. You will receive the gift card of your choice before starting the interview. It will not be taken away if, for any reason, you choose to stop the interview and/or withdraw from the study.

Confidentiality

You are participating in this study confidentially. We will not use your name or any information that would allow you to be identified. However, sometimes we can be identifiable through the stories we tell. No one but the student researcher (or other members of the research team like a second interviewer or the supervising professors) will know you participated unless you choose to tell them. We may use direct quotes from our interview in the final study product and will remove any identifying information such as your name and your child’s name.

The information you provide will be kept in a locked desk/cabinet where only the research team will have access to it. Information kept on a computer will be protected by a password. Once the study has been completed, the identifying data will be destroyed. Once the study is complete, an archive of the data, without identifying information, will be kept password protected on a USB flash drive.

Legally Required Disclosure

Although we will protect your privacy as outlined above, if the law requires it, we will have to reveal certain personal information (e.g., child abuse). As mandated reporters, if we observe or suspect child maltreatment, then we have a legal responsibility to report this concern to a local Children’s Aid Society.

Participation and Withdrawal

It is your choice to be a part of this study or not. If you decide to participate, you can decide to stop (withdraw) at any time, even after signing consent or part way through the interview or study. You can choose to withdraw the data you provided at any point during the study period up until the point of publication. If you decide to withdraw, there is will be no consequences to you. If you choose to withdraw, you have the option of removing your data OR information provided up to the point where you withdraw will be kept unless you ask that it be removed. If you do not want to answer some of the questions you do not have to, but you can still be in the study. You can enroll in other research studies while participating in our study.

Your decision whether or not to participate in this study will not affect your access to continuing services such as home care nursing or your complex care team. If you choose to withdraw from the study, please email or phone Andrea Fulton (student investigator) at fultoa1@mcmaster.ca or [Researcher's Phone Number – removed from thesis to maintain the researcher's privacy] to let her know you no longer wish to participate.

Information about the Study Results

We expect to have this study completed by approximately July 2021. If you would like a brief summary of the results, please let us know how you would like it sent to you.

Questions about the Study

If you have questions or need more information about the study itself, please contact Andrea Fulton at:

fultoa1@mcmaster.ca or [Researcher's Phone Number – removed from thesis to maintain the researcher's privacy]

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, HiREB, at 905.521.2100 x 42013.

CONSENT

I have read the information presented in the information letter about a study being conducted by Andrea Fulton and Dr. Michelle Butt of McMaster University.

I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.

I understand that if I agree to participate in this study, I may withdraw from the study at any time. I will be given a signed copy of this form. I agree to participate in the study.

______________________________ ________________________

____

Name of Participant (Printed) Signature Date

Consent form explained by:

______________________________ ________________________ -

____

Name and Role (Printed) Signature Date

Appendix B

Family-Managed Home Care in Ontario for Families with Technology-Dependent Children

Semi-Structured Interview Guide

Family Study ID	
Individual Study ID	
Interview number (first, second)	
Date of Interview	
Interview Platform (e.g. Zoom, phone)	
Consent form reviewed and signed	
How consent form was obtained (e.g. verbally, picture sent or proof on camera)	
Ecomap instructions sent to family (date)	
Honorarium provided	
Copy of ecomap (or photo) received	
Demographic data completed	
Length of Interview	

Introduction

Hi, ________, it's Andrea Fulton from McMaster University. Thank you for setting aside time and agreeing to be interviewed today. I am a graduate student at McMaster University in the School of Nursing, and we are doing research on the experiences of families with technology-dependent children who use the Family-Managed Home Care model.

The purpose of this interview is to get an understanding of your overall experiences using this model of care for home care nursing and care coordination. Some specific things I will focus on is your ecomap; factors that may have influenced you to choose this model for home care services; and supports and resources you had or wished you had from the discharging hospital and the community.

I would like to mention that I am a registered nurse employed at McMaster Children's Hospital, as well as working in the home care setting with technology-dependent children. I would like to make it clear that I am here today as a researcher only, and I cannot offer any kind of health advice. However, if you need health services or resources to support you after this interview, we can talk at the end and I can try and direct towards the right resources. Also, while I am a nurse, I do not have experience in parenting a child with medical complexity or coordinating any home care services. I am interested in your range of experiences, and you are the expert on that.

I would like to record our conversation so that I do not forget anything you tell me. This interview may last 60-90 minutes, but could be shorter depending on how much you want to talk. This is a voluntary interview, which means you can stop at any time. You can also choose not to answer a question, and there are no right or wrong answers. You can also choose with withdraw from the study at any time. You will not face any negative consequences, you may keep your honorarium, and I will not be upset if you choose to withdraw.

Even though the conversation will be taped, your name will not be used in any written transcripts or in the final study product. All information collected during this study will be kept confidential by using only an ID number on all written information. The audio-recording and notes I make during our conversation will stored in a secure, locked cabinet and destroyed after the study is finished. Only members of the research team, being myself and my three supervising professors, will have access to them. Do you have any questions or concerns before we start?

Review study information sheet and consent form with individual. Ensure voluntary nature of interview process and address any concerns or questions. Give participant honorarium – this will be done virtually through email. Begin recording and conduct interview.

Interview Questions (sub-questions are probes/prompts)

Prior to our interview, I asked if you could draw an ecomap so that I could learn more about the make-up of your family and the composition of the home care team that provides your family with care and supports for (name of child). If you could get the copy of your ecomap, I would like to start our interview learning about all the individuals who provide care.

1. On your ecomap, please tell me a little bit about (child's name)?
2. Within your immediate household, who are the individuals who provide direct care to (child's name)?
    a. What type of care is provided; how often; care responsibilities
    b. What has it been like for you to learn how to – and then be responsible for providing health/medical care to your child?
3. Outside of your immediate household, are there other family members (or close friends) who also have been trained to help provide (child) with medical care?
    a. Who? How often do they provide support? Nature of care?
4. Now, under the Family-Managed Home Care model, can you tell me about the health care professionals you have hired to provide care to (child)?
    a. What type of professional (are there more other than nurses); how many are currently on your payroll, how many nurses in total have you had; how long have they been working for you under this model
    b. Now to your ecomap, I would like you to add some additional lines between the home care nurses and your family. Where there is a strong, positive therapeutic

    relationship (or "professional friendship"), please add two straight lines; if the relationship between the family and the nurse is tenuous or stressful, please add dashed lines.
    c. I would like to switch the focus to describing the nurse-family relationship. What has it been like for you and your family to have nurses working in your home on a regular basis? Can you tell me about how those relationships are formed or maintained?

5. How were supported by NICU or PICU staff (or staff on the unit you were discharged from) for your transition home?
    a. Are there other ways they could have supported you?
    b. Is there anything about home care nursing or the Family-Managed Home Care model you think clinicians in the hospital should be aware of?
6. How did you discover the Family-Managed Home Care model?
    a. Can you tell me about your decision process in choosing this model to obtain nursing services in your home – why this particular model?
    b. At what point did you make the decision to use this care model e.g. preparing for discharge from the NICU/PICU; at a later date? Have there been other models of care you used prior to managing the care coordination yourself?
    c. Overall, what have been your general experiences of coordinating nursing care under the Family-Managed Home Care model?
    d. What have been the benefits of using this model of care to coordinate your child's services?
    e. What have been the main challenges you have encountered with this model? How have you addressed these challenges?
7. If you used other community agencies before using the Family-Managed Care Model, what was that experience like?
    a. What factors influenced your decision to switch from traditional home care (or other agency/methods) to the Family-Managed Home Care model?
8. What kind of support did you receive from the Local Health Integration Network (LHIN) when you expressed interest in the Family-Managed Care model?
    a. Did they provide any guidance on how to develop contracts for nurses, information on standards of practice, examples of how other families used the model; where nurses could receive extra training
9. As the family care manager, can you describe the process you followed in developing your home care nursing team?
    a. How did you recruit nurses? Via social media ads, friends of friends, other methods of promoting your need for home care nurses
    b. Once you recruited and hired your nurses, how do you manage them? Tell me about how you decided what kind of role/care responsibilities they would take on, how do you address conflict or issues, have you ever had to terminate a nurse?

c. Please describe how you coordinate scheduling – what happens if you get a last minute sick call; or on vacation?

Closing Question

Is there anything else you would like to add that we have not talked about or that you feel is important for me to know?

Before we finish, I would like to ask you to help me fill out my demographics sheet. There is very little demographic information about children with medically complexity and answering these questions would help fill this gap in the literature. You do not have to answer any questions that would do not feel comfortable with, and you can decline answering the questions altogether. *Researcher to complete form with participant answering questions.*

Thank you very much for you time. Is it ok if I contact you in the next few weeks or months by phone or email for a potential repeat interview? This interview would be to clarify or explore further something we have already talked about today and would last about 30 minutes.

Appendix C
Ecomap Instructions to Participants and Ecomap Example

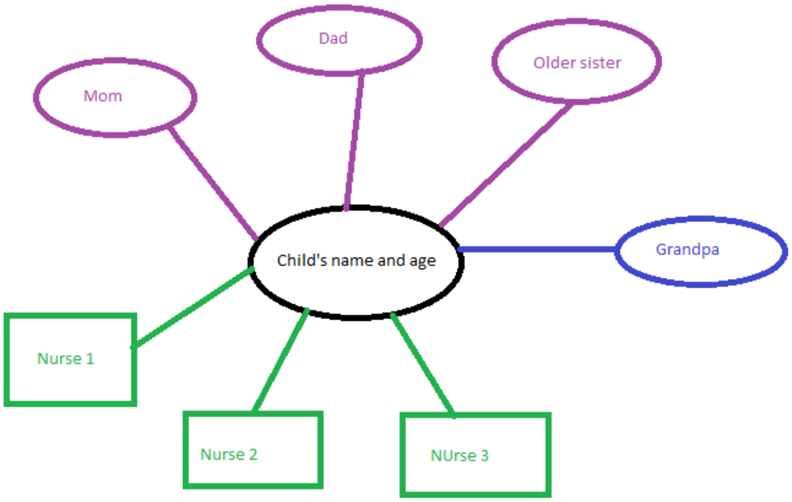
A few days before the interview, I would like to ask you to create a diagram outlining the members of your household and a description of the members of the team that provides care to your child. We will talk about your ecomap in the beginning of our interview. The ecomap is to help me understand who is in your home and caregiving circle, and to help me understand the nature of these relationships.

I have provided some instructions of how to draw this diagram (called an "ecomap") and an example of what a completed ecomap looks like below:

Instructions

1. Locate a blank piece of paper, and a pen or markers.
2. At the centre of the page, starting with your child's, add their name and age and draw a circle around their name. Then draw a family tree identifying if they have siblings (and their ages) and immediate family members in the household who provide care (e.g. parents). Use the **same colour** of pen or marker for all people who live in the same household. If there are also extended family members (e.g. grandparents, aunts, nephew etc.) who provide care, add them to the family tree but use a **different colour.**
3. Then, using a **third colour,** begin to add the names of the health care professionals (e.g. home care nurses) who, under the Family-Managed Home Care mode, enter your home to provide care for your child. Put their name in a square. Add additional information like how long they have worked for your, how many shifts per month they enter the home to provide care to your child, and how many hours per month or shifts per month they work.

Example of an Ecomap



Appendix D

Demographic Information

Family ID # ___________

1. Date of birth (month/year) _______________
2. Gender of baby
   - ☐ Male
   - ☐ Female
3. Gestational age at birth ______________weeks
4. Child's age at discharge ______________months
5. Current age of child _______________months/years
6. Medical reason for requiring tracheostomy and/or assisted ventilation _________
7. Length of time with tracheostomy and/or assisted ventilation ____________months
8. Time of birth to discharge (i.e. length of hospital stay after receiving tracheostomy to home) ___________months
9. Length of time since discharge (i.e. how long have you been home) ___________months
10. Which LHIN do you belong to? _____________
11. Please check your age range:
    - ☐ Younger than 20 years
    - ☐ 20-29 years
    - ☐ 30-39 years
    - ☐ 40-49 years
    - ☐ 50-59 years
12. Please check the highest level of education you have completed:
    - ☐ Grade 6 or less
    - ☐ Grades 7-9
    - ☐ Grades 10-11
    - ☐ High school graduate
    - ☐ Some college or university (at least 1 year or specialized training e.g. trades)
    - ☐ College or university graduate
    - ☐ Graduate professional training (e..g MA, MSc, MD, MBA, PhD)
13. Are you currently working?
    - ☐ Yes
    - ☐ No

    If yes, what is your current profession? _______________
14. Are you in family that is:
    - ☐ One-parent family
    - ☐ Two-parent family
    - ☐ Other (please specify) _____________
15. How many months have you been using the Family-Managed Home Care model? _____________months

16. How many hours per week of professional support are you entitled to? __________hours/week
17. How many of these hours is dedicated to nursing support? ___________hours/week
18. Could you estimate the number of hours you spend on coordinating care services (not direct care provision)? ____________hours
19. How many nurses, since being at home, have you worked with? ______________
20. Have you used any of your personal funds to support caregiving services for your child?
    - ☐ Yes
    - ☐ No

    If yes, how much approximately have you spent since coming home? __________ On what service(s) or supplies? _____________

APPENDIX E

Email Recruitment Script for Gatekeepers (e.g. LHIN care coordinators)

Study Title:

Family-Managed Home Care in Ontario for Families with Technology-Dependent Children

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E-mail Subject line: McMaster study about families with technology-dependent children using family-managed home care

Dear (name of gatekeeper)

My name is Andrea Fulton and I am a graduate student with the School of Nursing at McMaster conducting research as part of my graduate school thesis. I am hoping you will share my study information with families who you believe are eligible and would be interested in participating.

We are looking to recruit families of technology-dependent children who are 5 years of age or under and use the Family-Managed Home Care model to coordinate their home care nursing services. We are hoping to learn more about their experiences with home care nursing using this model of care, as there is a large literature gap as it pertains to these families and how they use home care services.

I have attached a recruitment poster you may share with families, that has details describing what participation entails, the study purpose, and contact information. Families will be compensated for their time with a $25 gift card to either Shopper's Drug Mart or Tim Horton's (participants' choice).

Below is an example of information to include in an email to potential participants:

Andrea Fulton, a McMaster graduate student, has requested we share her study information with families with technology-dependent children using the Family-Managed Home Care model to see if you are interested in participating in the research. Andrea is interested in learning more about your experiences with home care nursing using the Family-Managed Home Care model. This research is part of her Masters of Science in the Nursing Program at McMaster University.

If you are interested in getting more information about taking part in Andrea's study, please read the brief description below and **CONTACT ANDREA DIRECTLY** by using her phone number [Researcher's Phone Number – removed from thesis to maintain the researcher's privacy] or email address **fultoa1@mcmaster.ca**. Andrea will keep your choice to participate or choice to not participate confidential. Taking part or not taking part in this study will not affect any services you and your family receive for the care of your child.

Andrea Fulton is inviting you to take part in an interview with her that will last about 1 hour. This interview will be between you and Andrea only. Interviews will take place over the phone or Zoom. She will work out the details of when the interview will take place with you. Andrea hopes to learn about how families discovered this model of home care, why families choose this model of home care, how families coordinate nursing services using this model, and explore the different experiences that parents have when partnering with home care nurses who provide care for their children.

Andrea has explained that you can stop being in the study at any time during the interview or not answer questions that make you uncomfortable. She has asked us to attach a copy of her recruitment poster to this email. This poster gives you more details about the study. Andrea will also compensate you for your time with a $25 gift card to either Shopper's Drug Mart or Tim Horton's.

This study has been reviewed by the Hamilton Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have questions about your rights as a research participant, please call the Office of the Chair, HiREB at 905-521-2100 ext. 42013.

Sincerely,

Appendix F

Scripts for Commitment to Participate and Interview Scheduling

Option 1: Telephone

Hello, my name is Andrea Fulton and I am a graduate nursing student calling from McMaster University. Recently someone approached you concerning a research study about the family experience of using the Family-Managed Home Care Model to coordinate nursing services for your technology-dependent child. At that time you gave permission to release your name and telephone number to the researcher that is conducting the study. I am the primary researcher and was wondering if I could have a few minutes of your time to tell you about the study, and find out whether you are interested in participating.

I, alone with my supervisor and thesis committee members, am doing this research as part of my graduate school thesis. We want to know how parents with technology-dependent children, specifically those with a tracheostomy and/or ventilator, use home care services under the Family-Managed Home Care model. We are interested in learning about the overall family experience using this model of home care to obtain nursing services.

Your input as the parent/caregiver/service coordinator is valuable to this study. If you chose to participate, you will be asked to complete a diagram, called an ecomap, of your household, as well as participate in a one-on-one interview with me, the researcher. I will provide you with detailed instructions on how to draw the ecomap prior to the interview. Interviews will be completed over the phone or on a video conferencing app such as Zoom at a time that is convenient for you. The interviews will take about an hour. You can choose how you would like to interview, and all interviews will be done at a time and date convenient for you. With your permission, I would like to record our interview.

Participation is voluntary, and if you decide to participate, you will be compensated for your time with a $25 gift card to either Shoppers Drug Mart or Tim Horton's.

This study has been reviewed by the Hamilton Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have questions about your rights as a research participant, please call the Office of the Chair, HiREB at 905-521-2100 ext. 42013.

Would you be interested in participating?

1. <u>If response YES</u>

Thank you for agreeing to participate. To help arrange a time for the interview that is convenient to you, I was wondering…

- What days of the week are best for you to interview?

- What time of day would be most convenient – morning, afternoon or evening?
- How would you prefer to interview – over the phone or a web communication app such as Zoom?

Date, time and method of interview to be identified.
Thank you for your time and interest in participating.

2. <u>If response NO</u>

Thank you for your time and consideration of my request.

Option 2: Email
Hello, my name is Andrea Fulton and I am a graduate nursing student from McMaster University. Thank you for reaching out and expressing interest in my research study.

The researcher will ask if the potential participant would like to speak about the research over the phone or continue communication via email. If the potential participant consents to speaking on the phone, the phone number will be obtained and the script from Option 1 will be followed. If the potential participant would prefer to continue via email, the following will be sent:

I, along with my supervisor and committee members, am doing this research as part of my graduate school thesis. We want to know how parents with technology-dependent children, specifically those with a tracheostomy and/or ventilator, use home care services under the Family-Managed Home Care model. We are interested in learning about the overall family experience using this model of home care to obtain nursing services.

Your input as the parent/caregiver/service coordinator is valuable to this study. If you chose to participate, you will be asked to complete a diagram, called an ecomap, of your household, as well as participate in a one-on-one interview with me, the researcher. I will provide you with detailed instructions on how to draw the ecomap prior to the interview. Interviews will be completed over the phone or on a video conferencing app such as Zoom at a time that is convenient for you. The interviews will take about an hour. You can choose how you would like to interview, and all interviews will be done at a time and date convenient for you. With your permission, I would like to record our interview.

Participation is voluntary, and if you decide to participate, you will be compensated for your time with a $25 gift card to either Shoppers Drug Mart or Tim Horton's.

This study has been reviewed by the Hamilton Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have questions about your rights as a research participant, please call the Office of the Chair, HiREB at 905-521-2100 ext. 42013.

Would you be interested in participating?

1. If response YES

Thank you for agreeing to participate. To help arrange a time for the interview that is convenient to you, I was wondering…

- What days of the week are best for you to interview?
- What time of day would be most convenient – morning, afternoon or evening?
- How would you prefer to interview – over the phone or a web communication app such as Zoom?
- May I have your phone number and/or email for communication and interview purposes?

Date, time and method of interview to be identified.

Thank you for your time and interest in participating.

2. If response NO

Thank you for your time and consideration of my request.

Appendix G

Facebook Study Page

As part of this study's recruitment strategy, a public Facebook page will be created by the researcher to be shared across social media and in relevant social groups on Facebook. The following is a description of what will be included on this page:

1. Recruitment poster (as seen in Appendix H)
2. The McMaster University Logo
3. The researcher's name and email
4. A statement indicating the researcher is a master's student at McMaster University
5. HiREB approval number
6. Study purpose, benefits, and risks description

The following script will be included:

Hello Families!

Researchers at McMaster are looking for families with a medically complex child (aged 5 years old and under) who has had or currently has a tracheostomy with/without assisted ventilation, and who has experience in coordinating their nursing services using the Family-Managed Home Care Model in the last three years.

This study involves creating a diagram called an ecomap to visually map out your household and nursing care team, as well as taking part in a phone or Zoom interview, lasting 60 to 90 minutes. A repeat phone/Zoom interview might also be done within 4 months. You will be paid for your participation.

More details are provided below.

If you are interested in learning more about the study or have any questions, please contact Andrea Fulton at fultoa1@mcmaster.ca.

Thank you!

Study Purpose:

I, along with my supervisory and thesis committee members, am doing this research as part of my graduate school thesis. We want to know how parents with technology-dependent children, specifically those with a tracheostomy and/or ventilator, use home care services under the Family-Managed Home Care model. We are interested in learning about the overall family experience using this model of home care to obtain nursing services.

If you chose to participate, you will be asked to:

1. Draw a diagram of your household family members and nursing care team. This diagram is called an ecomap. I will provide detailed instructions of how to draw an ecomap.

2. Participate in a one-on-one interview with someone from the research team. Interviews will be completed over the phone or on a video conferencing app such as Zoom. The interviews will take about an hour. You can choose how you would like to interview, and all interviews will be done at a time and date convenient for you. With your permission, I would like to record our interview.

Potential Risks:

The risks involved in participating in this study are minimal. You do not need to answer questions you do not want to answer or that make you feel uncomfortable. We can stop the interview for a break at any time you want. You can withdraw from the interview or study at any time. Because the number of families with technology-dependent children is small, there is a chance you may be able to identify yourself in the final study version. Your personal information will be removed for analysis and in the final study product to minimize the chance of any participant being identified.

Potential Benefits:

The research will not benefit you directly. We hope to learn more about your experience with the Family-Managed Care model to help other families with technology-dependent children have easy transitions from hospital to home. We hope that what is learned because of this study will help us to better understand how nurses and doctors in the in the neonatal and pediatric intensive care units can support parents with technology-dependent children. There is not a lot of demographic information about technology-dependent children, what kind of home care nursing services they receive, or how much. We hope this study will contribute to understanding the home care nursing needs of technology-dependent children.

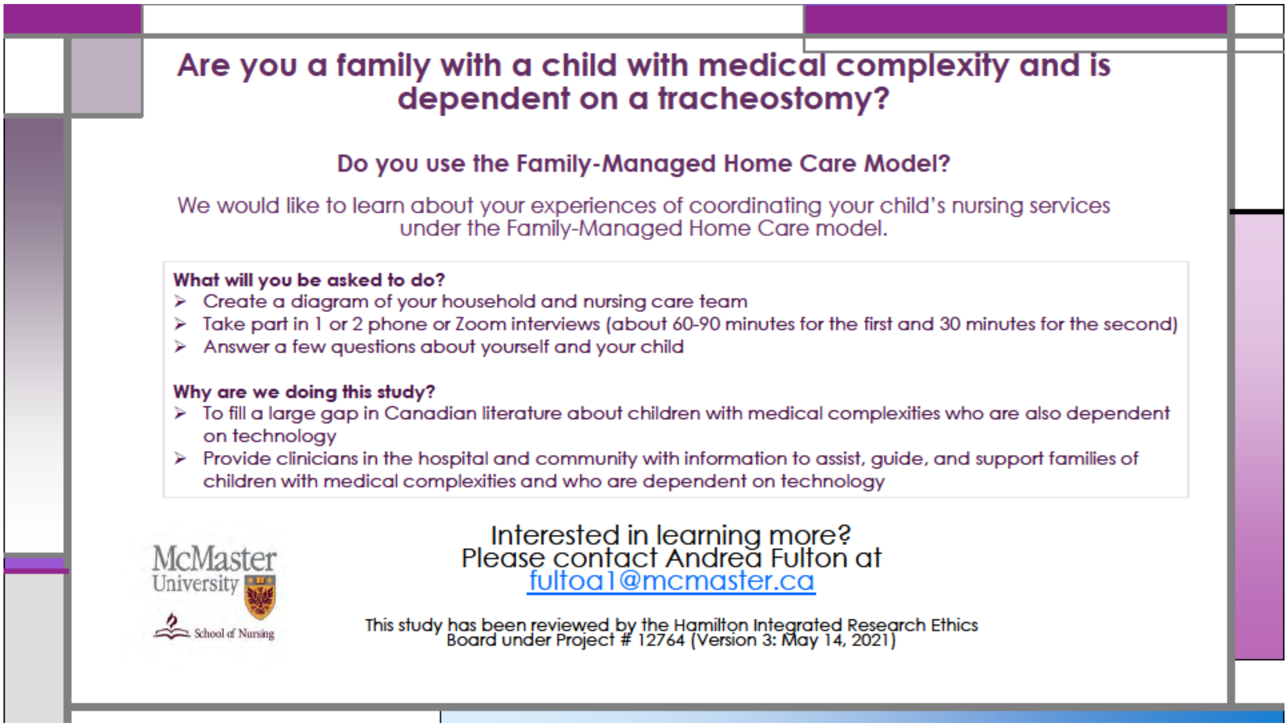
Honorarium:

If you choose to participate in this study, you will receive a $25 gift card to Shoppers Drug Mart **OR** Tim Horton’s. You will receive the gift card of your choice before starting the interview. It will not be taken away if, for any reason, you choose to stop the interview and/or withdraw from the study.

This study has been reviewed by the Hamilton Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have questions about your rights as a research participant, please call the Office of the Chair, HiREB at 905-521-2100 ext. 42013.

Appendix H: Recruitment Poster

Below is the recruitment poster that was shared on social media accounts via Twitter, Facebook, and Instagram. This poster was also shared via email amongst gatekeepers assisting with recruitment.



Are you a family with a child with medical complexity and is dependent on a tracheostomy?

Do you use the Family-Managed Home Care Model?

We would like to learn about your experiences of coordinating your child's nursing services under the Family-Managed Home Care model.

What will you be asked to do?

- Create a diagram of your household and nursing care team
- Take part in 1 or 2 phone or Zoom interviews (about 60-90 minutes for the first and 30 minutes for the second)
- Answer a few questions about yourself and your child

Why are we doing this study?

- To fill a large gap in Canadian literature about children with medical complexities who are also dependent on technology
- Provide clinicians in the hospital and community with information to assist, guide, and support families of children with medical complexities and who are dependent on technology

McMaster University
School of Nursing

Interested in learning more?
Please contact Andrea Fulton at
fultoa1@mcmaster.ca

This study has been reviewed by the Hamilton Integrated Research Ethics Board under Project # 12764 (Version 3: May 14, 2021)