Exploring Experiences of Parents of a Child with Medical Complexity: A Case Study Approach

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Abstract

Parents of children with medical complexity (CMC) have the unique experience of also being their child’s health care provider (HCP). This cross-sectional, qualitative single-case study sought to 1) examine experiences of parental caregivers of CMC whilst navigating healthcare and social systems; and 2) examine influences of urban/rural settings on parental caregiver experiences. An online demographic survey and semi-structured telephone interviews were utilized with two families, one urban (n=1) and one rural (n=2). A thematic analysis was undertaken using both intersectionality and the Conceptual Model of Health-Related Quality of Life (HRQoL) as frameworks to explore findings. This study revealed that challenges in communicating with HCPs and navigating the healthcare system, combined with the power and privilege experienced in interactions, affected the caregivers’ HRQoL, specifically in relation to individual and environmental characteristics. Focusing on alleviating systemic factors contributing to parental challenges will help to improve the HRQoL of both the parent and child.

Keywords: Children with Medical Complexity, Parental Caregivers, Rural and Urban, Health-Related Quality of Life, Paediatric Complex Care
Summary for Lay Audience

Parental caregivers of children with medical complexity (CMC) have the unique experience of being their child’s health care provider and primary advocate alongside their parental role. CMC are children who have one or more long-term conditions and require health services and health care that exceeds those used by children in the general population. Parents have expressed challenges when communicating with health care providers (HCPs) and issues with figuring out who to contact and for what purposes in the healthcare system due to its many departments. This case study aims to examine the experiences of parental caregivers as they navigate the healthcare and social systems and to examine whether living in urban/rural settings influences their experiences. An online survey was used to gather demographic information from participants and use it to form a more complete picture of their lives. Phone interviews were completed with participants to allow them to describe their caregiver experiences. All aspects of the parents’ lives, including their roles, were examined to ensure the power and privilege experienced by parents was considered. The health-related quality of life (HRQoL) of the parents was explored to identify how it is affected by their experiences as caregivers, which encompassed their individual and environmental characteristics. This study found that parents exerted power over their children in decision-making processes, given their expertise HCPs exerted power over parents, and the parents in the study expressed class privilege related to speaking English – the dominant language of the healthcare system – and having private insurance. Power within the parents’ interactions with others combined with experiencing communication difficulties with HCPs while they navigated the healthcare system affected their overall HRQoL as they consistently placed their child’s wellbeing above their own. Parents’ HRQoL was also influenced by their feelings of guilt, excitement, anxiety, and fear, their ability to adapt to their new role as parent and HCP, financial strain, and supportive social and physical environments. This study suggests that focusing on improving the systemic factors that contribute to the challenges parental caregivers face will help improve not only the parents HRQoL but also the HRQoL of their child.
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Chapter 1: Background and Significance

The experiences of parental caregivers of children with medical complexity (CMC) are shaped by the healthcare system, care providers, and the interactions between and among them. CMC are a subgroup of the larger classification of children with special health care needs (CSHCN) that are defined as children who are at an increased risk for chronic conditions and require health services/care exceeding the frequency used by children in the general population (Aboneh & Chui, 2017). CMC account for 3.2% of the CSHCN category and 1% of total children in Canada (Allshouse et al., 2018; Cady & Belew, 2017). Although CMC make up a small portion of children, they account for a third of child health care expenditures, 10% of hospital admissions, and approximately a quarter of hospital stays (Dewan & Cohen, 2013). Health expenditures are growing due to medical advancements expanding the survival rate for infants born prematurely or with chronic conditions (Cohen et al., 2011; Dewan & Cohen, 2013). The disproportionate health care utilization rates attributed to this small population underscores a significant need to examine this population’s interactions with and within our healthcare system.

The designation of CMC is broad and varies in terms of which complex chronic conditions are included (Cohen et al., 2018). The lack of a consistent definition makes it difficult to compare studies. Therefore, for the purpose of this thesis, CMC will be operationalized as children who have multiple chronic conditions, functional limitations, dependence on health services and technology, and as a result have increased medical costs (Cohen, Berry, Sanders, Schor, & Wise, 2018; Cohen et al., 2011). Due to the complexity of their needs, CMC typically require a combination of health care services such as hospitalizations and emergency visits, nursing care in the home, specialist visits, physiotherapy, over-the-counter and prescription medications, and medical equipment (Allshouse et al., 2018). Despite the universal health care coverage in Canada, families of CMC have out-of-pocket necessities not covered such as altered clothing, tailored food preparation, assistive tools for daily activities of living, utilities for equipment used, home accessibility modifications, and transportation modifications (i.e., adding in wheelchair accessibility to their family vehicle) (Allshouse et al., 2018). Given the number of appointments and financial burden, it is important to ensure parental caregivers have access to necessary resources to meet their child’s needs.
Parents of CMC express difficulty in navigating the healthcare system due to fragmentation and a lack of communication (Aboneh & Chui, 2017). The parents of CMC are typically the 24-hour primary care providers for their child and are responsible for advocating for and ensuring their child’s health care needs are met (Batchelor & Duke, 2019). The type of complexity, functional ability, and resources needed among CMC varies; therefore, health care for CMC involves a multitude of services and HCPs (Cohen et al., 2011; Dewan & Cohen, 2013). The difficulty experienced when navigating the healthcare system could be as a result of the care team and scope of care for CMC being extensive (Aboneh & Chui, 2017). The importance of a large care team is to help target CMC’s comorbidities and likely optimize care by taking those comorbidities into consideration when creating a treatment plan (Cohen et al., 2018). Complex care programs located in tertiary specialized care centers are highly beneficial if incorporated in the long-term care plan of CMC (Cohen, Lacombe-Duncan, et al., 2012). These programs are typically located in facilities within populated urban areas, which can make travel to these facilities stressful and difficult for families of CMC who are located in rural settings (Batchelor & Duke, 2019; Carnevale et al., 2006).

The difficulties parental caregivers experience in navigating complex healthcare systems, fragmentation in communication, and the financial burden of providing necessities for their children that are not covered by universal health care is an area of research that is not widely understood. To date, the literature has focused on experiences of parental caregivers of CMC in relation to the implementation of interventions designed to improve their child’s health and wellbeing with relatively few or no studies focusing on parental caregivers’ health-related quality of life (HRQoL) (Cohen & Friedman, 2012; Dewan & Cohen, 2013; Donohue et al., 2018; Edelstein et al., 2017; Kuo et al., 2018; Lin et al., 2018; Trowbridge & Mische-Lawson, 2014). Furthermore, the influence of geography (urban and rural) on the experiences of parental caregivers of CMC is an area that has not been studied in Canada and that merits investigation given one fifth of Canadians live in a rural context (Cohen et al., 2012; Statistics Canada, 2018). Parental caregivers are vital contributors to care and coordination for CMC making it essential to understand parental caregivers’ experiences (Donohue et al., 2018; Kuo et al., 2013; Nageswaran & Golden, 2018). Therefore, the purpose of this case study is to examine the experiences of and relating to the HRQoL of parental caregivers of CMC.
Chapter 2: Literature Review

2.1 The Need for Improvement in Caregiver-HCP Communication

Care coordination is essential to deliver high-quality health care services for CMC and should be structured around the needs and strengths of CMC and their families (Adams et al., 2017). Medical homes establish a comprehensive care team that is collectively responsible for the child’s care from childhood to young adulthood (American Academy of Pediatrics, 2020; American Academy of Pediatrics Council on Children with Disabilities, 2005). A medical home is not a physical place or set in a specific location, rather it is a model for family-centred care coordination that recognizes the importance of building a partnership between HCPs and families (American Academy of Pediatrics, 2020; American Academy of Pediatrics Council on Children with Disabilities, 2005). Despite pediatric medical homes being associated with better health outcomes for the child, communication between caregivers and HCPs can become difficult (Romley et al., 2017). A reduction in the frequency and quality of physician-parent communication can be experienced when there is a lack of an established long-term relationship between the family and physician (Donohue et al., 2018). Once the child transitions to a medical home, care coordination can become strained in comparison to when the child was in the hospital and had direct access to medical personnel (Donohue et al., 2018). In a study by Cady and Belew (2017), patient-and-family-centered care home models (FCMH) were implemented in tertiary-based settings to examine whether they improved communication gaps. When the model of care is implemented correctly, it is associated with an increase in caregiver satisfaction with overall care, a decrease in caregiver burden, a reduction in the number of unmet needs, and a decrease in hospital readmissions (Cady & Belew, 2017). Despite implementation successes such as including family as key members in the creation of the care plan for CMC, the medical home model has been shown to be difficult to incorporate in different care settings across the United States and Canada (Cady & Belew, 2017). These patient-and-family-centered models have been shown to increase the child’s quality of life and reduce the unmet health service needs and medical costs that are known to be sources of parental burden and stress (Aboneh & Chui, 2017; Cady & Belew, 2017; Dewan & Cohen, 2013). However, despite the model being beneficial, communication challenges still exist due to its lack of usage within the healthcare system making future improvements essential to the delivery of high-quality care coordination.
Communication challenges between caregivers and medical providers arise from the lack of general communication, lack of communication regarding resources and services, and a lack of continuity in patient information among health care departments which is influenced by the fragmentation of the healthcare system (Desai et al., 2016). Parents have expressed the need for better communication between primary care and specialty care coordinators to ensure vital information is not lost (Cady & Belew, 2017). Parental caregivers are not always part of the child’s interdisciplinary health care team which can also lead to important information being missed when exchanged between HCPs (Dewan & Cohen, 2013). A method of improving communication between patients and HCPs was examined in a study conducted by Adams and colleagues (2017), where care maps were used to help families and HCPs identify their care coordination needs and help the medical team refocus on the family’s goals for the child. Despite the perceived usefulness of care maps in facilitating communication and understanding the intricacies of being a caregiver of CMC, it is not a widely used method in clinical settings (Adams et al., 2017). Thus, while coordinating care for CMC, communication difficulties persist when methods of communication and understanding, such as care maps, are not used by HCPs in clinical settings.

2.2 Fragmentation

Fragmentation of the healthcare system can be understood as occurring when the divisions in the healthcare system cause difficulties for patients and parents when navigating resources and services (Romanow, 2002). Fragmentation of the healthcare system is reported as one of the greatest challenges caregivers of CMC face (Abraham et al., 2016; Cohen et al., 2018). Caregivers of CMC oversee the daily care of their child and are expected to work with multiple systems that often do not communicate and coordinate with each other (Cady & Belew, 2017; Kuo et al., 2013; Romanow, 2002). A consequence of fragmentation is that in emergency situations, it may be difficult for medical professionals to effectively gather all salient information to treat CMC (Christian, 2010). When care coordination across clinical settings and specialties is optimal, it not only improves the quality of care for the child but also the quality of life of the caregivers (Berry et al., 2011). However, the lack of communication and coordination that results from the fragmented healthcare system, where in many HCPs from various fields are a part of the sphere of care for CMC, leaves parents to navigate and implement the many prescribed care plans (Aboneh & Chui, 2017). In a study by Aboneh and Chui (2017) in the
United States, a secondary data analysis of the 2009-2010 National Survey of CSHCN revealed that 68% of parents expressed unmet care coordination needs compared to 40% of parents of pediatric patients who were not medically complex, primarily as a result of the many medical services and personnel CMC require. According to Kuo and colleagues (2011), who did a secondary analysis of the 2005-2006 National Survey of CSHCN, CMC were more likely to have numerous unmet medical needs and half of families with CMC were found to have unmet medical service needs and a third of them found it difficult to access nonmedical services. In a study by Leyenaar and colleagues (2018), 29 parental caregivers of CMC and 37 HCPs participated in a two-round Delphi process to evaluate the importance and feasibility of transitional care for CMC. The items rated not feasible by the HCPs – such as the child’s healthcare team contacting the primary care provider prior to discharge, documenting families’ post-discharge priorities in a child’s medical record, and the healthcare team contacting social supports to provide information – showcases the issues that arise with the healthcare system being fragmented (Leyenaar et al., 2018). These items were assessed as important but not practiced due to the structuring of the healthcare system.

Difficulties arising from the fragmentation of the healthcare system are not limited to hospital settings. Fragmentation is also experienced by parents of CMC at home when they try and prepare for their child’s discharge, which includes setting up medical equipment and ensuring they have necessary supplies. However, oftentimes these tasks are met with difficulty and frustration given the parents lack of health care training and knowledge of navigating the system (Cady & Belew, 2017). Difficulties preparing the home would be easier to overcome if parents could communicate with one individual from the hospital; someone to whom they could direct all their questions rather than spending time on navigating who to contact (Cady & Belew, 2017). Therefore, fragmentation of the healthcare system and a lack of communication between HCPs and caregivers makes it difficult for parents of CMC to achieve optimal wellbeing for themselves and their child.

2.3 Unnecessary Hospital Readmissions and Discharge Delays

Unnecessary hospital readmissions and discharge delays for CMC have become a measure of quality of care within the healthcare system (Maynard et al., 2019). Medical advancements have increased the survival rate of CMC, and as such the home care nursing demand has increased within the last two decades and has become a necessity in the respite care
team for CMC (Manhas & Mitchell, 2012; Maynard et al., 2019). The high demand of home care nurses has become an issue as there are not enough nurses to provide respite care for all CMC, leading to delayed hospital discharges and increased readmissions (Maynard et al., 2019). A prospective longitudinal study conducted over 12 months by Maynard and colleagues (2019) examined discharge delays and the availability of home health care for CMC and found that the unavailability of home care nursing was the main cause of 91.9% of discharge delays which decreases quality of life for the child and increases parental stress since they are in an uncomfortable environment. Although CMC are at an increased risk for readmissions, some may be avoidable as indicated in a retrospective cohort analysis study of 317 643 patients by Berry and colleagues (2011) that sought to describe pediatric hospital utilization characteristics for children experiencing continuous readmissions. They found that nearly a third of children with complex chronic conditions who were readmitted four or more times were admitted for a persisting issue previously treated during another hospital stay (Berry et al., 2011). In a Canadian study by Cohen and colleagues (2012), examining Ontario hospital discharge data from 2005 to 2007 of 15 771 CMC that were hospitalized, the authors reported two-year readmission rates of 39% of CMC with one chronic condition and technological assistance (TA) and 78.3% with multiple chronic conditions and TA (Cohen et al., 2012). Although CMC do have necessary hospital visits, the high frequency of readmissions coupled with the medical fragility of this population underscores a need to reduce the frequency of hospital readmissions to help prevent them from getting secondary diseases from their hospital stay.

Family engagement is essential to the transition of care, particularly during readmissions to the hospital. In a study by Nelson and colleagues (2016), qualitative, semi-structured interviews were conducted with 35 parents of CMC who were hospitalized in the United States to determine if parents believed their child’s hospitalizations were avoidable. The parents in the study did not indicate that any of the hospitalizations were avoidable but conveyed their belief of their child being highly susceptible to illnesses because of their many complex conditions which could lead to future admissions that could have been prevented (Nelson et al., 2016). Leyenaar and colleagues (2017) conducted a study interviewing 23 parental caregivers of CMC and 16 HCPs to explore hospital-to-home transition priorities of families. The authors found that parental perception of their child’s susceptibility to illnesses can contribute to the frequency of hospital admissions, particularly when new symptoms arise, leading to a lower threshold for
parents to seek medical help (Leyenaar et al., 2017). Hospital readmissions have been shown to decrease when parents support the discharge readiness decisions of HCP (Leyenaar et al., 2017).

The constant changes in clinical status of CMC while in the hospital make it difficult to discuss plans regarding discharge. Parents in the study by Leyenaar and colleagues (2017), introduced above, felt that the discharge process could be improved as they oftentimes left the hospital later than the time they were told and/or left feeling ill-prepared (Leyenaar et al., 2017). Parents were fearful of potential readmissions due to unattainable medical goals that were not met once home, coupled with the feeling of a loss of control via disruptions to their at-home routine when adjusting to the routine of the hospital (Leyenaar et al., 2017). The HCPs echoed the sentiment parents had about the discharge process feeling rushed and they indicated that it is uncommon for HCPs to ask parents their preference for the time of day to be discharged, leading to high-anxiety night discharges (Leyenaar et al., 2017). Alternative arrangements also need to be made if parents have other dependents as this often leads to families dividing themselves between their children (Cady & Belew, 2017). Therefore, there should be a focus on decreasing unnecessary hospital readmissions and discharge delays as it may decrease the HRQoL of the child and the parent.

2.4 Impact on Caregivers

Parental caregivers strive to overcome challenges and achieve optimal quality of life resulting in becoming increasingly adaptive by caring for their child (Peckham et al., 2014). In a pilot study led by the Hospital for Sick Children (SickKids), a Caregiver Framework was implemented for caregivers identified as at-risk due to frequently providing continuous high-level specialized care (Bradshaw et al., 2019; Peckham et al., 2014). Caregivers defined as “at risk” were those under stress due to the intensity in meeting their child’s health needs physically, emotionally, socially, and financially (Peckham et al., 2014). A study by Allshouse and colleagues (2018), written by four parents of CMC, provided a firsthand overview of the difficulties families of CMC experience. The authors reported that parents often experience feelings of emotional distress which was shown to decrease when parents had a peer support system or used peer support programs to discuss their feelings and struggles (Allshouse et al., 2018). Parents in this study experienced sleep deprivation, feelings of isolation, and chronic stress which have been shown to manifest into physical symptoms (Allshouse et al., 2018; Bradshaw et al., 2019; Peckham et al., 2014). However, not all parents have a peer support
system or the same level of access to these programs making the impacts of caring for CMC vary among caregivers (Manhas & Mitchell, 2012; Rennick et al., 2019).

Parents not only deal with the daily fluctuations in their child’s care and health status but also with the mental strain of being uncertain of their child’s illness trajectory (Donohue et al., 2018). In a study by Batchelor and Duke (2019), interviews were conducted to examine chronic sorrow in 12 parents, primarily mothers, who had children who were chronically ill. Although this study did not focus specifically on parents of CMC, it is important to include because of the overlap in experiences between parental caregivers of CMC and parents who have children who are chronically ill. Batchelor and Duke (2019) defined chronic sorrow in parents as an emotional response that is typical after experiencing a loss of what they would consider a ‘normal child’ or ‘idealized child’. One of the main themes in the study was the battle with daily life that parents reported, particularly while managing family roles, family needs, and their careers. Many of these parents indicated they prioritized their advocate role in order to do what they thought was best for their child (Batchelor & Duke, 2019). Parents in this study also discussed their battle with the healthcare system, which they believed did not understand their specific expertise and desires (Batchelor & Duke, 2019). Therefore, given the similarity between parents who have children who are chronically ill and parents who have CMC, it is likely that parental caregivers of CMC might also experience negative psychological impacts attributed to a lack of support and the constant balancing of life responsibilities.

Parental responsibility increases once the child transitions home as there are fewer immediate resources and people in comparison to when they were in the hospital sharing the responsibility with HCPs (Manhas & Mitchell, 2012). Parents are the ones faced with the challenge of adapting care plans to the home environment and to create a sense of normalcy (Manhas & Mitchell, 2012). A study conducted in Alberta, Canada by Manhas and Mitchell (2012) examined transitions from hospital care to home care by interviewing 19 health professionals, 3 family members, and 4 government representatives. The study reported that the relationship between families and hospital personnel was disconnected once the child was discharged; thereby, positing there was additional stress on families as they needed to forge new bonds with the home care team (Manhas & Mitchell, 2012). Once transitioned into home care, Mandic and colleagues (2017), who studied the impact on employment and time of parental caregivers of 153 CMC, found that the lack of home care nurses and unpredictability of respite
care services led to an increase in stress as caregivers were expected to fill in gaps of service and be available all times of the day (Mandic et al., 2017). On weekdays, 50% of parental caregivers reported on average spending 8 daytime hours (between 6am to 6pm), all 6 evening hours (6pm to midnight), and sometimes all 6 night-time hours (midnight to 6am) providing care for their child (Mandic et al., 2017). According to Cady and Belew (2017), who studied the parent perspective on care coordination services for their CMC, when home care nursing is available, there are variations in caregiver satisfaction of the home care received. The varying skill levels of the nurses who help with home care increased anxiety levels among caregivers, leading them to either train the nurses on how to care for their child or to supervise the nurse during the care process, as found in a qualitative study by Nageswaran and Golden (2017). These authors conducted 20 semi-structured interviews with caregivers of CMC and 4 focus groups with 18 home care nurses. The everyday demands of parental caregivers of CMC contribute to an increased likelihood of having poorer emotional and physical health in comparison to parents of children who are non-complex and healthy (Christian, 2010). Parents of CMC oftentimes sacrifice their own wellbeing to ensure their children are cared for, which can contribute to being overwhelmed and burnt out.

2.5 Financial Impact on Caregivers

Caring for CMC can have a detrimental impact on family finances despite Canada’s universal healthcare system. In Ontario, Canada, all hospital care and physician appointments are covered through the Ontario Health Insurance Plan (OHIP) (Cohen, et al., 2012). Other types of health services such as medications, home care, and devices, are covered by the government, private insurance companies, or out-of-pocket payments (Cohen et al., 2012). The Ontario Drug Benefit Program covers the costs of most medications required for low-income individuals and most children considered medically high-risk (Cohen, et al., 2012). Despite this universal coverage, in a study by Cohen and colleagues (2012), focused on Brampton and Orillia, the authors examined costs associated with care for CMC. Families reported an average of $2267 per month out-of-pocket (Cohen, et al., 2012). Parents of CMC reported an increase in out-of-pocket costs in the first 6 months of the study from a $813 median at baseline to $3111 median per month, but then experienced a decline to $538 median per month at the 12-month mark (Cohen, et al., 2012). Although this study reported a decline in out-of-pocket costs, it was a pilot study.
that has not been widely implemented. Families of CMC still report high health care demands associated with financial burden and unmet medical needs (Cohen et al., 2012).

More than half of families of CMC have one parent stop working after their child is born to provide the care the child needs (Cohen et al., 2018). Due to the frequency of families of CMC becoming single-income households, it is possible that they may experience a form of poverty (Thomson et al., 2016). A study by Thomson and colleagues (2016) assessed the financial and social hardships of 167 families of CMC and compared them to those experienced by families who have children with asthma. They found that the most common financial hardship reported by families of CMC was the need to borrow money in the last year and 33% could not rely on family or friends for a loan. In an American study conducted by Mandic and colleagues (2017) where a survey was distributed to caregivers, out of 95 respondents 75% of primary caregivers and 53% of spouses reported experiencing employment losses as a result of caring for CMC. As such, the monthly expenditures to provide adequate care for CMC as well as the financial burden of changing from a dual income to single income household together can increase the financial strain experienced by parental caregivers of CMC.

2.6 The Role of Geography

Specialized care clinics for CMC are generally within urban children’s hospitals, which can be inherently problematic if families live in rural or remote communities (Kuo et al., 2013). Research tends to only focus on families in urban areas which can lead to a lack information as to what rural families of CMC need (Skinner & Slifkin, 2007). In an American study, CMC located in rural communities (n =13 006) were less likely to be seen by a pediatrician (OR = 0.82, P <.01) and more likely to receive care at a health center (OR = 1.44, P < .01) than CMC from urban areas (Skinner & Slifkin, 2007). This aligns with another other study where parents of CMC in rural areas expressed the concern that their local medical system was unable to appropriately care for their child in the event of an emergency (Kuo & Houtrow, 2016). The inadequacy of health care services in local rural hospitals necessitates that if CMC need care, they must travel to hospitals in larger urban centers which are well resourced and better positioned to meet their complex health care needs (Cady & Belew, 2017). The difficulty in accessing care for CMC who live in rural communities is two-fold – time inequity and lack of access (Romley et al., 2017). Frequent travel to these specialized care centers can be stressful for parents due to time inequities as they experience quick physician visits in comparison to the
extensive travel time. Improving access to medical homes have been shown to improve health outcomes for CMC and their caregivers despite other worries that accompany home care (Donohue et al., 2018). Medical homes provide a continuity of care despite the location of the child, which is essential for CMC living in rural areas (Bristow et al., 2018; Nageswaran & Golden, 2017). Methods that have been piloted and found to decrease the need for constant travel for families living in rural areas should be more consistently implemented in these communities, which would benefit the quality of life of the parents.

Rural children face barriers in accessing care because of the current healthcare infrastructure that results in a greater likelihood of them having longer travel times to HCPs and a shortage of HCPs for the care they need (Skinner & Slifkin, 2007). In a study using data from the National Survey of CSHCN in the United States, by Skinner and Slifkin (2007), that looked at the rural and urban differences in barriers to care for CSHCN, they found that the reasons rural families with CSHCN delay getting some types of care were different in comparison to children in urban settings with the main reason being that the type of care needed for rural CSHCN was not provided in their area and they had challenges with transportation. Rural parents of CMC experience similar challenges to urban parents; however, due to their location they face the added challenge of long-distance travel, longer wait times, and a greater difficulty in accessing services because the services are non-existent in their small rural communities (Skinner & Slifkin, 2007).

2.7 Addressing the Gaps

Existing literature on the topic of CMC is limited and focuses on the experiences and wellbeing of the child, while typically negating the HRQOL of the parents who are the primary caregivers. The scant literature that addresses caregivers does so in relation to specific child-focused interventions designed to improve their life expectancy and quality of life and in which caregivers play a role. Moreover, there are very few Canadian studies related to the finances of parents of CMC and how to potentially lower their expenses; moreover, those in existence are also limited to piloted studies. There are very few Canadian studies in general about CMC and those that have been conducted were done so in highly populated urban areas such as Toronto and, as noted above, are primarily about the child’s health and experience rather than the parents (Dewan & Cohen, 2013; Manhas & Mitchell, 2012; Peckham et al., 2014). Currently, literature for Southwestern Ontario, specifically the city of London, does not exist despite there being a
specialized clinic for CMC in this city; thereby making it important to study the population in this area. It has been shown that when parents of CMC lack social support and feel as through their own HRQoL is suffering as a result of the continuous daily care they provide for their child, it has the potential to negatively affect their child’s HRQoL because of the reliance of the child on the parents (Kvarme et al., 2016). Therefore, understanding the experiences of parents of CMC is essential because by improving parental HRQoL, the child’s HRQoL is ultimately improved since these children rely on their parents throughout their lives.
Chapter 3: Methods

3.1 Purpose

The purpose of this case study is to examine the experiences of and relating to the HRQoL of parental caregivers of CMC. This study will further address gaps in the literature by examining both urban parents within London, Ontario and parents who reside in rural areas surrounding London, Ontario.

3.2 Objectives

The objectives are to 1) examine the experiences of parental caregivers of CMC whilst navigating healthcare and social systems; and 2) examine whether living in urban or rural settings influences the experiences of parental caregivers of CMC.

3.3 Case Study Method

This study used a single-case study exploration method which links data to propositions (Yin, 2003). The propositions are considered part of the criteria for interpreting any findings and are based on data collected from the literature review. Propositions are statements that allow the researcher to direct attention to an idea that will be analyzed in the case study (Baxter & Jack, 2008). Using the proposition method for analysis ensures that the scope of the study is followed and is the focus for data collection and analysis. Propositions can be viewed as hypotheses which overall answer a greater question for exploratory studies (Yin, 2003). While propositions are not always used for exploratory studies due to the potential lack of literature, the literature review done for this study served as a detailed guideline for the propositions that will be discussed during analysis. The following are the propositions that were used:

1. Communication challenges
2. Fragmentation of the healthcare system
3. Unnecessary hospital readmissions and discharge delays
4. Impact on caregivers – Note: this proposition includes all aspects impacting caregivers that are not financial in nature (i.e., emotional, psychological, physical)
5. Financial impact on caregivers
6. Rural and urban divide

An intersectional lens was used throughout this study to frame the contexts of the participants and help explore the ways in which caregiver experiences are impacted by various
factors that ultimately impact their HRQoL. According to Cho, Crenshaw, and McCall (2012), what makes an analysis intersectional is not the use of the term intersectionality within the writing but rather the use of an intersectional ideology to discuss the relation of power to the idea of sameness and differences (Cho et al., 2012). The concept of intersectionality involves the understanding and incorporation of the various interconnected identities of an individual or group that create their lived experience and ultimately contributes to their discrimination, disadvantage, and/or lack of privilege (Crenshaw, 1991). Employing this idea to the vulnerable population in this study, it can be proposed that CMC are a vulnerable population that are different, making their parents different from other parents who do not have CMC. Behind this recognizable difference is the theme of structural power and powerlessness.

3.4 Link to Health-Related Quality of Life Theory

The Conceptual Model of Health-Related Quality of Life theory presented by Ferrans, Zerwic, Wilbur, and Larson (2005) was used as the framework for analysis. The domains of Characteristics of the Individual and Characteristics of the Environment became codes, and the following factors became subcodes under each domain: biological function, symptoms, functional status, general health perceptions, and overall quality of life.

Figure 1: Revised Wilson and Cleary model for Health-Related Quality of Life (Ferrans et al., 2005).

The conceptual model incorporates individual and environmental factors that make up someone’s HRQoL. Quality of life has been redefined over the years as it has held a variety of
meanings within literature (Ferrans et al., 2005). The term HRQoL has been used to differentiate the aspects of quality of life specifically related to an individual’s health (Wilson & Cleary, 1995). The revised conceptual model of HRQoL focuses on individual and environmental characteristics as the main domains of the conceptual model, and the other aspects are explained in relation to those two domains. Characteristics of the individual in the revised model involve personal determinants of health and include factors that are psychological, developmental, and demographic. An individual’s social or physical environment are used to determine the specific environmental factors that affect their HRQoL. Social environment includes interpersonal relationships and social influences such as influences of family, friends, and HCPs on an individual’s health (Ferrans et al., 2005). Physical environment involves the actual environmental settings people experience that may impact their health such as their homes and workplaces (Ferrans et al., 2005). According to Wilson and Cleary (1995), any evaluation of quality of life should take into account an individual’s values and situation appraisals since life satisfaction is experienced differently even when in homogeneous situations. Life satisfaction should be assessed by asking an individual how they feel about their own quality of life, which can be achieved through a series of questions or one single all-encompassing question (Ferrans et al., 2005). This HRQoL model will be used to contextualize participants HRQoL in relation to their caregiver duties.

This model was selected as it incorporated both individual and environmental data to determine HRQoL which fits with the study’s purpose and data collection methods, specifically the nature of the questions asked in the interviews. Quality of life should not be based on medicalized ideals but rather how fulfilled individuals feel in their lives. There are many quality of life theories but not very many that are specific to HRQoL. Some theories include aspects in which this study cannot conclude such as goal creation and attainment or cross-cultural elements. Therefore, this revised conceptual HRQoL model by Ferrans and colleagues (2005) was determined to be the best suited for the analysis of this study.

### 3.5 Sample and Recruitment

This current study is part of a larger needs assessment and cost analysis for CMC in rural and urban areas called Complex Care Kids (CC Kids). Due to the COVID-19 pandemic and recruitment being unable to resume, the CC Kids study was closed on May 31, 2021. This current case study utilized the same sample and primary data collected for the CC Kids study but
analysed it for a separate purpose. The coding for the online questionnaire and the interviews utilized were conducted by the author of this paper.

Prior to recruitment, ethics was approved on July 20, 2019 by the Health Science Research Ethics Board and on October 21, 2019 by Lawson Health Research Institute (Appendix A; Appendix B). Participants were recruited through the Paediatric Complex Care Outpatient Program at the London Children’s Hospital. The clinic serves patients from both London and the surrounding areas. Posters were placed throughout the clinic as part of the recruitment process to engage families to participate in the study (Appendix C). COVID-19 impacted recruitment, as the goal was to recruit a sample of 40 caregivers (n=20 caregivers from urban areas and n=20 caregivers from rural areas). Recruitment was stopped at the discretion of the director of the Paediatric Complex Care Outpatient Program in London at the start of the pandemic and has yet to resume. As such, the methods for this study pivoted from an interpretive description approach to this single-case study approach focused on the existing three participants (two families total) that were recruited prior to the March 2020 pandemic lock down.

Parents attending the Paediatric Complex Care Outpatient Program were informed by a nurse practitioner about the ongoing study and asked if they were interested in learning more. If they were, their contact information was forwarded to the research assistant. The research assistant then either called or emailed the parent to provide a brief description of the study via the letter of information as well as the informed consent form (Appendix D). Parents were screened via a phone call or email and their eligibility was determined based on the following inclusion criteria. The parent: 1) had a child in their family with medical complexity between the ages of 0 to 18 years; 2) lived in London or at least a 30-minute drive from London; 3) spoke English; and 4) was willing to have an interview audio recorded (Appendix E; Appendix F). Eligible parents were asked to return the consent form via email.

3.6 Data Collection

Data collection was twofold: an online questionnaire and a semi-structured telephone-based interview. Each will be discussed below, in turn. Prior to any data collection, the researcher obtained informed consent by reviewing the letter of information again with participants before the interviews began and obtained verbal consent to record the interviews.

3.6.1 Questionnaire. The online questionnaire was facilitated through Qualtrics, and a link was distributed to participants via email. Only the demographic section of the questionnaire was
used in this study (Appendix G). Demographic data included: gender, age, marital status, education, employment status, gross family income, ethnic background, whether participants were born in Canada, whether participants lived in an urban/rural community, number of children, and whether the child was capable of physical activity.

3.6.2 Interview. The semi-structured interview occurred over the telephone and was arranged based on each participant’s availability. Interviews were audio recorded and used a semi-structured interview guide focusing on gaining an understanding of experiences, needs, challenges, and facilitators of families with CMC related to health and social services (Appendix H). The questions asked are listed below under each construct. The interviews lasted approximately 60 minutes and upon conclusion of the interview, the researcher thanked the participants for their time and participation in the study and provided them with a debriefing form (Appendix I). Interviews were transcribed verbatim by an undergraduate research assistant and finalized by the researcher. Fieldnotes were taken during the interview by the researcher.

3.6.3 Research Objective 1: Examine the experiences of parental caregivers of CMC whilst navigating healthcare and social systems.

The numbers below under each research objective correspond to the specific questions numbered in the interview guide that were used for data collection for each proposition (Appendix H).

3.6.3.1 Proposition 1: Communication Challenges

1) Can you describe what health care is like for you child? + probe: How would you describe the relationship with your child’s health care and/or service providers?; 3) What are the barriers for your child in accessing health care? + probe: are there any barriers for you or your family in accessing health care?; 7) Who is currently responsible for the coordination of your child’s care?; 8) Does your child have access to all the care they need? + probe: Why do you feel they are missing? 13) Can you describe your first transition home; + probe: Did you have a clear plan of action for ‘next medical steps’ for your child after arriving home?; + probe: What supports were available at the time of transition?

3.6.3.2 Proposition 2: Fragmentation of the healthcare system

1) Can you describe what health care is like for your child? + probe: How would you describe the relationship with your child’s health care and/or service providers?; 2) When have you used hospital-based services?; 5) What are some of the opportunities for enhancing or
improving existing care?; 7) Who is currently responsible for the coordination of your child’s care?; 8) Does your child have access to all the care they need? + probe: Do you feel there are any key players missing in your child’s care? Why?; 12) Can you describe the transition process + probe: What changes in the healthcare system would help families during the transition period?; 13) Can you describe your first transition home? + probe: What supports were available at the time of transition? (i.e., What did you know at that time and what have you learned since?)

3.6.3.3 Proposition 3: Unnecessary Hospital Readmissions and Discharge Delays

1) Can you describe what health care is like for you child?; 2) When have you used hospital-based services?; 3) What are the barriers for your child in accessing health care?; 4) What are the facilitators for your child in accessing health care?

3.6.3.4 Proposition 4: Impact on Caregivers

5) What are some of the opportunities for enhancing or improving existing care?; 10) What do you think is needed to improve the quality of life for your child? + probe: For you?; 12) Can you describe the transition process for your family? + probe: Can you describe the days before the transition? How were you feeling? + probe: How did you feel a week after the transition? A month?

3.6.3.5 Proposition 5: Financial Impact on Caregivers

3) What are the barriers for your child in accessing health care? + probe: What type of funding do you receive for your child specifically that you don’t pay out of pocket? (related to previous question answer) 6) What would make care for your child more effective? + probe: In terms of financial burdens, what would ease that stress? + probe: Of the changes you wish to make, which would be the main priority?

3.6.4 Research Objective 2: Examining whether living in urban or rural settings influences the experiences of parental caregivers of CMC.

3.6.4.1 Proposition 6: The Rural and Urban Divide

6) What would make care for your child more effective + probe: In terms of financial burden? + To enhance you and/or your child’s quality of life?; 8) Does your child have access to all the care they need? + probe: Are you able to follow through on what the health care provider(s) recommend? 12) Can you describe the transition process for your family? + probe: How long does it take you to travel to the hospital if you had to keep going back and forth? Was it a long distance?
3.7 Data Analysis

Data analysis began once all interviews were completed. Quantitative data from the demographic questions were used for descriptive purposes only. Content analysis of the interviews and fieldnotes were conducted after transcriptions were completed. A coding structure using the propositions (i.e. communication challenges, fragmentation, unnecessary hospital readmissions and discharge delays, impact on caregivers, financial impact on caregivers, and the urban and rural divide); domains of the HRQoL model (i.e. characteristics of the individual and environment); and the intersectional lens (i.e. structural power and powerlessness) was created prior to coding. This initial coding structure was inputted into NVivo, a qualitative data analysis software program. Then transcripts were read in their entirety prior to the start of coding. First, line-by-line coding was done wherein quotes were placed into the appropriate codes in the existing coding structures (Charmaz, 2008). Next, open coding of the qualitative data was conducted to find any larger themes that seemed to emerge (Corbin & Strauss, 1990). Following open coding, axial coding was conducted with the propositions in mind. The propositions were created based on the findings in the literature; however, axial coding was conducted to ensure that the propositions used were as relevant to the study data as possible. The propositions were used as a focus area while axial coding; therefore, it is possible that the propositions and axial codes may be the same or slightly modified. The goal of axial coding is to examine the relationship between the codes (Corbin & Strauss, 1990). During all stages of coding the initial coding structures created a starting place for analysis, but there was freedom to add codes to the existing coding structure or to not use codes based on what emerged from the data. Coding was done independently by the researcher, undergraduate research assistant, and one co-supervisor.

3.7.1 Data Trustworthiness

Data trustworthiness in this study was supported through attending to the four criteria indicated by Lincoln and Guba (1986): credibility, transferability, dependability, and confirmability. Their criteria stemmed from the traditional validity determinants of internal validity, external validity, reliability, and objectivity with data trustworthiness being similar to the term rigor (Lincoln & Guba, 1986).

3.7.1.1 Credibility. Credibility is determined by the confidence in that research findings are truthful and believable (Guba & Lincoln, 2005). For this study, credibility is held through a variety of factors, firstly by use of triangulation or cross-checking of the data through different
sources (Lincoln & Guba, 1986). A literature review was conducted to ensure there were gaps in the literature that would require a study to be conducted. The methods of the study also had to be changed because of the COVID-19 pandemic and this change was discussed with and approved by the researcher’s two co-supervisors and two thesis advisory committee members. Prolonged engagement and persistent observation are difficult factors to test for credibility in this study given there were only three participants total, and two were parents of the same child; however, the interviews conducted were insightful. Because participants directly answered the researcher’s questions during the interview, there was little need for exploration of negative case analyses since they expressed their reasoning for their answers. Member checking was continuously done during the interviews by the researcher reiterating to the participant their understanding of the responses given; thereby, giving participants the opportunity to correct the researcher’s interpretation or to expand on their answers.

### 3.7.1.2 Transferability

Transferability refers to the extent that research findings can be generalized to other contexts or settings which can be shown through data collection being representative of the population in some way (Guba & Lincoln, 2005). The demographic data collected during the questionnaire provides an accurate representation of participant contexts. Because the participants and the associated findings are analyzed through an intersectional lens, their contexts and social determinants of health are taken into consideration, making the transferability of data much easier.

### 3.7.1.3 Dependability and Confirmability

Dependability refers to the replicability of a study if it was conducted in another location under equal circumstances (Guba & Lincoln, 2005). Confirmability is related to the objectivity of the data and if findings can be traced through several analysis steps (Guba & Lincoln, 2005). This section of data trustworthiness is grouped together by Lincoln and Guba (1986). An external audit is required as part of the criteria to determine data dependability and confirmability. The final audit for this study was carried out by one co-supervisor. The audit of the process determines the dependability, and the audit of the findings determines the confirmability (Lincoln & Guba, 1986). Data analysis was conducted independently by the researcher, and an undergraduate research assistant and one co-supervisor aided in the dependability and confirmability judgement.
3.7.2 Reflexivity and Memoing

While conducting data analysis, memoing took place to ensure the acknowledgement of any potential biases. Reflexivity draws attention to the fact that a researcher’s own subjective biases may influence data collection and interpretation since researchers tend to immerse themselves in their data and the participants (Birks et al., 2008). Memoing helps the researcher record thoughts, feelings, and interpretations that would otherwise be lost if not written down (Birks et al., 2008). Memos work in tandem with fieldnotes and transcripts since they reflect the researcher’s personal insights at specific moments during the research process.

The case study method employed for analysis requires the researcher to immerse themselves in the data to develop and conceptualize propositions to ultimately produce knowledge (Yin, 2003). Therefore, memoing was used throughout this study process, specifically while collecting and analyzing data. Fieldnotes written during interviews were then followed by reflexive memoing to ensure a distinct separation from content expressed during the interview and the researchers own personal thoughts. It is also important to note that memoing was also conducted while creating the propositions used for the literature review and the focus for coding.

3.8 Self-Reflection

Although I do not have a direct personal connection with CMC, I acknowledge the potential biases I may have since I was raised by a single mother who has chronic conditions. Because I was raised by a single mother, my family has dealt with prolonged financial difficulties which caused not only myself but my mother tremendous stress. I have first-hand experience with how chronic stress can be detrimental to one’s body as this is what negatively impacted my mother’s health. My mother has always put the health of myself and my brother before her own, which impacted her quality of life. I acknowledge the potential biases I may have towards this similarity between what I am researching and my own life experiences.
Chapter 4: Results

4.1 Participants

Robert and Catherine are married and live together with their son, Alex, in a rural community. Robert is between the ages of 25-35 and has completed a university undergraduate degree. He was diagnosed with depression and is currently on a disability leave from work; therefore, both Robert and Catherine look after their 2-and-a-half-year-old son full-time. Their annual gross family income is between $50,000 and $99,999. Robert was born in Canada and identifies as a third-generation Dutch immigrant. Prior to Robert being on medical leave, Catherine chose to work from home so she could care for Alex throughout the day.

Wendy is a 45-year-old French-Canadian female who was born in Canada and lives in a large city. Wendy completed community college, is married, and chose to stay home as a full-time caregiver to her son, Connor, who has medical complexities and cannot walk. Connor is 17 and has one other sibling. While Wendy looks after her son, her husband goes to work to financially provide for the family. Their annual gross family income is between $50,000 and $99,999.

4.2 Summary of Case Study Findings

The results of the case study revealed five emerging themes based on the six previously created propositions: 1) communication challenges, which are any difficulties parents have communicating with HCPs in the healthcare system regarding their child’s health; 2) fragmentation, which can be understood as divisions within the healthcare system that cause difficulties for parents in navigating resources and services; 3) preventing unnecessary hospital readmissions, which includes any technology or supports that help keep the child in the home; 4) impacts on the caregiver, which encompasses any physical, psychological, and emotional effects the parents revealed were a result of being a parental caregiver; and 5) financial impacts, which are any financial difficulties that have occurred as a result of being a parental caregiver (Figure 2.). The experiences of caregivers are shaped by the themes listed above which all directly impact their HRQoL. The impact on caregivers theme and financial impact theme showcased data directly relating to the two main domains of the HRQoL theory: characteristics of the individual and characteristics of the environment. Therefore, these themes will be specifically explored in relation to the HRQoL theory through the inclusion of individual and environmental
factors that influence a person’s HRQoL per Ferrans and colleagues’ (2005) interpretation of the Conceptual Model of HRQoL.

*Figure 2:* Results framework, enacted within the context of structural power and powerlessness including the power relationships present, showcasing the interplay between and among the propositions, power relationships, and HRQoL.
4.3 **Context: Structural Power and Powerlessness**

The structural approach to power and powerlessness posits the creation of this power dichotomy within social groups can be attributed to pre-existing divisions within society (Tew, 2006). Certain groups within society have advantaged access to resources due to social privilege and as such, are positioned to exert power over others (Tew, 2006; Zoino-Jeannetti & Pearrow, 2020). Social privilege can be defined “as a set of unearned benefits conferred as a result of birth, skin color, social-economic status, or other advantages accessed by physical presence” (Zoino-Jeannetti & Pearrow, 2020, p. 508). Being socially privileged involves being a part of a mainstream group that traditionally has advantage over others “by virtue of historical precedent or racial, class and gender bias” (Zoino-Jeannetti & Pearrow, 2020, p. 508). Power and powerlessness in this case study manifested in three ways: protective power, expert power, and class privilege. Each will be discussed in turn.

4.3.1 **Protective power: Parent and child.** According to Tew (2006), protective power involves exerting power over vulnerable individuals to protect their interests and this was evident in this case study through parent-child relationships. The power parents exert over their child was not from them wanting to gain power or take power away from their child, but rather a product of their control over decision-making for their child. CMC oftentimes are not physically or cognitively independent; thus, putting parents in a position of power to provide their children with all their needs. This form of protective power can be seen in Catherine’s description of her decision-making for Alex based on his health status at specific moments as she said, “We don’t live in a ‘medically what’s next?’ kind of attitude for him. We’re kind of at a point now where we know he needs to have surgery this year to descend his testicles, but like we’ve never really taken that attitude with him because we know how rare he is.” Similarly, Wendy also exhibited protective power over her son as she described her reasoning for declining Connor’s back surgery. She said, “[Connor] probably would need surgery for his back but that’s not something that is feasible because he’ll probably end up being on a ventilated trach. I mean there’s things that can be done for him but unfortunately, *pauses* if I want him to have a good quality of life then it’s just best to leave him the way he is.”

4.3.2 **Expert Power: Health care professionals and parents.** Beisecker (1990) considers expert power to be created when an individual is perceived as having professional knowledge that only members of a specific group possess, which was showcased in the HCP-parent
relationships. Expert power was exhibited by nursing administration in their relationship with parents of CMC because, according to Robert, they determine the number of nursing hours allocated to families based on perceived need and availability with little input from parents. Robert expressed this along with his experience with the Local Health Integration Network (LHIN) saying, “The LHIN is really good in getting us nursing hours and the DON [Director of Nursing] who provides the nursing they’re excellent.” Although Robert indicated his appreciation of the nursing staff’s ability to provide night nursing hours, Catherine emphasized their great need for nursing during the day. Parents are left in a position of wanting more support but realize they lack control over the decision-making process and must accept what is offered, which is illustrated by Catherine saying, “Having additional nursing hours during the day, like I understand that we’re really blessed with having full night nursing…Additional support during the day would be helpful for us as parents.” The expert power HCPs have over parents of CMC was also apparent in the time inequity that is present as parents described long wait times for scheduled appointments. The expectation of HCPs was for parents to wait as explained by Wendy when she said, “…sometimes you have to wait in the waiting room for about an hour or two before the scheduled appointment but sometimes you’re there for 3 hours for the appointment before the physician even arrives.”

4.3.3 Class Privilege: Parents in the study and other parents of CMC. Zoino-Jeannetti and Pearrow (2020) describe class privilege as being members of a social group that is higher up in the social class hierarchy due to traditional societal ideals and this was evident in the relationship between parents in the study and other parents of CMC. Instances of class privilege were described by parents when comparing themselves to other parents of CMC. Catherine’s recognition of her being a parent who speaks English in an English-dominated healthcare system while navigating complex care systems illustrated her class privilege. Catherine said:

…we’re English-speaking parents of a child with complex needs so we’re pretty on the ball but if you don’t feel comfortable calling in and really advocating on behalf of your child, if you get lost in the system and an appointment doesn’t get to be booked, especially for something like neurology, that’s a problem.

Catherine also recognized her privilege in a situation where she did not need the help but was still offered it because her son was able to get a diagnosis for his condition which was severe. Despite Robert and Catherine being offered housing services from a charity to use while their
child was in the hospital undergoing treatment, they were able to decline the services as they preferred to remain in their home had the ability to travel to and from the hospital when needed. Catherine identified the inequity in their situation and said, “…the people who were in the pod across from us got a call after and were able to get that room. And the only reason that we had gotten it was [Alex’s] diagnosis was higher up on the severity level than her child. And that was wild to me, even though she had lived further away.”

Another way participants experienced class privilege was demonstrated when Wendy explained that her husband’s private insurance increased her access to necessary equipment. As a result of her socioeconomic status, Wendy and her husband have the benefit of relying on private health insurance rather than completely paying out-of-pocket for equipment they need. She showcased this when she said, “[Connor] just got an $8000 mattress and thankfully, my husband’s private insurance paid for it… like wheelchair accessible van, we had enough funding for that, we just had to pay $4000 out of pocket.”

4.4 Finalized propositions as themes

The propositions previously created from the literature review were the following: communication challenges, fragmentation, unnecessary hospital readmissions and discharge delays, impact on caregivers, financial impact, and the rural and urban divide. Themes were finalized using the propositions and changes to the names were established after analysis was completed. The names that remained the same were communication challenges and fragmentation. Analysis revealed evidence for preventing unnecessary hospital readmissions rather than experiencing unnecessary hospital readmissions or discharge delays. The finalized theme of impact on caregivers’ HRQoL incorporated the propositions of impact on caregivers and financial impact since they were specifically used to examine the HRQoL theory. The proposition of the rural and urban divide was not included as one of the themes, as there was insufficient data to support this as a theme. The following are the current themes: communication challenges, fragmentation, preventing unnecessary hospital readmissions, and impact on caregivers’ HRQoL. Each will be discussed in turn.

4.4.1 Communication Challenges

Communication challenges, as previously defined, can be understood as the difficulties parents experience when exchanging information with members of the healthcare system, primarily their child’s HCPs (Kirk & Glendinning, 2002). Catherine and Robert experienced
difficulties in communicating with HCPs when Alex was a newborn as they were not connected to the complex care team. The complex care team facilitates and streamlines appointments with all medical specialties; however, when Robert was not initially connected to this service it created chaos. He said, “It would’ve been nice to know going into things that complex care was gonna take the lead and would’ve set all these appointments up. Instead, we had all the specialists come in and set up all the appointments, so it was a huge whirlwind.” Barriers to effective communication in not being connected to the complex care team were echoed by Wendy when she said, “Everything was a barrier…we didn’t know where to go, we didn’t have a team, they just brought doctors individually, so they weren’t, maybe they were communicating but to us it felt like they were not.”

Beyond the communication challenges of knowing about the complex care team and the role they play in organizing care, Wendy expressed challenges in understanding HCPs when their son was a newborn. Wendy explained, “Just [the HCPs] talking to you was so confusing, we really didn’t understand…half the time what they were trying to tell us right?” Wendy has seen improvements in communication over the course of her 17-years as a mother of a child with medical complexity. She compared the differences in communication she experienced then and now as she said:

I mean they’re great, like I said, I think it's because they’ve been involved in so many years and know him so very well that I have no complaints in regards to the health care providers with [Connor]. Like I said, if you had asked me these questions 10 years ago, it would have been totally different answers.

Challenges experienced when their child was born were not the only communication difficulties experienced by parents. Ongoing communication challenges with HCPs was related to turnover. Establishing relationships with HCPs is a key component of effective communication for parents of CMC. Catherine described, “I think there was a time where we got lost in the neuro sphere simply because of the changeover of receptionist.” For parents, turnover in staff was one barrier to communication, but also not knowing about turnover and having to re-establish a relationship was another issue which resulted in parents feeling lost. Catherine explained, “…there was a little bit of inconsistency this year, where we just all of a sudden had a new coordinator.” This issue of staff turnover was echoed by Wendy when she noted that when staff leave positions, oftentimes they are not immediately replaced and said:
…now we don’t have any… that social worker left last June and hasn’t been replaced…And that would be just the whole transitioning to the adulthood because I know there’s going to be applications with DSO [Developmental Services of Ontario], I don’t even know what’s all involved but right now, no, we don’t have a social worker to get us through that.

The importance of the relationship with HCPs as a foundation for effective communication was underscored by Wendy saying, “Now…’cause we know the nurse practitioners, we can email them if we have questions between appointments, so everything seems to be much easier just ‘cause I know where to go and who to contact.”

4.4.2 Fragmentation

Fragmentation, as previously defined, can be understood as the divisions between healthcare departments both within the hospital and in the community which results in difficulties for parents in navigating and gaining access to resources for their children. The difficulties parents experienced navigating the numerous healthcare departments emerged in three areas: accessibility to health care services, community supports, and funding, each of which will be discussed in turn.

Accessing health care services was exhausting for parents as they needed to actively advocate for their children. Catherine explained, “You really do have to be a bulldog and that’s exhausting in and of itself.” Interacting with multiple physicians and specialists results in parents struggling to know what is available for their child. Robert explained, “…we don’t know the services that he’s missing until someone tells us. There’s no one person that needs to know everything, every new specialty that gets involved with him knows of something somewhere.” This fragmentation across medical departments left Robert feeling like he did not have a full picture of all accessible programs. He said, “Every specialty deals with their own specialty so they know of the programs to deal with…it’d be nice if there was one super social worker that know all the different programs that are available.” This fragmentation was reiterated by Catherine saying, “Even the social worker through the LHIN knows different things than the social worker through [alternative complex care program]…There’s those sorts of inconsistencies that a lot of times I think is just bureaucratic.” This fragmentation was echoed by Wendy and left her feeling lost as she said, “I wish services that we have now would’ve been…in place way back when, even to show us how to navigate the system and we never had
social work involved, so we were just lost, lost, lost as parents.” Wendy’s experience in learning to navigate the fragmented healthcare system allowed her to reflect on what was needed to support parents of CMC. She said:

…more support to the new families…how to navigate the system and make sure that a social worker, at least the hospital’s social worker…so that they can give them a call if they have questions of where to go to or how to do this, or how to do that, or I guess to educate the parents more.

The fragmentation of health care services created a void and at times informal community supports emerged to fill the gap. Despite Wendy living in the city, she described getting connected to a social worker who knew about services in the community through a neighbour. She explained, “…[there was] no one out in the community. It was actually my next-door neighbour that suggested somebody to me and that’s how I got a social worker involved.”

Fragmentation in funding was another barrier described by parents of CMC. The structure of a disability support fund for CMC is difficult to navigate and Robert explained that without support from a social worker they would not have received the financial benefit they were entitled to. He said:

Initially [Assistance for Children with Severe Disabilities] were giving us $75 a month for gas money but through the social worker, we were able to reapply, and they’ve increased the funding to $460 a month…but without that social worker we would’ve never known that we could’ve done that.

This was echoed by Wendy, in that without a social worker making her aware of funding for respite care from a community organization, she would not have received the financial support. Wendy described, “I didn’t even know that there was a medically technology dependent funding that is $3500 until a social worker was involved, so I was actually entitled to money that I wasn’t even getting for respite.”

4.2.3 Preventing Unnecessary Hospital Readmissions

Unnecessary hospital readmissions are described as instances in which a child has been sent home from the hospital but readmitted for the same issue for which they were previously treated during their last hospital admission (Berry et al., 2011). Interestingly, in this case study parents of CMC described actions taken to reduce unnecessary hospital readmissions. These actions included access to in-home technology and community supports. Catherine explained
that Alex “hasn’t had any admissions since being discharged.” Catherine attributed this to having access to a Bilevel Positive Airway Pressure (BiPAP) machine, instead of using a trach explaining:

Like he came home on a daily BiPAP when normally kids like him would skip right to a trach, because that’s just what you do. And [city], and this is such a unique thing with [city], [city] was like hold up, let’s try something less invasive and figure out what’s right for him. And that has really enabled him to succeed.

Unlike Catherine, Wendy struggled with not having a BiPAP in her home initially, meaning Connor was continuously readmitted to the hospital whenever he required oxygen. Wendy recalled:

I think back then, it’s been so long ago, was that they would never give us the oxygen in the home…then when he had to go back in the hospital, he just needed a little bit of oxygen. I think that part was a huge, huge struggle for us, because we never had the oxygen in the home for the longest time.

Wendy reflected on the challenges of readmissions from a parent’s perspective, specifically when they only needed what she perceived was a small amount of additional help that could be done in the home. Wendy explained this frustration saying, “I know some kids are there just because they need monitoring overnight, ‘cause you see so many things when you go to emerg, you just have to shake your head sometimes.” Despite these frustrations, Wendy did notice a change in the healthcare system over time saying, “…we have as much support as we have in the home in order to keep him in the home” which meant Connor had not been readmitted to the hospital for a couple years, “It will be 2 years actually, it’ll be 2 years in the summer…I think it’s because the technology that they give us in the home. Over the years, they keep giving us different equipment and so we’re able to manage in the home.”

Another factor that helped to prevent hospital readmissions was access to community supports. Catherine described that Alex was excelling because of the community-based supports and attributed this to his success in avoiding hospital readmissions. Catherine described that:

[Alex] is excelling…he wouldn’t be the kid that he is today if he wasn’t going to [alternative complex care program], if he wasn’t getting regular checkups from the hospitals, if we didn't have our own family doctor who’s so hands-on with his care where he can be, he wouldn’t be the same kid.
Community support was also identified by Wendy who noted the care provided in-home at times exceeded that of hospital-based care when she said, “We actually had more care in the home than we did in the hospital right ‘cause we had to be there 24/7” (p.9).

4.2.4  Impact on Caregivers’ Health-Related Quality of Life

As mentioned in Chapter 3 of this document, the Conceptual Model of Health-Related Quality of Life theory presented by Ferrans and colleagues (2005) has two domains: characteristics of the individual and characteristics of the environment. While this theory encompasses five factors that can all equally influence characteristics of the individual or environment, the analysis of this study revealed only the two broad domains. The following are components of the characteristics of the individual domain from the HRQoL theory that were seen in this study: affective responses, developmental factors, and demographic factors. The components of the characteristics of the environment domain from the HRQoL theory present in this study were social environments and physical environments. Each will be discussed in turn.

4.2.4.1  Characteristics of the Individual

Ferrans and colleagues (2005) categorized individual characteristics as “demographic, developmental, psychological, and biological factors that influence health outcomes” (p. 337). Demographic factors, according to Ferrans and colleagues (2005), are factors such as “sex, age, marital status, and ethnicity” and socioeconomic status (p. 337). Biological factors are considered to be factors such as skin colour, body mass index, and family genetic history related to the risk of diseases (Ferrans et al., 2005). Developmental factors consider the developmental status of individuals since although it is not static, it cannot be changed by interventions (Ferrans et al., 2005). Psychological factors are cognitive appraisals, affective responses, and motivations that are modifiable intrapersonal factors (Ferrans et al., 2005). Individual characteristics of the parents in the study primarily manifested in accordance with three factors listed in the Conceptual Model of HRQoL: psychological factors, specifically affective responses which are emotions evoked in response to a situation, developmental factors, primarily parental development, and demographic factors relating to socioeconomic status (Ferrans et al., 2005).

4.2.4.1.1  Psychological Factors: Affective Responses. The parents in this study elected to not do genetic testing prior to birth, resulting in having a child with medical complexity to be a surprise. Catherine explained the guilt she had as she learned it was her genetics that contributed to her child’s diagnosis saying:
We had declined genetic testing from the beginning so already right away, like the day after you have a c-section, you’re being bombarded with the genetic counselling…It also turned out that the version of T-13 that he had was actually genetically inherited and I carried the translocation of my 13th and 14th chromosome that caused him to have an extra chromosome. So, on top of everything, I also had to deal with that.

Catherine also carries guilt as the manifestation of Alex’s diagnosis is abnormal, meaning her child is still alive while other children with a similar diagnosis have passed away. This inhibited her from contributing to the online social support group she is a member of, as Catherine illustrated:

I’m in a Facebook group with parents of children who have this medical disorder and at least 80% of them don’t make it to their first month…You know what, to be honest I feel really guilty because our kid is doing so unbelievably well that it’s really hard sometimes to post and talk about hope. So, it breaks my heart every time I see some of the infants that are being born pass away, at the same time it makes me appreciate what we have with [Alex] so much more.

As with all children, there are many life transitions that are fraught with emotions and as such, parents in this study felt many emotions after their child completed transitions such as coming home from the hospital. The transition of bringing Alex home from the hospital was a mix of anxiety and excitement as Robert and Catherine had waited 125 days to bring him home. Robert explained, “I think that once the date was set for him to come home, things really got real. ‘Cause up to that point, it was we live each day as it comes, because we had no idea how [Alex was] gonna do.” This anxiety quickly morphed into excitement at the prospect of having their son at home with them as Robert said, “it was also super exciting because we got to take him home.” The joy of having Alex at home was echoed by Catherine saying, “so we were really able to enjoy hanging out with our kid and really getting the feel of him at home, it was just a much more relaxing experience because we didn’t have things beeping at you all the time.”

Similarly, Wendy emphasized that discovering her child was medically complex after birth was devastating and she felt lost. She said, “I know that you’re pretty lost when your child is born and has all these medical complexities and you’re just not sure as parents, like you’re just trying to cope with it at the beginning and then when everything arise[s].” Wendy experienced
fear after Connor came home from the hospital because she was afraid he would have to be readmitted at some point. While recognizing her relief in being home, Wendy also recognized her fear of the unknown and said, “I think we were relieved that we were home, but it was just like oh, when are we going to go back again, right, because there was always the next time and next time and next time.” While it may be common for parents to be fearful as their children become more independent and transition into adulthood, Wendy’s fear about Connor transitioning into adulthood was not about him starting to navigate the world on his own, but rather the fear and worry of the unknowns in navigating the healthcare system alone for her newly adult son with complex medical needs. This is illustrated when she said, “just the whole transitioning to the adulthood because I know there’s going to be applications with DSO [Developmental Services of Ontario], I don’t even know what’s all involved.”

4.2.4.1.2 Developmental factors. When new parents prepare to welcome their child into the world, they prepare to become parents; however, parents with CMC have the added role of HCP. Catherine underscored this when she said, “Because we’ve prepared to be his parents and not his nurse.” This shift in roles from full-time parent to full-time parent and HCP takes a toll on parents as they need to develop an entirely new role and feel as though they must always be monitoring their child. Catherine explained, “It’s exhausting”, which was reiterated by Robert when he said, “It’s exhausting, you have to watch him all the time.” Individual characteristics play a huge part in how caregiver experiences affect each parent because their coping mechanisms and approaches to their full-time parent and HCP role are different. This was showcased in Catherine’s description of the adaptive coping differences between her and her husband as she explained:

[Robert] and I deal with things very differently as well. [Robert] very much bottles things up and I just kind of let it go. So, for me, having one specific person to get angry at and deal with things is usually him and then he takes it to his therapy sessions [laughs]. I don’t know, I don’t live with the same anxiety, I don’t think that [Robert] does around it because I’m just enjoying our kid.

Given Robert’s anxious personality, as he describes it, finding out his child was born with a terminal diagnosis exacerbated his own psychological condition. He said:

[Alex’s] condition has exacerbated my own. I’m always a nervous/anxious person but since [Alex’s] diagnosis, I’ve slipped into a depression. So, at the hospital I
started seeing a psychologist just to help me cope with [Alex’s] diagnosis, because at the time, we had to be prepared to let him go. So, they were getting us ready for end-of-life care type of stuff. This role shift was further established as Robert and Catherine became the sole care providers for Alex during the day once Alex was at home which was a huge change from having help at the hospital, as Robert explained, “It took a bit to get used to not being at the hospital all the time and having a backup if anything went wrong, it was always up to us.” Being overwhelmed by the constant monitoring from a medical perspective was echoed by Wendy saying, “…there was no way I’d be…um yeah, there’s no way you can look after a child 24/7.” Despite Wendy admitting it was an impossible task to monitor her child constantly, she described finding a way to make it work; thus, showcasing her ability to adaptively cope with her new role as a full-time parent and HCP. Wendy said, “I think we’re just so used to living the way we are right. People always tell us like ‘oh my gosh, I don’t know how you do it, how you do it’, but when you’ve been doing it for 17 years, we don’t even know what normal is really.”

Learning to care for their child and address their needs is a part of parental development as they discover what works well and adapt their approaches accordingly. Catherine emphasized that for her child it is important to be flexible with his care plan because he does not present the same as other children with his medical complexity. She said, “I mean [Alex’s] diagnosis itself is a hypothetically life-limiting diagnosis. But at the same time, he doesn’t present the way a child with his diagnosis should…So yeah, it’s transitioning I think from step to step and like kinda rolling with it as things change, as he starts to grow, things look different.”

4.2.4.1.3 Demographic Factors. Participants in this study were both in single-income households which contributed to financial strain. Robert and Catherine expressed the benefit of having Robert on medical leave and Catherine working from home because it allowed them to qualify for more funding. Robert said, “If I was at work full-time, we would not qualify for nearly half the stuff that we currently do.” Catherine added that they “wouldn’t be able to support [Alex] in that way if [Robert] was back at work full-time. Losing that funding would wreck us”. Conversely, Wendy’s financial strain stemmed from her husband making too much money for them to qualify for financial support, despite their need. Wendy explained:

…emergency respite funding that you can…get in the summertime and it’s not very much money and so it helps pay for a nurse. It’s usually about between $700-1000
that I get for the summer…we constantly get declined for that because my husband makes a bit over their threshold but they prove how much medical expenses are so they usually will give us the minimum $25 a month, just so, more for the benefits so that’s usually a struggle.

The financial strain left Wendy contemplating going back to work in times when they needed additional equipment saying, “…that would be the only thing that would ease the burden…when we need equipment.”

4.2.4.2 Characteristics of the Environment

As mentioned in Chapter 3 of this document, Ferrans and colleagues (2005) consider environmental characteristics to be either social or physical. Social environmental characteristics are characterized as “interpersonal or social influences on health outcomes, including the influence of family, friends, and healthcare providers”, whereas physical environmental characteristics are categorized as settings such as their “home, neighbourhood, and workplace” (pp. 337-338). Each will be discussed in turn.

4.2.4.2.1 Social Environment. Having access to supportive environments that are able to meet the needs of CMC impacted the parents’ HRQoL as it gave parents peace of mind. Catherine described the peace of mind she had because Alex was part of complex care program in her community as she said:

But we’ve been really lucky because we’ve had access to programs like [alternative complex care program] and that’s an invaluable program for care for our children because they don’t just follow your therapy, they also follow you medically, so they see things from a day-to-day basis because they get him for a full week when he goes Monday to Friday from 9-4. Their staff and their doctors are all able to assess him month to month on like a full daily basis so they see things that we might not necessarily notice as parents because we’re not doctors. Honestly the program has been invaluable.

It is vital for parental caregivers to have supportive individuals in their social environment to help them adjust to their lives as caregivers. Robert commented on the fact that him and Catherine did not always rely on each other for support but have found ways to be each other’s support system, and said, “We’ve learned ways to be, we weren’t at first.” Having familial
support was also identified as an important factor in reducing the daily stress for both parents as Catherine said:

Yeah, there was a period of training your parents, they had to come over first and learn to care for [Alex] with our presence before we took that leap of faith and allowed them to care for him on their own kind of thing. But then once that happens it also was very remedying because we got to go on a date after a year and a half and that was pretty cool.

Some environments, regardless of intention, can be seen as not beneficial in practice for some caregivers, such as the Facebook group Catherine and Robert were members of along with other parental caregivers. Although the online Facebook group was meant to support parents with children who have a similar diagnosis to their son, the fact that the members were primarily from the United States resulted in the support group to be an unreliable source of information as Catherine said, “Yeah, a lot of them are American residents so their healthcare system and access to therapy and things like that are very different from what we have”.

4.2.4.2.2 Physical Environment. Parents described adapting their physical environments to suit both their needs and the needs of their children. One small but meaningful modification Catherine made was to how Alex and the family travelled in the car explaining:

When they send you home from the hospital, they tell you one of you will always have to sit in the back seat of the vehicle with [Alex]. And we were like well, okay we both like sitting in the front together because we are married and it’s nice to have conversations together, we invested in a mirror. So, it’s the little things like that I think as parents of kids with special needs you don’t really realize you have to think about.

Parents also discovered a balance in what would ensure both parents were comfortable at home while still meeting their child’s needs. Catherine explained they needed to “…learn what works for [their] family” and modified certain needs according to what would help them adjust after the transition from hospital to home care. A part of finding that balance involved them purchasing equipment to modify their home that would make their lives easier, “…we invested in a video monitor and by golly that was the best thing we ever did.” As Catherine and Robert adjusted to life with Alex at home, they also had to become accustomed to having the night nurses and the
machinery present. Catherine explained, “But it’s also getting used to having those people at your house and understanding the quirks of the machines themselves, because some of them are a little quirky.”

This idea of changing the environment to better suit the family’s needs was echoed by Wendy who explained, “[Connor] is, well our lives revolve around him so whatever he needs, we just do it.” This meant for Wendy that travelling as a family was not feasible, and instead, if they are going to travel, they ensure it is done on weekends when Connor already has alternative overnight care in place as Wendy described, “Like if we want to go away for a weekend, like oh my gosh we need to pack a U-Haul truck, so we just don’t go away, right. So, we just do things when he’s at [alternative institute].”

The value of physical environments that can support CMC is a significant consideration for parents in all decision-making. This is showcased in Catherine’s thoughts around creating a supportive school environment for Alex’s in his upcoming enrollment saying:

…we need to start talking about school and there’s limited options to where he could possibly go to school, and class sizing is adding an extra nurse to that it’s a whole different whirlwind we’re going to have to deal with. It’s going to look different for him because of rural instead of city kids.

The need for physical environments that positively influence health outcomes for CMC was highlighted as Wendy struggled to find such environments for Connor saying:

I wish there was more things out there for kids with special needs that they can actually do, they’re just so limited to things…he can’t go anywhere unless there is a nurse with him right, and there’s nothing out there that provides nursing services for any activities.
Chapter 5: Discussion

This exploratory single-case study explored the experiences of and relating to the HRQoL of parents who have CMC in and surrounding London, Ontario. A secondary purpose was to examine the role of geography, specifically living in rural and urban settings, on parental caregiver experiences. To understand parents’ experiences of HRQoL, first an exploration of several power and privilege dynamics relating to the propositions was undertaken. Parents exerted protective power over their child in their health-related decision-making power and HCPs exerted expert power over parents through nursing time allocation and HCP office wait times. Parents of CMC experienced class privilege based on being English-speaking parents and having private health insurance. The power, lack of power, and privilege parents experienced shaped the propositional themes, namely communication challenges, fragmentation, preventing unnecessary hospital readmissions, and impact on caregivers’ HRQoL. Parents experienced barriers in communication in understanding the role of the complex care clinic, understanding information provided by HCPs, and establishing a working relationship with the clinic. Parents experienced difficulty navigating healthcare departments due to fragmentation, explaining they were unsure where to go to get the resources their child required. Unnecessary hospital readmissions and discharge delays, while well-established in literature from the United States (Berry et al., 2011; Berry et al., 2011; Cohen et al., 2012; Leyenaar et al., 2017; Maynard et al., 2019) and limited in Canadian literature (Manhas & Mitchell, 2012), were not found in this study, but rather parents reported substantial effort on the part of HCPs to prevent unnecessary hospital readmissions through having technology supports at home. Together, the context of power and privilege and propositions informed parents’ HRQoL, which was explored using characteristics of the individual and the environment (Ferrans et al., 2005). Parental individual characteristics such as the affective responses of guilt, anxiety, excitement, and fear, developmental factors of coping and adapting to the role of parent and HCP, and financial strain all played a role in the parents’ experiences of HRQoL. Having supportive environments, including support from the complex care team, family members, and significant others, and changing physical environments such as use of technology, equipment, influenced parents’ HRQoL. Parents did not consider their geographic location to be a major influence on their
experiences and therefore, the proposition of ‘rural and urban divide’ was not considered to be a theme after analysis.

Parents made health care decisions for their children – a form of protective power to optimize their child’s health outcomes. In Madrigal and colleagues’ 2012 prospective cohort study based in the United States, the decision-making preferences of 87 parents with children in the pediatric intensive care unit (PICU) who had complex chronic conditions and were cognitively incapable of making their own decisions were examined. Madrigal and colleagues (2012) found when parents were faced with difficult decisions in the PICU, those that had higher positive affect preferred shared decision-making over making decisions on their own or having a physician make decisions. Madrigal and colleagues (2012) also reported when parents were in high-stress environments they preferred the support of HCPs, which is similar to the parents in the current case study who also used shared decision-making. However, parents in the case study internalized input from HCPs and considered factors related to their child’s long-term HRQoL. Therefore, the protective power exerted by parents of CMC can be beneficial for their child’s overall health outcomes as parents believe they know what is best for their child.

In this case study, parents experienced expert power from nursing administrations that allocated the number of nursing hours and through the time inequity with long wait times for scheduled appointments with HCPs. While previous literature has not described challenges in terms of nursing hour allocation, a study in the United States by Nageswaran and Golden (2017) did qualitatively explore factors associated with stability of nursing services for CMC. Using 20 semi-structured interviews with 26 caregivers of CMC, they found that all 26 caregivers reported at least one instance of agencies not being able to provide nurses for all nursing hours allotted for the child, difficulty retaining nurses, or high nurse absences (Nageswaran & Golden, 2017). In each of these instances, nursing administrations are exerting power, while likely unintended, over parents who have little recourse to address challenges or gaps in care for the CMC. The urban family in the present case study reported experiencing excessive wait times when scheduled to see a physician. Current literature looks at time inequity in relation to rural families experiencing excessive wait times and quick physician visits after traveling a great distance to see HCPs, which is different than what was expressed by parents in the case study since the rural family did not mention experiencing time inequity. Time inequity has been previously studied by Skinner and Slifkin (2007) using cross-sectional data gathered from the National Survey of
CSHCN within the United States via a telephone surveying method that received 13,006 rural responses and 25,860 nonrural responses. They reported urban-dwelling parents are more likely than rural-dwelling parents to report issues specific to HCPs such as long office wait times (Skinner & Slifkin, 2007). Although this is consistent with the current case study in that it was the urban-dwelling parent who explicitly reported excessive wait times to see HCPs, the time inequity they found in rural-dwelling parents was not found in the current case study. Given this experience of power, it is important for HCPs to be mindful of the expert power they hold in their interactions with patients and vulnerable individuals as it can be easily exerted, intentionally or unintentionally, given that it is rooted within the healthcare system.

Class privilege was evident in this study through the parents being native English speakers and because they had private health insurance. One family in the study recognized their privilege being English speakers advocating for their child in a predominantly English-speaking healthcare system. In a retrospective cohort study conducted by Nageswaran and colleagues (2020) with 70 CMC in a complex care program in the United States, communication challenges of Spanish-speaking caregivers of CMC were examined and it was found that a language barrier made verbal and written communication extremely difficult, especially when interpreters were not available. The lack of interpreters and willingness of HCPs to provide instructions to caregivers in Spanish worsened the unmet needs for their children as they were not able to advocate for their child and themselves (Nageswaran et al., 2020). Being able to speak the dominant language in which the healthcare system is situated, namely English, like the parents in the present case study is a privilege not extended to everyone and should be accounted for in caregiver/patient and HCP interactions. One of the families in this study explained that their access to private health insurance afforded them opportunities parents without these benefits do not have access to – a form of class privilege. Despite the private health care benefits, parents in this study vocalized experiencing financial strain. Although the effects of private health insurance in relation to CMC have not been studied, experiences of financial strain among families with CMC have been established such as in a cohort study by Thomson and colleagues (2016) in the United States examining the financial and social hardships of 167 families with CMC compared to 774 families of children with asthma. Thomson and colleagues (2016) reported that while the families of CMC had a higher SES, they often experienced more hardships as 80% of families of CMC reported experiencing at least one hardship with 68% of
those hardships being financial and nearly 50% reported that financial issues stemmed from their child’s health needs. Despite the study by Thomson and colleagues (2016) being from the United States, CMC by definition require more health care resources and monitoring than other children which can lead to financial strain on caregivers. Therefore, the meaning behind the results is important in other contexts as well. Although parents of CMC in certain countries might experience more financial strain than others due to differing healthcare systems, overall, parents of CMC who are referred to complex care programs are more likely to experience hardships than the general population of CMC due to more extreme health care needs (Thomson et al., 2016).

A contributing factor to the financial strain for many families with CMC is they are single income households as it is not feasible for both parents to work as one parent is needed to care for the child full-time. The financial strain experienced by families of CMC as they become single income households is well established in the literature (Cohen et al., 2018; Cohen & Patel, 2014; Thomson et al., 2016). Although private health insurance is a beneficial resource for parents, parents in the current case study were single-income households and reported feeling financial strain because they still had to pay out-of-pocket for some equipment. Caicedo (2015) conducted a longitudinal study in the United States to examine physical and mental health outcomes of 76 families of CSHCN in three healthcare settings: home care, long-term care, and medical day care. Caicedo (2015) reported parents who had children in home care settings had a higher financial demand and overall lower HRQoL when compared to parents who had children in long-term care or medical day care settings. When parents had low income and restrictive insurance policies, the benefits of continuous home care did not outweigh the great emotional and financial toll placed on parents (Caicedo, 2015). Despite Caicedo’s (2015) findings being based in the United States, making the prevalence of families with private health insurance different, class privilege was evident because having private health insurance is still a form of income that parents relied on that not all parents are able to obtain. Because it is established in the literature that families with CMC are more likely to experience financial hardship, there should be a focus on alleviating the strain to improve their HRQoL.

Parents in this case study experienced communication challenges with HCPs specifically related to difficulties in knowing the role of the complex care clinic, understanding HCPs when their child was a newborn, and establishing relationships with HCPs during staff turnover periods. Cady and Belew’s (2017) conducted a United States-based cross-sectional study using
focus groups introduced a new care model called Primary-Specialty Care Coordination Partnership for Children with Medical Complexities (PRoSPer) and sought to understand how parents perceived communication and care coordination within the first year of the partnership. The study was a component of the larger PRoSPer program evaluation that originally had 30 participants but ended up with two parents at each of the four focus groups for a total of eight parents. The authors found that the greatest challenge was gaps in the continuity of information and communication between HCPs both within and across the healthcare system. Two of the clinics participating in PRoSPer were pediatric medical homes and the implementation of family-centered medical home (FCMH) models which have been shown to increase communication across care settings and increase the quality of life of parents because it reduces parental burden, lessens unmet health service needs, and prevents unnecessary hospital admissions (Cady & Belew, 2017). Although the benefits of FCMH models are recognized by HCPs, the lack of personnel to facilitate the model is a barrier to its implementation (Cady & Belew, 2017). There needs to be an emphasis placed on ensuring the care families of CMC receive incorporates their specific needs and challenges so their HRQoL can be optimized. The communication challenges found in the study by Cady and Belew (2017) are similar to those found in the current case study; however, the current case study is different in that it found when communication challenges are combined with navigating the numerous healthcare departments within the healthcare system, it has can negatively impact the overall HRQoL of the caregivers. Therefore, gaps in communication could be lessened if more tangible community and HCP supports (i.e., community point person to provide information, community scheduled emotional support sessions for parents, office in the hospital where specific staff could help them navigate the system in layman’s terms) were readily available to parents when navigating the healthcare system to overcome the existing fragmentation.

Parents described the prevention of unnecessary hospital readmissions by having adequate technologies and supports in the home. Interestingly, although having a BIPAP machine at home was experienced at different times for each family, both reported community supports, namely complex care programs and at-home personnel, as facilitators preventing unnecessary hospital readmissions. One family had to continuously readmit their child to the hospital due to his poor oxygen levels and the other was immediately able to have a BiPAP machine at home, which demonstrates the changes in technology that is readily available for
parents in home care settings. A retrospective longitudinal study by Bucholz and colleagues (2019) analyzed nationwide trends in pediatric hospitalizations and readmissions from 2010 to 2016 in the United States. The authors reported that while the total number of pediatric admissions decreased by 21.3%, admissions for children with complex chronic conditions increased from 16.6% in 2010 to 20.2% in 2016 (Bucholz et al., 2019). Given the rising readmission rates for CMC, it is important to consider and continuously improve factors that have been identified to help prevent unnecessary hospital readmissions such as having technology within the home that parents in the current case study reported. Thus, families of CMC that are provided with necessary technological equipment within the home are likely better able to prevent their child from unnecessary hospital readmissions.

Parents in this case study described that their lives revolved around their child and oftentimes this interfered with meeting their own needs and exacerbated their existing mental health conditions. Batchelor and Duke (2019) conducted an interpretive phenomenological study of 12 parents from the United States who had chronically ill children to explore parental chronic sorrow and reported some parents described self-care as “a waste of time” because they felt that the small relief they would get was quickly lost as they returned to complete the demands not done within that self-care time-period (p. 170). Parents who do not practice self-care are more likely to fall ill, causing them to find others to help care for their child in the meantime (Gallant & Connell, 1997). Another key finding from Batchelor and Duke (2019) was that some mothers described scheduling an “escape” (p. 170) by going away every few months with their spouse which allowed parents reprieve from daily stressors (Batchelor & Duke, 2019). However, travelling is not a luxury all parents of CMC can afford. One parent in the current case study indicated that they are only able to go away for a short amount of time while their child is at a program centre. It is important for parents to be given supports that would allow them to feel comfortable to take time for self-care more often without feeling that it was futile, which could help to improve their HRQoL.

The parents’ prioritization of their child’s needs above their own can have an impact on the parents HRQoL specifically as their roles shift to being a parent and HCP. In a study by Boss and colleagues (2020) in the United States, telephone interviews involving semi-structured surveys were conducted with 48 parents of CMC to explore pediatric home health care among this population. Parents expressed their new role takes an abundance of time and energy and
wished that HCPs had prepared them for the role rather than learning by trial and error (Boss et al., 2020). One parent compared their new role to being a case manager because of all the coordinating responsibilities involved, and another indicated that advocating for their child was their top priority because they could not live with the guilt if they did not express their opinion and something went wrong (Boss et al., 2020). Similar to the parents in this present case study, parents advocated for their child’s needs without thinking about the impact it would have on their own HRQoL and also wished HCPs had prepared them from the outset. Parents in this case study reported that being parents, HCPs, and advocates for their child was exhausting due to the conflicting demands of the roles. This underscores the need to focus on implementing care coordination resources from the beginning and informing parents of CMC about existing resources from the outset to support them in their roles.

The individual affective responses of parents in this study included guilt over the genetics parents passed on to their child and excitement and anxiety when bringing their child home from the hospital for the first time. In a study by James and colleagues (2006), 112 members of families with chronic granulomatous disease (an immunodeficiency disease) were surveyed to understand the psychosocial effects of the inheritance of a genetic condition. Mothers who carried the x-linked disorder felt significantly more guilt for their child inheriting the disorder in comparison to fathers with the x-linked disorder. Similar to the current case study, one mother expressed her guilt for carrying the gene that resulted in her child’s medical complexity and her difficulty in coming to terms with the discovery. Parents of CMC in this case study also expressed fear of the unknown illness trajectory for their child. In a study conducted in the United Kingdom by Neill (2010) that interviewed 15 families with children who have acute illnesses, parents indicated that the reality of their child’s illness set in when it persisted, or the severity of symptoms increased beyond their expertise as caregivers. The uncertainty left parents feeling exhausted from the constant worry (Neill, 2010). Although acute childhood illness is not the same as having a child with medical complexity, the same fear and corresponding exhaustion was seen in both parental caregiver populations which underscores the need to focus on alleviating parental stressors in times of heightened parental concern. Psychological factors such as affective responses are modifiable and subject to change based on interventions; therefore, improvements made must be intentional to successfully improve an individual’s HRQoL (Ferrans et al., 2005).
The social environments discussed by parents in the case study involved multiple supportive environments such as complex care programs, family members, and significant others. One environment intended to be supportive was an online Facebook support group which led parents in this study to experience guilt when other children with similar diagnoses were dying but their child was thriving. Moreover, there was a lack of Canadian support groups for parents with CMC which led the parents in the current case study to become a part of one in the United States; however, the country differences rendered the Facebook support group unhelpful as resources being discussed such as complex care programs were American-specific. Robert and Catherine’s online support group experience is contrasted by Ammari and Schoenebeck (2015)’s study that looked at networked empowerment on Facebook support groups for parents of children with special needs. The authors found that online support groups allowed participants to better navigate the healthcare system by closing gaps in their knowledge. Because parents in the current case study could not rely on the online support group like those in the study by Ammari and Schoenbeck, they turned to their spouses and parents for support and in fact, parents said relying on others provided them a momentary relief of caregiver duties. Aside from caregivers seeking support from their own parents and spouses, it is essential to provide parents with an accessible and relevant environment, either in-person or online, to allow the discussion of both their difficulties and triumphs with other caregivers as well. Although familial support is necessary, having the opportunity to talk with others who have a better understanding of being parents of CMC has the possibility to provide some cognitive relief. Creating a Canadian online forum or local online forums would provide an accessible hub of information amongst parents of CMC to facilitate knowledge translation and provide support to those who cannot attend in-person support groups.

Parents described adapting their physical environment through in-home and in-car modifications to meet their family’s needs. The physical environment in which parents and their children live create the foundation of factors that influence their HRQoL; however, there is currently no literature regarding the impact of changes to physical environments on the parents of CMC. In a study by Doutcheva and colleagues (2017) to determine the interaction between the physical home environment and the complex work system within the home care setting for CMC (which includes physical environments, technologies, equipment, and people), 30 semi-structured interviews were conducted with family caregivers of CMC. These caregivers
discussed how features of their physical environment – such as home location, home layout, and storage space – either increased efficiency of care or complicated their care delivery, with many of them reporting the latter (Doutcheva et al., 2019). Some caregivers explained their home layout prevented them from delivering care in certain rooms which led them to change their care routine, whereas other caregivers described building or remodeling their homes to increase mobility and accessibility for their child with a wider hallway and room layout that is more open (Doutcheva et al., 2019). Aside from making home modifications to accommodate medical technology, parents in this current case study opted for smaller changes such as a video monitor and a car mirror to make their daily lives easier. Although parents reported these smaller changes made a positive impact in their overall daily life, home remodelling to provide better accessibility for care, as indicated by the Doutcheva and colleagues study, has the potential to further improve their HRQoL. However, even if parents would prefer to make home changes, it is not always within their financial means to do so and has the potential to create more financial strain which could then take away from their HRQoL; thereby emphasizing the need for more financial supports to be in place to better aid in their transition to home care. Rather than parents figuring out on their own what physical environmental modifications are in their capacity to make, providing them with a list of possible adjustments that other parents have found helpful could allow them to figure out what works for their family easier.

Parents in this case study described a local supportive informal network which helped them find local resources. The informal support networks described by parents in this study were similar to those that make up the Canadian WrapAround process evaluated by Wallace and colleagues (2015) in a pilot case study based in Hamilton, Ontario which evaluated the effectiveness of the framework in Canada compared to standard models of care primarily using grey literature in combination with their case study findings. The Canadian WrapAround started in 2008 and focused on connecting families with social networks within the community to build a foundation of resources they can continuously use, which significantly increased the resilience of parents and improved overall family functioning (Wallace et al., 2015). The advantage of local informal supports needs to be considered for parents of CMC particularly for rural families who live outside of the catchment of support programs connected to the urban hospital that oversees the care of the CMC.
5.1 Limitations and Future Directions

The findings of this case study need to be considered within the context of the study’s limitations. First, this was a case study of two families with three participants. While initially the plan for this study was to recruit 40 families, the onset of the COVID-19 pandemic resulted in the need to stop recruitment. Differences between urban and rural parents could not be meaningfully explored given that the objectives were framed around a larger sample size. This is a gap in the literature that still merits investigation in future studies.

A limitation of the single-case study methodology is the rigor and lacking generalizability to the wider population. This case study involved parents at different stages – a mother with a 17-year-old son and a mother and father of a 2-and-a-half-year-old son. Although data was enriched by different perspectives based on the length of time participants parented a child with medical complexity, there are also inherent limitations. Given the differences, it was difficult to draw comparisons of parental experiences at the same point in their children’s lives because they are 15 years apart and there have been changes in the healthcare system and best practices in care over that span of time. Additional studies should be conducted with a larger sample size of parents who have CMC with smaller age gaps to allow for a more diverse and representative sample of the population. Interpretative biases can also be present in case studies due to the small sample size and more opportunity for the researchers’ assumptions to make its way into analysis. Although this can still occur, efforts to limit the biases and improve rigour have been made, such as an audit by one co-supervisor and data analysis being independently conducted by the researcher and a research assistant.

5.2 Conclusion

Parenting a child with medical complexity encompasses both the role of a parent and HCP and the duality of these roles impacts parents’ HRQoL. The dichotomy between structural power and powerlessness was evident in the interactions of parents with their child, HCPs, and other parents of CMC which played a role in their experiences of HRQoL as they faced systemic challenges when navigating healthcare and social systems. Communication challenges, fragmentation, and preventing hospital readmissions exerted stressors on the parental caregivers; therefore, together with navigating the healthcare system the parental caregivers’ HRQoL was impacted. The experiences of parental caregivers are interconnected with the wellbeing of their
child as parents strive to give their child the best life possible. This willingness of parents to prioritize their child’s wellbeing can have a detrimental impact on parents’ own HRQoL which makes studying this population essential. The impact of living in urban or rural settings on the experiences of parental caregivers of CMC could not be explored in depth as there was insufficient data to determine whether their experiences could be attributed to their geographical location. CMC research in Canada is primarily conducted with the idea of optimizing childcare interventions and improving the child’s quality of life; however, parents of CMC and their experiences cannot be overlooked or forgotten because apart from parents providing unconditional love and support to their child, they are also their primary caregiver, making their child’s wellbeing dependent on the parents’ ability to provide for them. The lack of Canadian literature regarding parental caregiver experiences showcases the importance of this research as it can be used as a starting point to fill the gap in knowledge. This case study can be used as a basis for further research to be conducted in other areas of Canada, including remote areas, using a larger sample size in which data could be used to influence policy reform. Therefore, it is important to use the information gathered in this exploratory single-case study to help alleviate the difficulties parental caregivers of CMC face to improve the HRQoL of both the parents and the children. This case study highlighted areas needing improvement within the healthcare system and that implementing informational programs for HCPs and social care workers would benefit patients and their families since the care providers would all have the same information.
References


https://doi.org/10.1542/peds.2017-1284E


https://doi.org/10.2174/157339612800681253


Appendices

Appendix A - Health Science Research Ethics Board Approval Notice

Dear Dr. Tara Murrier

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above mentioned study as described in the WRBM application form, as of the HSREB Initial Approval Date noted above. This research study is to be conducted by the investigator noted above. All other required institutional approvals must also be obtained prior to the conduct of the study.

Documents Approved:

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<tr>
<th>Document Name</th>
<th>Document Type</th>
<th>Document Date</th>
<th>Document Version</th>
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<td>Written Consent/Assent</td>
<td>09/Jul/2019</td>
<td>5</td>
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<td>Debriefing Script</td>
<td>16/May/2019</td>
<td>2</td>
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<td>Email Script</td>
<td>16/May/2019</td>
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<tr>
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<td>Recruitment Materials</td>
<td>18/Jan/2019</td>
<td>4</td>
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<tr>
<td>CCKids Recruitment Telephone Script June 6 2019</td>
<td>Telephone Script</td>
<td>06/Jan/2019</td>
<td>3</td>
</tr>
<tr>
<td>CCKids Research Protocol April 16, 2019</td>
<td>Protocol</td>
<td>16/Apr/2019</td>
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No deviations from, or changes to, the protocol or WRBM application should be initiated without prior written approval of an appropriate amendment from Western HSREB, except when necessary to eliminate immediate hazard(s) to study participants or when the change(s) involves only administrative or logistical aspects of the trial.

HSREB members involved in the research project do not participate in the review, discussion or decision.

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonization Good Clinical Practice Consolidated Guidelines (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00090960.

Please do not hesitate to contact us if you have any questions.

Sincerely,

Nicola Geoghegan-Morphet, Ethics Officer on behalf of Dr. Joseph Gilbert, HSREB Chair
Appendix B – Lawson Health Sciences Ethics Approval Notice

LAWSON FINAL APPROVAL NOTICE

LAWSON APPROVAL NUMBER: R-19-554

PROJECT TITLE: Complex Care Kids: A Needs Assessment and Economical Evaluation

PRINCIPAL INVESTIGATOR: Dr. Tara Mantler

LAWSON APPROVAL DATE: 21/10/2019

ReDA ID: 7605

Overall Study Status: Active

Please be advised that the above project was reviewed by Lawson Administration and the project was approved.

Please provide your Lawson Approval Number (R#) to the appropriate contact(s) in supporting departments (eg. Lab Services, Diagnostic Imaging, etc.) to inform them that your study is starting. The Lawson Approval Number must be provided each time services are requested.

Dr. David Hill
V.P. Research
Lawson Health Research Institute
PARTICIPANTS NEEDED FOR RESEARCH ABOUT CHILDREN LIVING WITH MEDICAL COMPLEXITIES

We are looking for parents of children with medical complexity to take part in a study looking at the challenges and opportunities for families.

Is there a child in your family with medical complexity?

Do you live in London or at least a 30 minute drive from London?

If you answered ‘Yes’ to the above questions you are eligible

If you are interested and agree to participate, you would be asked to meet with the researchers (either in your home or a community location) for a max of 2 hours to answer questions about your experiences with health care. This will involve both an interview and a short survey that can be done either in person or over the phone. Your participation in the survey will help us to better understand how the health care system is and is not supporting families.
If you would like more information please call or email Kelly from the University of Western Ontario:
CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Project Title: Complex Care Kids: A Needs Assessment and Economic Evaluation

Principal Investigator:
Dr. Tara Mantler, PhD, Health Studies
Western University, ext. 85541

Co-Investigator:
Dr. Dirk Bock, MD, Department of Paediatrics
Children’s Hospital, LHSC

Background
Our team is interested in examining the needs of families of children with medical complexity in rural and urban areas. Our hope is that we can get a better understanding of aspects of care that are going well, not going well, and things that can be changed.

Invitation to Participate
You are invited to participate in the study looking at the care needs of children with medical complexity. The purpose of this study is to conduct preliminary research, with 40 participants, on the specific needs, challenges, and opportunities for families who have children with medical complexity. You are eligible to participate if you 1) are a parent of child with medical complexity; 2) either live in London or a 30 minute drive from London; 3) speak English; and 4) are willing to complete an interview that is audio recorded.

How Long Will You Be in This Study?
The length of this study is one visit, either in person or over the phone that will take a max of two hours.
What are the Study Procedures?
The study includes one 60 minute interview and the completion of a 30 to 45 minute questionnaire online. The questionnaire will include questions about you, your family, and your healthcare experiences. Prior to the start of the online questionnaire you will be asked to return a signed copy of this document, the letter of information, to the research team (please know, email is not a secure form of communication).

What are the Risks and Harms of Participating in This Study?
There is minimal psychological and social risk identified in the study; however, you may feel discomfort answering certain questions.

What are the Benefits of Participating in This Study?
There are no direct benefits of participating in this study. However, indirect benefits include contributing to the body of research helping us to better understand the current health care system and how it is and is not working for children with medical complexity and their families.

Can Participants Choose to Leave the Study?
You can choose whether to be in this study or not and your choice will in no way impact the care you received from Dr. Bok. If you volunteer to be in this study, you may withdraw your participation at any time prior to the competition of data analysis. Once questionnaires are collected they will be de-identified and the researcher and Dr. Bok will be unable to identify your questionnaire. There will be no consequences for withdrawing your data. You may also refuse to answer any questions you don’t want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise warrant in doing so.

How Will Participants’ Information be Kept Confidential?
Any information that is obtained in connection with this study and that contains identifying information will remain confidential and will be disclosed only with your permission.

Personal identification information will be collected such as name, telephone number, and email and these will be retained separately from the questionnaire data. Data from both the questionnaire and interviews will only be presented in aggregate form, meaning averages that reflect all participants in the study. Individual quotes may be used in publication but we will
ensure that individuals participants can not be identified or traced back to their contribution to the research study.

The signed consent forms will be kept separate from the survey and only the researchers involved will have access to the data that you provide. You will place your consent into a brown envelope and seal it, and then the questionnaire will be placed into a separate envelope and sealed as well. They will be transported and locked in a cabinet in the nursing research office at the Western University. The research team will be the only individuals who have access to the locked cabinet. Only the researcher will have access to this data for the purpose of analysis. Dr. Bok will not have access to your individual answers for the questionnaires or the interviews.

Information from this study may be published at a later date, but only the group information will be discussed. Data will be retained for a period of 15 years, after the publication, in a secure place, after which will be disclosed of in a secure manner, e.g. shredded, and electronically deleted.

If you tell us that you are at risk of harming yourself or others, by law we have a duty to breach confidentiality and report the relevant information that was disclosed. If we are going to share this information, we will talk to you first.

If you tell us about any current abuse of children, by law we have a duty to breach confidentiality and report the relevant information that was disclosed and report this to the local child protection agency. Before reporting, we will discuss this with you.

**Are Participants Compensated to be in This Study?**

Participants will not receive payment for this study.

**What are the Rights of Participants?**

You may withdraw your consent at any time and discontinue participation without penalty. If you have any questions about your rights as a research participant or the conduct of this study, you may contact LHSC Patient Relations Office at [redacted] ext. [redacted]. The REB is a group of people who oversee the ethical conduct of research studies. The HSREB is not part of the study team. Everything that you discuss will be kept confidential.
Whom do Participants Contact for Questions?

If you have any questions or concerns about this research, please feel free to contact Dr. Tara Mantler at tara.mantler@uwo.ca or 519-661-2111 ext. 85541.

Consent

This study has been explained to me and any questions I had have been answered. I know that I may leave the study at any time. I agree to take part in this study.

My signature means that I have explained the study to the participant named above. I have answered all questions.

No legal rights are waived as a result of signing the consent form.

________________________  ___________________  ___________________
Print Name of Person       Signature           Date (DD-MMM-YYYY)

________________________  ___________________  ___________________
Print Name of Person       Signature           Date (DD-MMM-YYYY)

Obtaining Consent

My signature means that I have explained the study to the participant named above. I have answered all questions.

I agree to have the interview audio recorded: Yes No

________________________  ___________________  ___________________
Print Name of Person       Signature           Date (DD-MMM-YYYY)

Obtaining Consent
Appendix E – Recruitment and Eligibility Telephone Script

Western

Recruitment and Eligibility Script - Telephone

Complex Care Kids: A Needs Assessment and Economic Evaluation

Date: 20____/____/____

Participant’s ID: __________________________________________________________

ELIGIBILITY CRITERIA

Is there a child in your family with medical complexity  
Yes  No

Do you live in the city of London, or at least 30 minutes from London?  
Yes  No

Do you speak English?  
Yes  No

Are you willing to have an interview audio recorded?  
Yes  No

For RA Use: If NO to any of the questions above= NOT ELIGIBLE

Say "Thank you for contacting us but we can only include participants who are XXXX (insert the criteria that the woman did not meet). Thank you for your interest in the study and conclude the phone call.

For RA Use: If YES to all questions above= ELIGIBLE- proceed to INFORMED CONSENT PROCESS

INFORMED CONSENT PROCESS
You are eligible to take part in this study. I would like to give you some information so that you can make an informed decision about whether you would like to take part or not. 

[Read Letter of Information, checking in with the participant as you go to ask if he/she understands or has questions].

Say: Do you have any other questions about this study? [provide answers]

Are you interested in taking part? No Yes

IF NO: Thank you for your interest in this study. It would be very helpful to know why you decided not to take part. Would you mind sharing this with me?

IF YES: Great! We can either collect data over the phone or meet up- which would you prefer?

When is a good time for us to conduct the interview/questionnaire?

______________________________________ (Day and Time)

Where would you like to meet to conduct the interview? At home or in a community location?

What is the address? ________________________________

Great! Would you like a reminder call prior to the interview? Yes/No.

Thanks again for your interest in the study if you need to reach me for any reason please feel free to use this number. I look forward to seeing you (insert date and time of the interview).
Appendix F – Recruitment and Eligibility Email Script

**Recruitment and Eligibility Script - Email**

Complex Care Kids: A Needs Assessment and Economic Evaluation

Subject Line: Thank you for your interest in the study- we need a little more information.

To (insert name),

Thank you for your interest in the CCKids research study. The purpose of the CC Kids research study is to help understand the needs of families who have children with medical complexity. Before I can enroll you in the study I need to ask you a few questions.

1. Is there a child in your family with medical complexity? Yes/No
2. Do you live in London or at least 30 minute drive from London? Yes/No
3. Do you speak English? Yes/No
4. Are you willing to have an interview audio recorded? Yes/No

If you could ensure you answer all the above questions, then I can determine if you are eligible to participate in the study.

Thanks,

(insert RA Name)

(RA phone number)

Note: Emails are not a secure method of communication
Not Eligible Email
Subject Line: Thanks for your interest in the research study

Hi (insert name),

Thank you for your interest in the CCKids research study unfortunately, based on the answers to the questions you provided you are not eligible to participate in the study.

Thanks
(insert RA Name)
(RA phone number)
Note: Emails are not a secure method of communication

For RA Use: If NO to any of the questions in the email= NOT ELIGIBLE

Invitation to Participate- Email

Subject Line: Eligible to Participate in CCkids

To (insert name),

Thank you for your responses. You are eligible to participate in the CCKids research study. I have attached the letter of information outlining the study procedures, benefits to participation, and potential risks. To summarize participation in this study involves:

1) This study will a short demographic questionnaire and an online questionnaire that will take approximately 30-45 minutes to complete.
2) One 60 minute interview that will be audio recorded and done at a mutually convenient time and location (either over the phone or in person [in your home or at a community location]).

You are welcome to withdraw from the study at any time and participation in this study will in no way effect your health and social services.

If you have any questions about the study procedure, please do not hesitate to ask (you can call or email). I have attached the letter of information, which outlines all aspects of the study to this email for your review.

**Would you like to participate in this study?**

If yes, please let me know when a good time to call or meet (and where you would like to meet- we can meet at your home or at a community location like a library)? When we meet we can review the consent form. If you have any questions please do not hesitate to ask. I will send you a reminder email about this study in 10 days.

Thanks
(insert RA Name)
(RA phone number)

Note: Emails are not a secure method of communication

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**Follow-Up Email**

Subject Line: Follow Up- CCkids Research Study

To (insert name),
I just wanted to follow up with you as I have not heard back. I was wondering if you were still interested in the study? If so I am happy to answer any questions you have. Is there a time that we could arrange to meet or talk on the phone?

Thanks

(insert RA Name)

(RA phone number)
Appendix G – Complex Care Kids Questionnaire (Demographics)

Complex Care Kids Questionnaire

Thank you for agreeing to answer this questionnaire. We anticipate it will take between 30-45 minutes. There is no right or wrong answer, we are simply looking for what is true for you. Please feel free to skip any questions you do not feel comfortable answering. This questionnaire has five parts: 1) Demographic Information; 2) General Health; 3) Health Care Needs of Your Child; and 4) Satisfaction.

DEMOGRAPHIC INFORMATION

This section asks about your personal demographics.

What is your gender?
- Female
- Male
- Other
- I prefer not to answer

What is your age in years?
- 18-24
- 25-35
- 36-45
- 46+

What is your current marital status?
- Single
• Married/common law/engaged
• Divorced/separated
• Widowed
• I prefer not to answer

What is the highest level of education that you have completed?
• Less than high school
• High school completed
• Community college and/or apprenticeship/skilled trade completed
• University undergraduate degree completed
• University graduate degree or higher completed
• I prefer not to answer
• Other

What is your current employment status?
• Employed full-time
• Providing full-time care for my child
• Providing part-time care for my child
• Employed part-time
• Unemployed
• Other

If unemployed, are you: (please select one)
• Unemployed but looking for paid work
• A stay-at-home parent
• On maternity or parental leave
• On sick leave
• Disabled or unable to work due to health reasons
• A student
• I prefer not to answer
• Other

What is your estimated (best guess) annual combined GROSS family income (after taxes are deducted), including employment, government cheques, child support, and other sources of income?
  • Less than $19,999
  • $20,000 to $49,999
  • $50,000 to $99,999
  • Greater than $100,000
  • I prefer not to answer

What is/are the ethnic or cultural background(s) you identify with most? (For example: Canadian, English, French, Chinese, East Indian, Colombian, etc.) Please specify as many origins as you like:

________________________________________________________________

Were you born in Canada?
  • Yes
  • No

If no, how long have you lived in Canada?

____________________________

What is your relationship to the child with medical complexity?
  • Mother/Female Guardian
  • Father/Male Guardian
  • Other adult relative
  • Other

If other, please specify

____________________________

This section asks about demographic information of your family and the child in your family with medical complexity.
What is the age of your child with medical complexity?
- Infant (less than 1 year old)
- 1 to 3 years old
- 4 to 12 years old
- 13 to 17 years old

What is the gender of your child?
- Male
- Female
- Other
- I prefer not to answer

Counting yourself, how many adults over the age of 18 live in your home?
- 1
- 2
- 3
- 4
- 5+

How many children under the age of 18 live in your home?
- 1
- 2
- 3
- 4
- 5+

How many children under the age of 18 have special health care needs that require them to see multiple health care providers?
- 1
- 2

If child is infant or 1 to 3 years old the kids screen quality of life questionnaire will be skipped
Is your child with medical complexity capable of physical activity (i.e. walking)?

- Yes
- No

If child is unable to walk any questions regarding physical activity will be skipped
Appendix H – Interview Guide

Interview Guide

Preamble: Thank you so much for agreeing to participate in this interview. As a reminder this interview is being audio-recorded, which I am going to turn on now. You are welcome to skip any questions you do not wish to answer.

1. Can you describe what health care is like for your child?
   a. Can you walk us a through “a day in the life”?
   b. Who is involved (care givers, service providers, educators, other)?
   c. How do you access the care? What is this like for you? Barriers/opportunities?
   d. What makes health care for your child easy?
   e. What makes health care for your child difficult?
   f. How would you describe the relationship with your child’s health care and/or service providers? (satisfaction)

2. When have you used hospital-based services?
   a. What reasons?
   b. How often?
   c. Scheduled? Unscheduled?
   d. What is it like for your child?
   e. What is it like for your family?
   f. What is it like for you?

3. What are the barriers for your child in accessing health care?
   a. For you?
   b. For your family?
   c. Which barrier is the most important?

4. What are the facilitators for your child in accessing health care?
   a. For you?
   b. For your family?
5. What are some of the opportunities for enhancing or improving existing care?
   a. If you could envision accessing care in other, more family-friendly ways, what might that look like?

6. What would make care for your child more effective?
   a. In terms of access?
   b. To enhance you and/or your child’s quality of life?
   c. In terms of financial burden?
   d. Less stressful?
   e. Of the changes which would you prioritize? Why?

7. Who is currently responsible for the coordination of your child’s care?
   a. Who manages/oversees daily care in the home? In the health care setting?
   b. Who manages the care plan?

8. Does your child have access to all the care they need?
   a. What kind of things might make accessing care easier or simpler than it is now?
   b. Are you and/or your child able to follow through on what the health care provider(s) recommend?
   c. Do you feel there are any key players missing in your child’s care?
   d. Why do you feel they are the missing? (what is the barrier?)

9. What do think is needed to improve or optimize the health of your child?

10. What do you think is needed to improve the quality of life for your child?
    a. For you?

11. The first time you transitioned from the hospital to home what city were you living in?

12. Can you describe the transition process (i.e. moves from hospital to home, from different hospital units or to different specialists) for your family? For your son/daughter?
    a. Can you describe the days before the transition? Walk me through how you were feeling? How your child was feeling?
    b. Can you describe the day of transition? What did it look like for you? How did you feel? What was easy? What was difficult?
    c. How did you feel a week after the transition? A month?
    d. What changes in the health care system would help families during the transition period?
13. Can you describe your first transition home?
   a. what did the day to day look like for your child during those first few days at
      home? For you? For your family?
   b. Did you have a clear plan of action for ‘next medical steps’ for your child after
      arriving home?
   c. How did the plan work?
   d. What made the plan easy?
   e. What made the plan difficult
   f. What from your perspective was good/easy about the transition from hospital to
      home? What was difficult?
   g. What supports were available at the time of transition? What supports are available
      now? (i.e. What did you know at that time? What have you learned since?)

14. Is there anything else regarding your experiences that you would like me to know, before we
    close the interview? (closing remark)
Appendix I – Debriefing Form

Debriefing Form

**Project Title:** Complex Care Kids: A Needs Assessment and Economic Evaluation

**Principal Investigators:**

Western University, [redacted] ext. [redacted]

**Co-Investigator:**

Children’s Hospital, LHSC

Thank you for participating in this study. The purpose of this study was to conduct preliminary research on the specific needs, challenges, and opportunities for rural/remote families with complex care children. A needs assessment was conducted to better understand the issue of transitions in care for children with medical complexity and their families as they move from hospital to community-based care in rural compared to urban settings. There were no predictions for this study, the role of the research team was to only gather information from this population. This was carried out by interviewing children with complex care needs and their families to identify the everyday experiences this population faces and the effect of rurality on the processes.

Here are some references if you would like to read more.


Appendix J – Literature Review Methods

Five databases were used to ensure a comprehensive literature search of peer-reviewed articles: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Ovid EMBASE, PsychINFO, Ovid MEDLINE and Scopus. The following search terms were used in each database: *children with medical complexity or children with medical complexit*, *medically fragile children*, *caregiver experience*, *parental caregivers*, and *caregivers*. In each database, the terms about caregivers were combined using the operator “OR” and the terms regarding medical complexity were combined using the operator “OR”. Using the operator “AND”, the resulting number of articles were then combined. These parameters resulted in a total of 569 articles across the five databases. After screening for duplicates and relevance, 349 articles remained for abstract screening. Articles were excluded if the abstract could not be located. After deduplication and abstract screening, 150 full-text articles were screened for relevance to the experiences of caregivers of CMC. Any published conference abstracts found, regardless of their relevance, were excluded if the article could not be located. Studies that primarily focused on the cost of CMC’s care with no mention of the caregivers were also excluded. All studies included were written in English and published in peer-reviewed journals. There were no restrictions on dates, study design, methods, or geographical location. Studies that included interviews with medical professionals were included as long as caregivers were discussed in relation to their experiences. A total of 38 articles were used in the synthesis of the literature review. Figure 3 provides the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow-diagram used to showcase the screening process of each article.
Once all the relevant literature was reviewed and narrowed down to the 38 included studies, a deductive mapping analysis approach was used to note any findings relevant to the research statement (Bitektine, 2008). The following literature review will include a discussion of major themes relating to the health-related quality of life of parents that emerged throughout the literature examination. Parental experiences regarding care coordination will be explored and encompass the impacts of fragmentation. Next, the reasons and effects of hospital readmissions and discharge delays for CMC will be discussed. The impacts of being the primary caregiver of CMC will be discussed as well as any financial impacts. Lastly, the effects of geography will be discussed in relation to the residential location of families of CMC.
Curriculum Vitae

1. NAME: Vanessa Rocchese

2. EDUCATION
The University of Western Ontario, London, ON, Canada
Master of Health Promotion (MSc), Health and Rehabilitation Sciences 2019-2021
Honors Bachelor of Health Sciences (BHSc) with a minor in Psychology 2015-2019

3. SPECIALTY QUALIFICATIONS/CERTIFICATIONS
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<td>Lawson Health Research Institute</td>
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<td>St. John Ambulance</td>
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<td>Stop the Bleed Training</td>
<td>American College of Surgeons: Committee on Trauma</td>
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4. HONOURS AND AWARDS

Ontario Graduate Scholarship, Recipient 2020-2021
- Awarded based on merit to ~200 students in a graduate program who have achieved a minimum of 80% in either their graduate program admission average and/or their cumulative Western graduate average.

Western Graduate Research Scholarship, Recipient 2020-2021
- Nominated by graduate program and awarded to a select few students based on merit.
Dean’s Honor List,Recipient 2018-2019
- Recognizes full-time students registered in the faculty of Health Sciences who completed a minimum of 4.0 courses during previous fall/winter semesters and earned an average of 80% or more with no failed courses.

The Western Scholarship of Distinction, Recipient 2015-2016
- Awarded $1500 based on undergraduate admission average.

5. RELEVANT EMPLOYMENT HISTORY

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<td>2018-2019</td>
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<tr>
<td>Research Assistant</td>
<td>School of Health Studies</td>
<td>Western University</td>
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6. PRESENTATIONS

