

**HEALTH CARE INTERACTION EXPERIENCES OF PARENTS OF CHILDREN
LIVING WITH MEDICAL COMPLEXITY DURING COVID-19**

by

Kathryn Emma Smith

B.Sc.N.,Thompson Rivers University, 2011

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The following individuals certify that they have read, and recommend to the College of Graduate Studies for acceptance, a thesis/dissertation entitled:

Health Care Interaction Experiences of Parents of Children Living with Medical Complexity During COVID-19

submitted by Kathryn Emma Smith in partial fulfillment of the requirements of the degree of Master of Science in Nursing.

Dr. Lise Olsen, UBC Okanagan, Faculty of Health and Social Development, Nursing Supervisor

Dr. Kathy Rush, UBC Okanagan, Faculty of Health and Social Development, Nursing Supervisory Committee Member

Dr. Florriann Fehr, Thompson Rivers University, School of Nursing Supervisory Committee Member

Dr. Christine Cassidy, Dalhousie University, School of Nursing, Faculty of Health University Examiner

Abstract

Children with medical complexity (CMC) are a growing population who often access health care services more frequently than children without medical complexity and whose parents commonly assume the medical caregiver role in addition to their regular parenting responsibilities. CMC usually have high care needs, frequent use of health care services, functional limitations, and at least one complex, chronic condition. Despite the growing population, the frequency of accessing health care services, and the role of parents as medical caregivers, there is a lack of focused research regarding the experiences of parents following hospital discharge or medical interactions. This research study aimed to explore parents' experiences and provide clinicians with recommendation from parents on how to improve in-patient hospital discharge or medical interaction processes. Using interpretive description methodology, this study was conducted using semi-structured interviews with five parents of CMC living within the interior of British Columbia about their experiences with in-patient hospital discharge or medical interactions of their CMC. The study identified five main themes related to parents' experiences: parents' emotional response to interactions; being acknowledged as an expert; providers building connections with children; accessibility to health care services; and COVID-19 pandemic-related challenges. In addition, six themes related to recommendations from parents for clinicians to improve processes were identified: the importance of forming connections with children; the importance of clear and effective communication; individualized approaches to care; creating and communicating a plan of care; including parents and children as part of the health care team; and the importance of clustering care. The results indicate parents' experiences during and after health care interactions are complex events which can be influenced by the clinician providing care to

the CMC and their family. This study can help providers learn how to better support parents during and after medical interactions.

Lay Summary

The aim of this study was to explore the experiences of parents of children living with medical complexity during and after interactions with the health care system. Additionally, this study provided recommendations from parents for health care workers on how to better support parents during these interactions. The results showed that parents' experiences during interactions with the health care system are complex, often challenging, but can also be supportive. Nurses, doctors, and other health care workers can influence a parent's experience during and after an interaction and are well-situated to help improve the support system for parents of children with medical complexity.

Preface

The qualitative research study was conducted using interpretive description methodology by Ms. Kathryn Emma Smith under the supervision of Dr. Lise Olsen at UBC Okanagan. Data collection and analysis were conducted by Ms. Smith and followed the principles of interpretive description methodology. In addition, Dr. Kathy Rush at UBC Okanagan and Dr. Florriann Fehr at Thompson Rivers University were the further members of the thesis committee. Dr. Olsen, Dr. Rush, and Dr. Fehr provided ongoing feedback, guidance and support for Ms. Smith throughout this research study and have reviewed this completed report. Ethics approval for this research project was sought and obtained by the UBC Okanagan Behavioural Research Ethics Board and the Interior Health Authority Research Ethics Board and was classified as a minimal risk study. Dr. Lise Olsen was listed as the Principal Investigator and the certificate number is H19-03228-A002.

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Dedication

To Michael, Eliana, and Libby. This wouldn't be a reality without your support, encouragement, and understanding. Thank you for being the best part of my life.

Chapter 1. Introduction

The number of children with chronic, complex medical needs is rising; partly a result of improvements with treatments and intensive care (Dewan & Cohen, 2013). According to the Canadian Institute for Health Information (CIHI) (2020), “in 2015-2016, the age-adjusted rate of medical complexity was 948 per 100,000 children and youth” across Canada (p. 7). The same study estimated the medical complexity rate for children and youth in British Columbia to be approximately 802 per 100,000 children and youth (Canadian Institute for Health Information, 2020). ‘Children with medical complexity’ (CMC) are considered a subpopulation of a larger group described as ‘children with special health care needs’ (Cohen et al., 2011). No universal definition exists for this population; however, Cohen et al. (2011) provide an operational definition that will be utilized throughout this study: CMC are children who have high care needs, functional limitations, frequent use of health care services, and the existence of one or more chronic complex conditions. Examples of chronic, complex conditions include (but are not limited to) congenital heart defects, genetic conditions (i.e. neurological or metabolic), cystic fibrosis, and/or autoimmune disorders.

Children with medical complexity (CMC) often require much more frequent access to health care services compared to children without medical complexity. According to the CIHI (2020), CMC were found to access primary care services twice as often as children without medical complexity and accounted for approximately one-third of hospital admissions and one-sixth of emergency department visits in Canada between 2015-2016. In 2012, research completed by Cohen et al. established that children with medical complexity accounted for nearly 30 percent of pediatric health care expenditures in Ontario.

Additionally, analysis of CIHI data showed that children and youth with medical complexity

in Ontario, Alberta, and the Yukon were responsible for approximately 17% of visits and 21% of total costs for all children and youth accessing emergency department services in these provinces between 2015-2016 (CIHI, 2020).

It is therefore clear that the care for children with complex disorders comprises a substantial portion of services provided to children in Canada. While there is emerging evidence related to the frequency and type of health care services that are being accessed by children with medical complexity (CMC), there remains a gap in research that describes the experiences of CMC and their families during and after these health care services are accessed. As parents often assume the role of primary medical caregiver for their child, Cohen et al. (2011) suggest that the inclusion of parents in research efforts aimed at understanding this population and its unique needs is vitally important. Therefore, the overall aim of this project was to help address the research gap within the Canadian health care system and provide clinicians with tangible ideas to influence the provision of care for this population. The following key terms were used in this thesis and are described below.

1.1 Definition of Key Terms

1. **Children with Medical Complexity (CMC).** CMC are considered a subpopulation of a larger group described as ‘children with special health care needs’. CMC are children who have high care needs, functional limitations, frequent use of health care services, and the existence of one or more chronic, complex conditions (Cohen et al., 2011).
 - a. **High care needs.** When a child requires a high level of health care services that can include but are not limited to medical care, specialized therapy,

and/or educational requirements. These services usually have a large financial, social, or time impact on the whole family unit (Cohen et al., 2011).

- b. **Functional limitations.** Limitations that exist as part of a medical condition which restrict the child's ability to perform functions associated with everyday activities in life independently. Examples include feeding tubes, use of a wheelchair, or medical technology equipment like a ventilator (Cohen et al., 2011.).
- c. **Frequent access to health care services.** The use of health care services above what is expected of other children with special health care needs and children without a complex condition. Examples of the health care services that CMC might access on a more frequent basis than other children include but are not limited to the following: hospitalizations; specialized therapies; specialized health care providers or services; and surgeries (Cohen et al., 2011).
- d. **Complex chronic conditions.** A medical condition(s) or complications from a condition that the child is expected to have for their entire life. The condition could be diagnosed or unknown and is generally associated with high death or complication rates (Cohen et al., 2011). Examples include (but are not limited to) genetic conditions or autoimmune disorders.

- 2. **In-patient hospital discharge, hospital discharge, or discharge.** For the purpose of this thesis, discharge refers to transferring a patient from an acute care facility to their home after being classified as 'admitted' within that facility.

3. **Health care interaction or medical interaction.** For the purpose of this thesis, health care or medical interaction refers to any interaction with, or delivery of, care from a health care professional or health care service that was required outside of routine care (i.e. not a wellness checkup). Medical interactions only include outpatient interactions when no admission to an acute care facility occurred. Interactions include but are not limited to those occurring in-person, virtually, or over the phone.
 - a. **Health care professionals.** For the purpose of this thesis, health care professionals include but are not limited to family practice physicians, specialist physicians, Nurse Practitioners, Registered Nurses, Licensed Practical Nurses, occupational therapists, physical therapists, and respiratory therapists.
 - b. **Health care services.** For the purpose of this thesis, health care services include but are not limited to any service received in hospitals (inpatient or outpatient services), specialty clinics, doctors' offices, or diagnostic services.
4. **Parent.** For the purpose of this thesis, parent refers to the child's primary caregiver or legal guardian.
5. **Clinician or provider.** For the purpose of this thesis, clinician or provider will be used interchangeably to refer to any health care professional the child or parent encounters or interacts with as defined above.

1.2 Problem and Significance

As established above, children with medical complexity (CMC) require more frequent access to health care services as compared to children living without medical

complexity (CIHI, 2020). These health care services can include admissions to hospitals, outpatient services, and/or specialty clinics and usually always require some form of interaction with a health care professional. In addition, parents of CMC are often responsible for providing certain ongoing medical care or support for their children in addition to their regular parenting role (CIHI, 2020). For example, one survey of CMC and their families conducted in British Columbia found that 112 out of 156 respondents (71.8%) described themselves as being their children's sole medical caregiver 75-100% of the time (Baumbusch et al., 2020).

Despite the necessary frequency with which children with medical complexity (CMC) access health care services, the subsequent interactions that occur with health care professionals, the well-supported fact that parents assume medical caregiving roles for their children, and a body of research that focuses on the transitions and discharges of children with medical complexity there continues to be a limited amount of research that focuses specifically on the experiences of parents following in-patient hospital discharge or medical interactions. In addition, there is a lack of research that utilizes parents' perspectives and knowledge to learn how hospital discharges and health care interactions affect CMC and their families as well as recommendations from parents on how discharge or medical interaction processes could be improved. Therefore, little evidence exists that can be used to evaluate current hospital discharge or interaction processes, identify successes and/or challenges, and make suggestions to improve the care of CMC during these experiences.

1.3 Purpose and Objectives

The purpose of this study was to explore the experiences of parents of children living with medical complexity (CMC) after an in-patient hospital discharge or health care

interaction in order to inform the provision of care by clinicians who work with this population. Three objectives guided this project. First, to gain an in-depth, comprehensive understanding of parents' perspectives of the in-patient hospital discharge or health care interaction process for their CMC. Second, to address the current research gap present within the Canadian health care system. Lastly, to provide parent recommendations for clinicians to be able to support parents of CMC throughout the hospital discharge or health care interaction experience.

1.4 Potential Contributions

This project holds the potential to deepen understanding of the experiences and perspectives of parents who are caring for CMC and help to bridge the knowledge gap that exists within the current literature on this topic. It is important to note that the study was conducted within Canada, a context which to date had lacked research focused in this area. This project gathered information about how parents of children living with medical complexity (CMC) experienced their children's health care interaction(s) and how these medical interactions impacted parents.

In addition to increasing the understanding of the experiences of parents of CMC during medical interactions, the study also provided opportunities to guide and shape the practice of clinicians working with this population by including recommendations from parents on how clinicians could provide supportive care during interactions. Ideally, the qualitative evidence provided through this study may help lead to clinicians participating in self-reflection to identify areas within their own practice that could benefit from incorporating parent perspectives. Clinicians can then utilize this information to evaluate current interaction processes and policies, identify potential problem areas, and champion

changes that will include increasing parental involvement in the medical interaction process. Additionally, this project would stimulate further research within this area.

1.5 Overview of Thesis

The remainder of this thesis includes a review of the literature, an explanation of the methods utilized, a report of the results from data collection, a discussion of the findings, a conclusion, followed by appendices that include the study documents.

Chapter 2. Review of the Literature

A three-step process was utilized to review literature related to the study topic. An initial literature search was first conducted to capture research regarding discharge experiences for children in general to provide a basic understanding of current discharge processes for this population. Subsequently, two separate, more specific and tailored searches were conducted; one to identify the current literature related to parental experience of discharge processes for children with medical complexity, and the other to identify current literature related to the parental experiences of medical interactions for children with medical complexity. The specific search strategies are described below for each literature review.

First, a literature search was performed to assess existing research regarding the discharge process for children in general. The search was conducted through the University of British Columbia Okanagan's library using the Medline database. Search terms included child, patient discharge, and process. The results were screened based on their title and abstract to determine which were to be assessed more thoroughly. Only articles available in English were included.

Second, a more focused literature review was conducted to identify current research related to parental perspectives and experiences of discharge processes for children with medical complexity (CMC). This search was conducted through the University of British Columbia Okanagan's library using CINAHL, Medline, and Embase databases. The search strategy, which was reviewed with a UBC-O Librarian to ensure a complete and appropriate search strategy, included the following terms: child ("child", "child health", "child disabled"); parent ("parents", "parents of disabled child"); medical complexity ("chronic disease", "child, medically fragile", "medically fragile", "child, disabled"); and patient

discharge (“discharge”, “transfer, discharge”, “discharge planning”). Additional search criteria included the following limitations in order to focus on accessible and recent results: access to full-text, peer-reviewed articles; published within the last ten years (2011-2021); and available in English. Reference lists of the identified articles were also manually searched to locate further articles to include in the literature review.

As a third step, a literature review was conducted to identify current research that existed regarding parents’ experiences of medical interactions for children with medical complexity (CMC). This search was also conducted through the University of British Columbia Okanagan’s library using CINAHL, Medline, and Embase databases. The search strategy included the following: child (“child”, “child health”, “child health services”, “child health care”, “hospitalized child”); parent (“parent”, “parents”); medical complexity (“medical complexity”, “chronic disease”, “disabled children”); outpatient (“outpatient”, “outpatient clinics”, “hospital”, “outpatient care”, “outpatient department”); and parent-provider interaction (“parent-provider interaction”, “professional-family relations”, “child health services”, “professional-parent interaction”, “child health care”, “patient care”, “doctor patient relation”). The additional search criteria utilized included the following: access to full-text, peer-reviewed articles; published within the last ten years (2011-2021); and available in English. The reference lists of identified articles were also manually searched to locate other articles that could be included in the literature review.

2.1 Findings

The first step of reviewing literature pertaining to the general discharge process for children yielded a total of four primary studies, all completed in the United States. Authors of these studies discussed the lack of standardization in pediatric discharge processes that

exist within the United States, despite thousands of pediatric discharges daily (Berry et al., 2014; Blaine et al., 2018; Holland et al., 2014; Holland et al., 2016). As pointed out by the authors of these four studies, there is a lack of standardization within the discharge process which can negatively impact the quality of pediatric discharge, the health and well-being of patients and their families, potentially lead to higher rates of readmission for patients, and limit quality improvement projects within health care systems (Berry et al., 2014; Blaine et al., 2018; Holland et al., 2014; Holland et al., 2016).

The second step of the literature review undertaken was specific to parent perspectives of discharge processes for children with medical complexity. This step yielded a total of seven studies, five of which were conducted within the United States, one within Ireland, and the last one in Italy. One of the identified articles was a systematic literature review that included ten studies that focused on the transition to home with a child with a congenital heart defect (March, 2017). The remaining articles were qualitative research studies using various designs that utilized either telephone or face-to-face interviews with parents, most of which were considered semi-structured. Canary and Wilkins (2017) was the only study included to also utilize focus groups. Two of the seven studies included interviews with primary care providers and hospitalists in addition to parents to discuss the discharge process of children from the hospital (Canary & Wilkins, 2017; Leyenaar et al., 2017).

Four of the seven identified studies were specifically focused on children living with a chronic condition (Brenner et al., 2015; Lerret et al., 2015; Leyenaar et al., 2017; & Zanello et al., 2015) while two studies interviewed parents whose children had been admitted to hospital with an acute condition (Canary & Wilkins, 2017; & Desai et al., 2016). The studies

that listed inclusion criteria for children included age ranges from zero to sixteen years old (Brenner et al., 2015; Desai et al., 2016; Lerret et al., 2015). Sample sizes varied from eleven to forty-seven participants. In the studies which included demographic data of the parents, mothers participated significantly more frequently than fathers (Desai et al., 2016; Lerret et al., 2015; Leyenaar et al., 2017; and Zanello et al., 2015). The time from discharge to interview of parents varied in each study: Brenner et al. (2015) included discharges within the last five years; Canary and Wilkins (2017) focused on discharges within three months for the children with acute illnesses and did not place a time limit on parents with children living with a chronic condition; Desai et al. (2016) included discharges within the last three months; Leyenaar et al. (2017) initially aimed to interview parents in hospital and then one to two weeks post-discharge but for a variety of reasons, only interviewed parents in hospital: and the remaining two studies did interviews six months after discharge (Lerret et al., 2015; Zanello et al., 2015).

The third step of the literature review search regarding parents' experiences with medical interactions did not yield any studies that focused broadly on the overall experience of parents. However, there were a number of articles identified which focused on specific aspects of parents' experience with medical interactions or provided parent recommendations for how to better support parents of children living with medical complexity during medical interactions. In the following section, the findings from each of the two tailored literature reviews are discussed.

2.2 Discussion of Findings

2.2.1 Parental Experiences with Discharges

Despite the frequency of discharges for CMCs, there is little research that specifically explores the parental perspectives and experiences of discharge processes. A total of seven studies were found that specifically addressed the experiences, suggestions, and insights from parents of CMC to guide care provision. From the review of these articles, several themes emerged: disorganization of current discharge processes; the importance of discharge readiness; engagement and communication; the emotional aspect of the discharge process; and supports for parents. These will be discussed in depth in the following sections.

Current Discharge Processes are Disorganized. One theme that appeared across three of the identified articles was that parents experienced the discharge process as disorganized and fragmented (Brenner et al., 2015; Canary & Wilkins, 2017; Leyenaar et al., 2017). Brenner et al. (2015) reported that parents frequently experienced frustration over the amount of time it took to have all the appropriate arrangements made for their child to be able to go home. Similarly, Canary and Wilkins (2017) found that parents were frustrated by delays in the discharge process, particularly the prescription and medication process. Parents reported that many aspects of the discharge process were complete but they were unable to leave for home until the prescription was filled, which sometimes took several hours. Canary and Wilkins (2017) also interviewed primary care providers (PCP) along with parents. When discussing problems with current discharge processes in relation to timing, PCPs suggested that delays in discharges were often multifactorial in nature but some aspects could be explained by the competing priorities of the PCP caring for the child. It was found that other factors, such as the schedules of medical residents, influenced the daily schedules of PCP

more than the priorities of families. Another study by Leyenaar et al. (2017) found very similar results from both parents and PCPs. Parents in this study reported they were originally told a discharge time of early in the day but were then not actually discharged until late in the evening which left little time to organize and settle back into their home before the night. The PCPs that participated in this study agreed with the parents, stating that the discharge process occurred primarily around the schedule of the health care providers which meant that parents were left waiting for long periods of time. The PCPs also spoke about the potential impact the timing of the discharge can have on families. They reported that discharges that occurred in the evening instead of earlier in the day were not well synchronized with family routines and could therefore contribute to higher parental anxiety levels (Leyenaar et al., 2017).

Importance of Discharge Readiness. The second theme that emerged from these studies was the importance of discharge readiness of parents, which can be explained as to how ready parents felt they were to go home with their children living with a complex condition. There were four ways discharge readiness was discussed in the studies included in this section of the review. First, the articles by Lerret et al. (2015) and Desai et al. (2016) found that parents with higher discharge readiness prior to leaving the hospital reported fewer problems coping with the responsibility of caring for their children's additional needs and reported feeling more successful in the transition to home. Second, Lerret et al. (2015), Desai et al. (2016), and March (2017) reported similar results regarding a link between discharge readiness and the quality of discharge teaching the parents received. These studies found that comprehensive and consistent discharge teaching was found to increase parent's confidence levels at home and was linked to lower parental anxiety levels (Lerret et al.,

2015; Desai et al., 2016; March (2017). Third, Brenner et al. (2015) and Canary and Wilkins (2017) both reported parents found phased approaches to discharge helpful because these styles of discharge allowed them to recognize any gaps that were present in knowledge, equipment, or skills and then work towards addressing those gaps so they could understand and organize all the different aspects that taking a complex child home includes. In addition, it was noted that phased approaches to discharge allow for parents to gradually accept the changes in monitoring and care that occur when a child is discharged home (Brenner et al., 2015; Canary & Wilkins, 2017).

Engagement and Communication. Another theme identified from the articles regarding discharge was the engagement of participants, specifically the inclusion of parents in discharge planning and communication. Parents spoke about the importance of creating a sense of teamwork amongst everyone involved in the discharge of the child and stressed that communication between all parties was key, not only during admission but also once they were home and settled (Canary & Wilkins, 2017). Similarly, parents in the study conducted by Leyenaar et al. (2017) reported how they wanted to feel included in all aspects of care and discharge, that their perspectives were valued by other members of the health care team, and that health care providers communicate more with them to help them to feel more like a member of the team. In addition, Zanello et al. (2015) found that communication between parents and health care providers was not only a critical component of interactions between the team members but also influenced the confidence levels of parents.

Emotional Aspects of the Discharge Process. In many of the studies included, parents spoke about their emotions during various phases of discharge. Many parents discussed feelings of worry, isolation, fear, and anxiety. Lerret et al. (2015) reported that

parents' feelings of worry were persistent over the six months during the study, specifically in relation to what the child's future would look like and potential complications of medications. Brenner et al. (2015) found that parents experienced worry when they thought about the burden of illness the child would have to deal with in the future. In addition, Brenner et al. found that parents often felt isolated once they had transitioned home. Desai et al. (2016) reported that parents often felt isolated because they did not know what to anticipate in regards to their child's recovery. Leyenaar et al. (2017) described parental ambivalence with fear of readmission mixed with feelings of excitement about the ability to transition home. Brenner et al. found parents often reported experiencing fear during the first few days at home regardless of how prepared the family felt prior to discharge while March (2017) described these parental emotions during the early days at home as anxiety.

Support for Parents. The last theme that emerged from the literature review related to formal support for parents. March (2017) found that parents reported experiencing insufficient support systems once they were discharged home but did not want to over-use the informal support systems they had in place for fear of becoming a burden to those support people. Canary and Wilkins (2017) found that parents reported not only a general lack of formal support for themselves as caregivers but also for their child once they were home. Brenner et al. (2015) described parents' frustration at often having to fight to secure and maintain support at home for their child; reporting they sometimes made compromises in the amount of home support they agreed to just to end the conflict with the service providers. In addition, many parents in this study recounted their worries over the quality of the home care supports available. Health care providers in smaller hospitals or in the community setting were perceived by parents as often lacking adequate education about how to care for

children with complex needs, making it difficult for the parents to feel secure in allowing these providers to work with their children. Further, Desai et al. (2016) discovered that parents reported higher confidence in their ability to care for their child at home when they were given adequate support from providers, hospitals, family and friends, and schools during the discharge home. Examples of these supports included the following: providers being knowledgeable about the child; hospitals helping families arrange transport home; parents having access to pharmacy services; ensuring a strong social support network to help families cope with the emotional aspect of caring for a child with medical complexity; and ensuring the health care team communicates with the child's school to ensure they are aware of the needs of the child.

2.2.2 Parental Experiences with Medical Interactions

There were no identified articles within the literature search that focused broadly on parents' experiences of medical interactions; however, there were seven articles identified for review which included specific aspects of parents' experiences or provided recommendations for clinicians on how to better support parents during medical interactions. These articles will be discussed below.

The aim of the first article identified was to build understanding about the experiences of parents of children living with medical complexity during their admission to a pediatric intensive care unit (Rennick et al., 2019). This interpretive description study was conducted at a Canadian pediatric hospital and included in-person interviews of parents of CMC who had been admitted to the pediatric intensive care unit (PICU) over a twelve-month period. The authors identified four main themes from their research: we know our child best; when expertise collides; negotiating caregiving boundaries; and the importance of being

known. The theme of we know our child best was described as parents having intimate and extensive knowledge of their child's condition, care needs, communication methods, and responses to treatments or interventions. Rennick et al. (2019) explained the next theme of when expertise collides as the struggle parents experienced when they were not acknowledged as experts in their child's care or included in the decision-making process. Negotiating caregiving boundaries referred to the collaboration between parents and providers during the admission. Parents reported wanting to be involved, feel heard, and valued as a member of the health care team. The importance of the being known theme was explained as the parents' desire to have consistency and continuity in their child's providers in order to build trusting relationships.

The next article found within the literature search was a grounded theory study conducted in Western Canada which aimed to explore and explain the characteristics of health care professionals who were considered to be providing best practices during interactions with parents of children with medical complexity who were receiving care at one of three identified facilities (Davies et al., 2017). The authors utilized interviews as well as observations of interactions between parents of CMC and health care professionals in order to determine characteristics of health care professionals that were present during each encounter with parents. Some of the identified characteristics included respecting the worth of all persons, providing equitable care to all, striving to know parents as people, building and maintaining trust, empathizing, showing kindness, supporting, sharing information, seeing parents' perspectives, and flexibility or open-mindedness (Davies et al., 2017).

One article was identified within the literature search that focused specifically on parent-provider communication and the impacts it has on the experiences of parents (Adams

et al., 2021). Adams et al. (2021) conducted an interpretive description study in Ontario, Canada and interviewed parents of children living with medical complexity (CMC) as well as health care professionals and teachers who worked with this population. The aim of this study was to identify any barriers in communication that occurred across the multiple caregivers of CMC and provide recommendations from parents, health care professionals, and teachers to help address and resolve these barriers in communication in order to improve the overall care of CMC. The study identified three main barriers to communication for the caregivers of CMC: organizational policy and technology systems barriers; inadequate access to health information; and lack of partnership in clinical decision making. Examples of organizational policy and technology systems barriers included security policies within organizations that limited the type of communication allowed between caregivers of CMC or the use of outdated communication systems which made it difficult for caregivers to connect with each other hindering their access to new information and therefore negatively impacting the care CMC received. The authors explained that inadequate access to health information included parents not having access to their child's health information (especially in an electronic format), health care professionals having difficulty accessing information about the CMC from other organizations or professionals, and teachers facing physical barriers to accessing the limited information that is given to educational institutions. Adams et al. (2021) described lack of partnership in clinical decision making as the challenges caregivers face in connecting with the other professionals or caregivers of CMC, specifically when health care decisions are being made. For example, the parent participants in the study reported feeling like the expert in their child's care but not always being accepted as the same by health care professionals involved in their child's care. Another example included

health care professionals across community settings reporting issues in communication and shared decision-making with health care professionals in the hospital setting. After discussing the main communication challenges identified from their analysis, Adams et al. (2021) discussed three potential resolutions for these communication barriers including a shared system that can be accessed in real-time, universal access to health information, and partnered contribution to care which was explained as the inclusion of parents and families in the decision-making process.

In another study identified in the literature search, researchers aimed to understand how parents and nurses experienced continuity of nursing care for children living with medical complexity in a pediatric intensive care unit (PICU) (Baird et al., 2016). Baird et al. conducted this grounded theory study interviewing and observing parents and nurses in a PICU in the United States. The objective of the study was to explore what continuity of nursing care meant to both parents and nurses in the PICU to understand the concept of continuity of care as part of best practices in parent-provider interactions. The authors found that both parents and nurses felt continuity of care was important for children living with medical complexity (CMC) but felt it was not always possible to achieve. Parents in this study explained that continuity of care helped to also achieve individualized care for their child as nursing staff were given the opportunity to get to know their child and his/her unique needs which helped parents to feel more comfortable and trusting of the care their child was receiving while in the PICU. When continuity of care was not able to be achieved parents in this study reported feeling frustrated with having to continually explain their child's needs to new staff. The authors also found that a lack of continuity of care could negatively impact trust in the parent-nurse relationship. Nurses who participated in this study had varying

degrees of investment in providing continuity of care for CMC in the PICU. While it was identified that continuity of care was beneficial for families and nurses for a variety of reasons, some of the nurse participants also felt there were potentially negative implications for their practice in terms of expanding their technical skills if they were to always participate in continuity of care assignments.

The next study identified from the literature search was conducted by McNeilly et al. (2017) in Northern Ireland and aimed to explore how parents experienced their participation in the decision-making process for their disabled child's care. This mixed-methods study utilized surveys and interviews and found that 91% of the parents who participated felt it was vitally important for parents to be involved in the decision-making process. McNeilly et al. found that parents reported how they were often required to be strong advocates for their children in order to receive the care their children needed and that parents greatly valued health care professionals who listened to them, were considered trustworthy, and cared about their children. The study found parents placed particular importance on working with health care professionals who valued their opinion and knowledge regarding their children and included them in the decision-making process.

One opinion article identified within the literature search was written by Carosella et al. (2018) and was selected for inclusion in this section of the review because it was derived from a research project in Massachusetts that included over 700 surveys that were completed by parents. In this study, parents completed a survey regarding barriers they faced when trying to access health care services for their children living with medical complexity. From the survey data, the authors compiled ten requests or recommendations for clinicians from parents on ways to help parents of children living with complex medical conditions.

Examples of the ten recommendations included the following: view their child as a person outside of their medical needs; utilize and respect parents' knowledge and skills they have gained while caring for their children; include their children in age-appropriate discussions and decisions about their health and care; and reduce the number of medical interactions and appointments to help improve quality of life (Carosella et al., 2018).

The last article identified in the literature search was written by parents of children living with medical complexity and aimed to explain the challenges that parents and families of CMC face within the United States health care system (Allshouse et al., 2017). The authors identify a number of important concepts they wish providers, policy-makers, and insurance companies to consider when working with parents and families of CMC. For example, the authors state that families want to work with providers, policy-makers, and insurance companies who view their child as a person, not just a diagnosis. They also explain that flexibility in health services delivery and inclusion of parents and families in the decision-making process are essential components to providing quality care for CMC. In addition, Allshouse et al. argue that it is imperative to include parents and families in the creation of a plan of care for CMC as they are often the primary medical caregivers of their children and therefore need to be included as equal partners in the health care team.

2.3 Literature Gaps

2.3.1 Parental Experiences with Discharges

While results from these seven studies reviewed about parents' experiences with discharge processes indicated some of the challenges parents experience, there remains a lack of evidence regarding the experiences of parents within the Canadian health care system. For example, five of these studies were conducted in the United States, one was

conducted in Ireland, and one in Italy. Although much can be learned about potential processes to follow or those to avoid from studies conducted within other countries, other specific aspects, such as evaluation of formal support systems for parents, are unique to the Canadian health care system and therefore need to be studied in a Canadian context in order to provide relevant evidence for Canadian parents.

Also noted to be absent from the literature were details and examples which help apply the research to current practice. For example, while discharge readiness was identified as a very important aspect of the discharge process for parents, details regarding how health care teams and parents currently communicate about this topic were absent. This could reduce the ability of health care managers to improve discharge processes in hospital settings as they would be unsure exactly which aspects of current practice to adapt. Another example of a lack of specific findings within the literature was found within the engagement and communication theme. While these authors highlighted some aspects of engagement and communication that parents found to be important, there remained many unknown components that will require further exploration. These include the effectiveness of professionals in roles related to discharge coordination along with the types and timing of communication that parents find most helpful. Lastly, although some of the authors of these studies discussed common emotions parents experienced after discharge, there was a lack of examples and suggestions for ways in which the discharge process could be optimized to better support parents and lessen the negative emotions they may experience during and after their child's discharge.

2.3.2 Parental Experiences with Medical Interactions

After reviewing the literature search results regarding the experiences of parents of children living with medical complexity (CMC) during medical interactions, it is apparent there is a lack of research surrounding the overall experiences of parents. Among the seven studies reviewed there were none that focused broadly on the overall experiences of parents; although three of the articles focused on specific aspects of parents' experiences during interactions, for example, parent-provider communication, continuity of nursing care, and parental participation in the medical decision-making process. The lack of results from the literature review could be partly due to terminology; it appears there is no standard phrase or word that is used to universally label medical interactions which make it challenging to find literature that is available for this topic. Along with the general lack of research available on this topic is the lack of research being conducted within the Canadian health care system. Only three of the articles identified within the literature search on medical interactions were carried out within Canada. This can make it challenging to apply these findings within the Canadian health care context as there are such fundamental and variable differences in processes and delivery of health care services between countries.

2.4 Implications

There is a small body of evidence that exists surrounding the topic of parents' experiences of discharge processes with their children with medical complexity; however, the evidence is not comprehensive. In addition, there appears to be a general lack of research regarding parents' overall experiences during medical interactions. Further, findings from these literature reviews reveal a lack of studies that address this topic specifically within the Canadian health care system despite initiatives in multiple provinces that identify the value

of parent/family evaluation and participation in addressing multiple aspects of care provision for CMC (Child Health BC, 2016; Fayed et al., 2018). It is important to highlight the missing voice of parents in Canada as there are many aspects within our health care system and culture that differ significantly from those of other countries. This research project will help to address these gaps as it aims to build understanding about the overall experiences of parents during discharges and medical interactions and will be conducted within the Canadian health care system, specifically in British Columbia.

2.5 Summary

In summary, two main literature searches were conducted for the literature review chapter of this project. The first literature search identified seven articles that were found relating to parental perspectives and experiences of discharge processes for children living with medical complexity. From the literature, five themes were identified that exist within current discharge processes: disorganization; the importance of discharge readiness; engagement and communication; the emotional aspect of the discharge process; and supports for parents. The studies included within this review were conducted in the United States, Ireland, and Italy. The second literature search identified seven articles that were found to be related to parents' experiences of medical interactions for children living with medical complexity. Out of the seven articles identified, three focused on specific aspects of the parent-provider interaction including communication, continuity of care, or the decision-making process. The remaining articles were either specific to inpatient admission experiences, opinion style articles written from the viewpoint of parents of CMC, or studied best-practices of providers during parent-provider interactions. Of the studies included within this review, three were conducted within Canada, one in Northern Ireland, and three within

the United States. The gaps identified from the literature included a lack of research that was conducted within the Canadian health care system in addition to a lack of details and examples within the various themes that would allow practitioners to apply this research to practice. This project aims to help reduce these literature gaps by focusing on processes within the Canadian health care system as well as inviting parents to provide suggestions on ways clinicians can better support parents of CMC during discharges or medical interactions. These aspects of the project will help provide clinicians with the evidence needed to deepen their understanding of the perspectives of parents in order to improve the care provided to these parents and their children.

Chapter 3. Methods

3.1 Research Questions

As there is limited research into the in-patient hospital discharge or medical interaction experiences of parents of children with medical complexity, this study addressed this research gap by utilizing two research questions. The first question was ‘What are the experiences of parents of children with medical complexity during in-patient hospital discharge or medical interaction via any delivery method (i.e. in person, virtual, telephone, etc.) that was required for more than routine care purposes?’. This question utilized data gathered from parents to contribute to a richer understanding of this topic. The second question, ‘How can clinicians effectively support parents and families of CMC during the in-patient hospital discharge or completed medical interaction process?’, was used to gain more insight into ways clinicians can support children living with medical complexity (CMC) and their families as suggested by parents of CMC.

3.2 Study Design

The idea for this project arose from my clinical experiences while providing care for children living with medical complexity (CMC) in acute and community care settings. I am a Bachelor of Science in Nursing prepared Registered Nurse who has worked the majority of my ten-year career in both acute pediatric inpatient wards as well as in the community providing respite care for medically complex pediatric patients and their families with different diagnoses and care needs. I have worked with many families and children at different stages of health, illness, and life, which has afforded me the opportunity to observe processes and discuss many topics with parents of CMC, including in-patient hospital discharge processes and medical interaction experiences. During discussions with parents of

CMC, I found that while the experiences of parents varied greatly, there also appeared to be common, shared experiences among parents. These interactions with parents caused me to start questioning how individual parents experienced these events, if commonalities between experiences exist, and how clinicians could positively influence these events for parents and their children which then lead to the development of this research project.

The interpretivist paradigm was chosen to provide the theoretical framework for this project as it encourages researchers to honour multiple truths, multiple realities, and the relationship between researcher and participants in order to gain knowledge of the phenomena from those who experience it (Ponterotto, 2005). Consequently, I believed this paradigm aligned well with my own values and beliefs and would ensure the data were collected and analyzed in a way that would honour the individuals involved and their stories. Interpretive description (ID) was then identified as a methodology that would enable the gathering of information from participants who have intimate knowledge of the topic and create a description of the phenomenon that both acknowledges multiple truths or experiences while also highlighting patterns across events (Thorne et al., 2004). These descriptions can then be utilized by clinicians to gain a deeper insight into the phenomena and adjust their practice accordingly (Thorne et al., 2004). Interpretive description also contributes to the achievement of study objectives by facilitating the exploration of original clinical questions/issues with the ultimate desire to generate practice implications (Thorne et al., 2004). The use of interpretive description allowed me to develop a deeper understanding of parental experiences and provide tangible ideas for clinicians on how to change in-patient hospital discharge or medical interaction processes as suggested by the population with intimate knowledge and experience with this topic. By deepening the understanding of this

topic and creating clinically relevant ideas for use in practice, interpretive description enabled me to answer the research questions and fulfill the goals of this project while also contributing to the development of knowledge in this area for use by other clinicians and researchers. This study provided new knowledge to help tangibly inform clinicians' practice, acknowledge the need for flexibility in practice application, and account for emerging contexts, concepts, and meanings (Thorne, Kirkham, & MacDonad-Emes, 1997; Thorne, Kirkham, & O'Flynn-Magee, 2004).

In addition, a patient- and family-centered care (PFCC) theoretical perspective was utilized to help shape the study approach. Patient- and family-centered care is a care delivery model that encourages and emphasizes collaboration among health care professionals, patients, and their families in all aspects of care in order to foster the health, well-being, and empowerment of individuals and their families (Institute for Patient- and Family-Centered Care, 2021). I utilized this theoretical perspective to help guide the study approach because of my previous professional experience working as a Registered Nurse in pediatrics where PFCC was the adopted care delivery model. I saw the many benefits children and their families experienced when PFCC was implemented. In addition, the principles of PFCC aligned with my personal and professional viewpoints as they place emphasis on establishing and maintaining a collaborative relationship between patients, families, and health care professionals as well as valuing the opinions and experiences of the patient and their family (Institute for Patient- and Family-Centered Care, 2021). I shared the perspective of PFCC that patient and family viewpoints matter and that patient and family experiences are important to understand and should be central to care provision. These principles helped shape the overall study approach as well as specific study design elements such as the

interview guide questions. For example, PFCC theory shaped how I approached and interacted with the participants to encourage them to feel valued and respected as members of the health care team, parents of a CMC, and contributors to the study. Another example of a PFCC informed approach included the development of interview guide questions that were worded to encourage participants to feel that their experiences were important and their perspectives valuable.

3.3 Setting, Participants, and Sampling

3.3.1 Study Setting and Participants

The study took place within the interior of British Columbia with all participants residing within the Interior Health Authority boundaries, which is a region in BC with a population of approximately 795, 000 (Interior Health Authority, 2019). Participants were identified from the larger population of parents who have a child living with a chronic, complex condition under the age of 19. Cohen et al.'s (2011) definition of children with medical complexity was used to help determine the eligibility of participants. The definition includes the following: children with high care needs, presence of one or more chronic complex conditions, functional limitations, and frequent use of health care services. Participants were all parents who had experienced a medical interaction related to their complex child from the Interior Health region between March 2020 and March 2021. None of the participants had experienced an admission or discharge from an Interior Health acute care facility inpatient ward between March 2020 and March 2021. The inclusion and exclusion criteria of the study are listed below for clarification.

Inclusion Criteria.

- Parents (mothers, fathers, and/or legal guardians) who are the primary caregiver(s) or legal guardian(s) of a child under 19 years of age who has all of the following:
 - High care needs (medical, educational, or specialized therapies)
 - One or more chronic complex conditions
 - At least one functional limitation
 - Frequent access to health care services (i.e. at least 2 or more medical interactions between March 2020 and March 2021)
- Resided within the Interior Health Authority region
- Experienced or participated in an in-patient hospital discharge or medical interaction of their child from the Interior Health region between March 2020 and March 2021
- Working knowledge of English to be able to participate in interviews

Exclusion Criteria.

- Parents with complex children over 19 years of age
- Absence of high care needs, one or more chronic complex conditions, functional limitations, and/or frequent use of health care services
- Resided outside of the Interior Health Authority region
- Parents of a child with a complex condition who have not experienced an in-patient hospital discharge or medical interaction from the Interior Health region between March 2020 and March 2021
- Primary diagnosis of a psychiatric condition

3.3.2 Sampling

Interpretive description methodology encourages clear, thoughtful, and contextual sampling strategies in order to address the concept of representativeness of findings (Thorne, 2014). For this project, participants were recruited from the specific population of parents who have a child with a chronic, complex medical condition and who have experienced an in-patient hospital discharge or medical interaction. As this population is considered small and specific in nature, purposeful sampling was utilized as it allows researchers to recruit participants from a specific population group that has intimate knowledge or experience with the topic under study (Patton, 2002). Focusing on sampling from this specific population enabled the concentration to remain on parental experiences of their child's hospital discharge or medical interaction while also studying why these experiences occur (Thorne, 2016).

3.3.3 Sample Size

Interpretive description methodology does not prescribe specific sample sizes, but rather encourages researchers to justify their chosen sample size based on the number of cases they feel is needed for the results to have value (Thorne, 2016). Although there is no specific sample size associated with interpretive description, common sizes are often between five and thirty cases or participants (Trotter, 2012). As the overall aim of this project was to understand parents' perspectives of the in-patient hospital discharge or medical interaction process for their child living with medical complexity (CMC) in order to address the current research gap and help influence clinicians' practice, I wanted to identify a sample size that would allow the project to produce valuable clinical results. The final sample size for the study was five participants due to several reasons. First, as data collection

and analysis were an iterative process for this project, preliminary results were provided to the study committee for discussion and review. While the sample size was five, the number of interactions each participant discussed ranged from one to seventy, with an approximate total number of interactions from all participants of 166. Secondly, the participants were all parents of children with chronic complex conditions that had been diagnosed, at minimum, one to two years prior to the study timeframe, which allowed the participants to compare and contrast the interactions experienced during the study timeframe with the multitude of interactions they had experienced prior to the study. Thirdly, participants genuinely wished to help create opportunities for improvement within a system their child had to navigate frequently and therefore provided rich, compelling feedback and thoughtful recommendations for clinicians. Fourth, this project, while small in size, helped to reduce the identified literature gap within Canada as it was conducted entirely within the Canadian health care system. Thorne (2016) suggests that the researcher should remain realistic about the full potential of the results from a smaller study but by ensuring transparency regarding what the study aims to achieve based on its size, the researcher can justify their choice of sample size. Considering the approximate number of interactions, the richness of the data provided by participants, and guidelines for sample sizes within the interpretive description methodology, it was determined by the study committee that a sample size of five would still provide valuable impact on a local level as well as provide findings to fill gaps that currently exist within Canadian research and potentially provide a starting place for future studies within this area.

3.3.4 Recruitment

Recruitment efforts were undertaken through inpatient pediatric wards in acute care facilities, pediatric care clinics, infant development programs, public health offices, private pediatric respite care companies, and social media accounts of various family or parent support organizations all within the Interior Health Authority. Paper and/or electronic copies of the information poster (see Appendix A) and parent consent form (see Appendix B), which both contained study information and contact details of the researcher, were sent to recruitment sites for distribution. Participants made first contact by email to express their desire to participate in the study, at which point, a phone call was arranged to discuss the study further and determine eligibility of the potential participant (see Appendix C). Once eligibility was determined and informed consent was reviewed with the participant, participants were asked to provide a signed electronic copy of the consent form. The interview date and time was then arranged. Approval for this study was obtained from the UBC Okanagan Behavioural Research Ethics Board and the IHA Ethics Board (H19-03228-A002).

The recruitment efforts of this study were impacted by the COVID-19 pandemic in several ways. Initially, the study was aimed at interviewing parents of CMC about their experiences with their child's in-patient hospital discharge from an acute care facility only. Recruitment using the original criteria of only acute care in-patient hospital discharge experiences of parents took place from August to November of 2020 with no participants identified. The presence of barriers to recruitment efforts were acknowledged, including fewer pediatric inpatient admissions and decreased engagement from parents of CMC, likely as a result of the COVID-19 pandemic and the many challenges families were experiencing

at this time. In consultation with the supervisory committee, changes were then made to the eligibility criteria and timeline which were approved by the University of British Columbia Okanagan and Interior Health Authority ethics boards. Recruitment began again in January 2021 at which point current recruitment sites were supplied with the updated study information and several new sites were contacted. All five participants were recruited and interviewed between January and March 2021. Despite extensive recruitment efforts, no participants who had experienced an acute care in-patient hospital discharge with their child living with medical complexity (CMC) were identified; instead, all participants met the other inclusion criteria of having experienced a medical interaction.

3.4 Data Collection

This study utilized individual, semi-structured telephone interviews with participants. This method of data collection was used for multiple reasons. First, this interview style is a flexible way to collect rich data while allowing the researcher to guide the interview and still be responsive to participant answers (Tod, 2015). Second, the use of semi-structured interviews aligned with the qualitative, interpretive description approach utilized for this study. Third, there were COVID-19 related restrictions on in-person data collection at the time of the study which limited study data collection methods to telephone interviews vs in-person interviews. Lastly, telephone interviews were utilized to increase feasibility for participants and to reduce the potential for barriers to participation such as geographical location or access to an adequate internet connection to support virtual interviews.

Potential participants were invited to contact for details of the study via email or phone. During the first contact, eligibility was confirmed and participants were then asked to pick the date and time for the interview to occur as well as provide a signed copy of the

consent form. All participants were able to return an electronic version of their signed consent form via UBC-O email prior to the interview. At the beginning of the interview, the purpose of the study was reviewed with the participant and a confidential and supportive environment was established. Participants were then sent an electronic gift card for a small sum (\$20) to acknowledge their contribution to the study. The gift cards were provided at this time in order to acknowledge participants desire to be involved in the study, recognize the potential time commitment associated with study involvement, and ensure they knew the study was voluntary and they were not obligated to confirm their consent or fully complete the interview questions before receiving the gift card. Langer et al. (2021) point out the value of providing incentives in real-time rather than delaying payment and suggest this can be helpful when conducting research with vulnerable populations. Verbal consent to participate in the study was then confirmed and the demographic form was completed with each participant (see Appendix D). The semi-structured interview guide consisting of 17 questions with probes (see Appendix E) provided a general outline and was used to help initiate the interview and maintain a flow of conversation. Interviews varied from 45 minutes to 1 hour and 20 minutes in length and were audio-recorded to aid in transcription and analysis. Audio files were transcribed into Word documents to prepare for analysis and then deleted for confidentiality. Field notes were completed after each interview to note reflections on the interview process and content discussed.

3.5 Data Analysis

The data analysis process followed guidelines within the interpretive description (ID) methodology as described by Thorne (2016). During data analysis, to maintain methodological alignment as the analysis occurred, three important guiding principles from

the ID methodology were utilized. First, ID acknowledges that it is the researcher(s), not the analysis method, that determines what are data, what are relevant data, the composition of the final description, and how to distribute the findings (Thorne et al., 2004). In this project, I acknowledged and stated my epistemological and theoretical positioning in order to recognize how this affected the selection and interpretation of data. Second, ID encourages an iterative analytic analysis process that focuses on integrating, formulating, and recontextualizing the data to move beyond what is currently known towards a new understanding (Thorne et al., 2004). For this project, the same systematic analysis process was utilized for all the interviews which helped to organize the information for formulating new insights. Lastly, the project should maintain inductive logic processes throughout so that clinicians and researchers are able to follow the processes that led to the description in order to enhance applicability (Thorne, 2014). The individual data analysis steps will be described below. Data collection and analysis initially occurred concurrently during the project until data collection ceased, at which point, data analysis continued until I distinguished what I felt was the most significant and coherent arrangement of the data.

The process of data analysis began with my acknowledgment that my past experience would affect the way data were analyzed by influencing which data were seen as important and which data might have been overlooked (Thorne, 2016). To help mitigate this influencing factor, ID encourages researchers to keep accurate and precise records, be involved in the transcription process, and allow themselves time to be present and immersed within the data (Thorne, 2016). To achieve this, I kept an analytic journal to document the individual steps of data analysis, transcribed each interview, and did not place time limits on any portion of the data analysis process.

3.5.1 First Step

The first step of data analysis was to transcribe the interviews into word documents after the completion of each interview. Next, the transcriptions were checked against the recordings for accuracy. Finally, the documents were formatted to aid in the manual analysis of data such as allowing space on the page for coding and notes to be added.

3.5.2 Second Step

The second step of data analysis entailed broad-based iterative coding of each interview as ID encourages caution during the initial coding phases to help avoid sorting and labeling the data into categories early on which might affect how the data is further analyzed (Thorne, 2016). I achieved this by conducting two separate readings of each transcript. For the first reading, I acknowledged my past clinical experience working with children living with medical complexity and their families in both acute and community settings and how this could shape data analysis. This allowed me to view the data through the lens of a clinician with experience working within this population. During the first reading, I wrote the codes within the margins of the transcripts beside the data and did not limit what was written to only a few specific codes, but rather wrote words or phrases that I felt summarized the data. In addition, I identified any data that provoked a strong emotional response within myself, either personally or professionally, as well as identified initial impressions and assumptions from the data. Colour-coded notes were made on the back of the transcripts to record any triggers, assumptions, and impressions.

The second reading was aimed at reviewing the data from a different lens to capture what wasn't highlighted from the first reading. In order to do this, I envisioned myself as a mother who had just entered the world of being a parent to a child living with medical

complexity and was seeking the advice of other parents who had been living within this world for some time in order to prepare myself for the experiences to come. Again, broad codes were utilized and colour-coded notes were taken during the second readings. Any additional notes regarding assumptions, general thoughts, or patterns were made on the back of the transcript. I made efforts to physically, emotionally, and mentally separate the first and second readings from each other in order to allow for time to adjust to the different viewpoint needed for the second reading as well as not associate the selected codes from the first reading with the creation of codes during the second reading.

3.5.3 Third Step

Thorne (2016) suggests data analysis steps are iterative processes that occur while the researcher is immersed within the data, allowing it to be sorted and resorted into categories and themes until the researcher has identified the most meaningful presentation of the data. In order to accomplish this, after the initial coding from the first two readings, I transferred all codes from each transcript to an initial coding table in a Word document. The table had three columns for each transcript: codes from the first reading; codes from the second reading; and initial categories. Thorne (2016) encourages the use of neutral category headings to help reduce the feeling of rigidity once data is coded; therefore, once the codes were transferred, I went through the table to consolidate and condense as many codes as possible into broad categories to list in the category column of the table. Next, the condensed categories from the interviews were placed in another table to compare and contrast categories between interviews. I organized and reorganized this table until similar categories from each interview were placed in the same row. Cells were left blank if the category did not show up in a specific interview. This allowed me to compare and contrast the interviews

to see what data were consistent amongst interviews and which data were unique to certain interviews. After completing the table, I reviewed and contemplated the identified categories until distinguishing five broad themes I felt summarized the data: response; acknowledgement; connection; accessibility; and recommendations.

Using the five broad themes identified, I then used a colour-coding system to sort the codes and categories within the initial coding table and the compare and contrast table into the five themes. This enabled me to see what data could be situated under the five broad themes and what data I felt did not align with these themes. In addition, I created a mind map and sorted the initial codes into the five themes on the map as another way to evaluate the inclusiveness of the five broad themes. The mind map also provided a way for me to find connections between the different themes and codes which helped to better understand the relationships amongst the data. It was at this point that I realized the themes were better understood if they were separated by which research question they answered. For example, response, acknowledgement, accessibility, and connection were all data I felt provided an understanding of how parents experienced their child's medical interactions which was the essence of the first research question. Whereas recommendations should not be considered a theme but rather a section broken down by more specific themes which would answer the second research question of what recommendations parents had for clinicians to help support parents during medical interactions. Once these distinctions were made, I went back through each transcript using a colour-coded highlighting system and recoded the transcripts under the four themes as well as identified recommendations from parents and potential quotes to use within the final report.

3.5.4 Fourth Step

The next step that occurred in data analysis was a meeting between the graduate thesis supervisor and I to review and discuss the work I had completed up to that point to ensure proper methodological rigor was being upheld and further develop the analysis. During this meeting, it was recognized that the four broad themes answering the first research question should be expanded from single-words to phrases to ensure clarity and understanding and the recommendation data should be further sorted into themes. Consequently, I worked to adapt the four single word themes into phrases that captured the essence of the data. The following phrases were identified: parents' emotional responses to interactions; being acknowledged as an expert; providers building connections with children; and accessibility to health care services.

3.5.5 Fifth Step

The fifth and last step of the data analysis process for this study was the writing and editing of the results section of the final report. The writing and editing processes allowed me to further organize, sort, and understand the data as I endeavored to explain the results from the study in a way that would be easily understood by others reading the report. For example, sub-themes were identified within the being acknowledged as an expert theme and within the accessibility to health care services theme to help provide further clarification and understanding. In addition, the recommendations section was sorted into six main themes which helped organize the data into tangible ideas for clinicians to utilize in their practice.

3.6 Enhancing Credibility

In order to enhance the credibility of the findings from this study, I worked towards the criteria as discussed by Lincoln and Guba (1985) and Thorne (2016). According to the

criteria created by Lincoln and Guba in 1985, credibility is how close the interpretation and report of data are to the “truth” of the participant experience (Cope, 2014). To uphold credibility within the project, I ensured transparency of my previous clinical experience with the population to allow others to understand how this experience might impact the interpretation of the data. In addition, details have been provided in this report of the coding methods and rationale for the creation of themes in order to show readers how the final results were formed.

Further, Thorne (2016) describes a number of criteria interpretive description studies should meet to ensure the credibility of the study. The first criterion is known as epistemological integrity, which occurs when the research follows a logical path through the research question, epistemological stance, and the strategies used to collect and analyze the data (Thorne, 2016). Credibility will be enhanced if the researcher demonstrates that the process and subsequent knowledge flow logically from the underpinnings and stance of the research itself (Thorne, 2016). In this study, epistemological integrity was preserved by utilizing an interpretive description methodology to help align the collection, analysis, and interpretation of the data under an interpretivist paradigm that guided the study. For example, the research questions addressed parent experiences with their child’s medical interactions and sought their perspectives on how practitioners might improve their practice to better meet family needs. This aligns with the interpretive description study approach by increasing the knowledge of a phenomenon in order to provide direct influence to practice.

The second criterion is known as representative credibility. This occurs when the knowledge gained from the study is consistent with the way the data were collected (Thorne, 2016). In other words, the interpretation of the data is known and understood fully only when

we look at how it was collected. Without knowing the data collection and sampling information, the data interpretation could be taken out of context and applied in inappropriate ways. For example, knowledge gained from a study that focuses on one particular group of individuals experiencing a very specific event should not be applied to members of the general population that experience the same specific event. For this study, representative credibility was maintained by acknowledging that the understanding gained from parents of a child living with medical complexity (CMC) in regards to medical interaction experiences should not be applied to parents experiencing an in-patient hospital discharge from an acute care facility with their CMC or to other populations experiencing medical interactions or in-patient hospital discharges.

The third criterion discussed by Thorne (2016) is analytic logic. This concept refers to the researcher ensuring they plainly state their reasoning throughout the entirety of the study instead of simply stating that a logical process was followed. The researcher must include the steps of their reasoning in the explanation of the study so that others may follow the process as they learn about the study. For this study, the individual steps of the inductive analysis that occurred were stated and explained in this report.

The fourth criterion is known as interpretive authority which refers to the ability of the researcher to ensure that the knowledge they have gained from the study has not been influenced by their personal bias or experience (Thorne, 2016). For fellow researchers and others utilizing the information from the study, it ensures that the interpretation of the data is as authentic as possible. I ensured the interpretive authority within the study by participating in an iterative bias recognition throughout data collection and analysis. I used field notes and the transcripts to identify any personal or professional triggering pieces within the raw data.

Once identified, I allowed myself time and space to explore the triggering data in order to separate my emotional response to the data from the analysis process. By viewing the emotional response as separate from the data, I was able to remain aware of these biases or triggers and continually challenge my interpretations of the data to ensure it remained as accurate as possible. In addition, the graduate committee had access to the raw data and the analysis. Further, this study ensured interpretive authority by maintaining the transparency of the processes identified above in the dissemination of the findings.

3.7 Ethics

As per the Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans, research is considered an important contributor to human society (Canadian Institutes of Health Research, et al., 2018). As such, researchers should be afforded certain rights to encourage the advances that research can bring us (Canadian Institutes of Health Research, et al., 2018). For example, the right to academic freedom allows researchers to disseminate their findings, bring new insights forward, and question previously held notions (Canadian Institutes of Health Research, et al., 2018). However, the Tri-Council Policy Statement (Canadian Institutes of Health Research, et al., 2018) also recognizes that researchers have a responsibility to maintain certain standards and practices to ensure they are respecting human dignity when conducting research and have included three core principles within their policy statement to help guide research. These principles include respect for persons, concern for welfare, and justice (Canadian Institutes of Health Research, et al., 2018). In order to abide by these standards, the TCPS 2 Tutorial (2014) Course on Research Ethics was completed prior to initiating this research study. In addition, during the research process, several steps were taken to ensure the core principles were upheld as well

as steps to ensure privacy and confidentiality were maintained throughout this project. These steps will be discussed below in detail.

3.7.1 Respect for Persons

Respect for persons includes the acknowledgement that every person has worth and deserves to be treated with respect and consideration (Canadian Institutes of Health Research, et al., 2018). This core principle ensures researchers respect a person's autonomy and ability to make choices without interfering in the decision-making process while also guarding persons who do not necessarily have the ability to make autonomous decisions (Canadian Institutes of Health Research, et al., 2018). In order to maintain respect for persons throughout this project, potential participants were all given copies of the consent form which contained an explanation of the study, what their involvement would entail, the risks and benefits to participation, and the study contact information to utilize if they wished to proceed with the study. Once participants expressed interest in joining the study, it was ensured they had received, read, and understood the consent form and did not have any outstanding questions regarding the study. Participants were asked to return a signed copy of the consent form for the study records prior to the interview; all participants supplied an electronically signed consent form prior to their interview.

At the start of the interview, participants were informed they had the right to withdraw their consent at any point in the study without being required to explain. Participants were also informed of the potential future uses of the data including graduate thesis work, potential application to clinical practice, and/or publication. Verbal consent was then confirmed with all participants before initiating the interview questions.

3.7.2 Concern for Welfare

Concern for welfare looks at the potential influencing factors to an individual's quality of life and ensures research aims to guard and foster these factors (Canadian Institutes of Health Research, et al., 2018). This core principle encourages researchers to have safeguards in place in the research process to avoid harm to participants, which is considered any damaging effects on welfare (Canadian Institutes of Health Research, et al., 2018). Concern for welfare was upheld during this project by having the research study reviewed and approved by the University of British Columbia Okanagan Behavioural Research Ethics Board and the Interior Health Authority Research Ethics Board (H19-03228-A002) before commencing the project. This ensured the study was considered ethically sound and did not pose any undue risk or harm for participants. Furthermore, the research topic was acknowledged as a potentially sensitive and distressing subject matter for participants by informing participants at the start of the interview that they were not required to answer any of the questions posed throughout the interview. In addition, participants were informed they were not required to give a reason for declining to answer any question(s) and were specifically reminded of this before they were asked the two COVID-19 pandemic-related questions. Participants were also advised that regardless of whether they participated in the study or not, the health care services they accessed for their child would not be negatively affected. Participants were given a list of resources (see Appendix F) to access if they experienced negative psychological consequences of participating in this study. This list included the contact information for the Central Patient Care Quality Office for Interior Health Authority so participants were able to have their concerns with the research interactions investigated.

3.7.3 Justice

The core principle of justice is explained as the researcher's responsibility and commitment to treating all persons with fairness and equity (Canadian Institutes of Health Research, et al., 2018). It is important to note that the policy statement describes equity as not necessarily treating all persons the same, but rather ensuring the risks and benefits of research are not placed only with one part of a population while excluding another part of that population (Canadian Institutes of Health Research, et al., 2018). For this project, recruitment did not place limits on the definition of 'parent' to ensure equal access to participation in the study. As well, the inclusion and exclusion criteria were limited to only those needed to reach the specific population of parents of children living with medical complexity and remain realistic to the scope of this research project. In addition, I aimed to create and maintain a supportive and safe environment for participants during the interview process to help address any perceived power imbalances in the researcher-participant relationship.

3.7.4 Privacy and Confidentiality

The Tri-Council Policy Statement explains that every person is entitled to their privacy, without the threat of others impinging on this right (Canadian Institutes of Health Research, et al., 2018). Confidentiality is explained within the policy statement as the researcher's responsibility to protect a person's information (Canadian Institutes of Health Research, et al., 2018). To follow these principles by the Tri-Council Policy Statement (Canadian Institutes of Health Research, et al., 2018), data was kept in either private, lockable locations or on password-protected and encrypted devices. Telephone interviews were conducted within a confidential space on the part of the researcher and participants

were made aware of this before the interview started. Interviews were audio-recorded on a voice recorder that was kept in a lockable location and the recordings were deleted once the interviews were transcribed and confirmed. Any electronic files were stored on a secure, password-protected, and encrypted computer that was only accessible to the graduate researcher. Any paper copies of consent forms or other documents were kept in a lockable location. Data was not downloaded on any shared devices and file sharing between the researcher and committee members was through UBC secure file transfer. As per UBC policy, all data collected will be kept for up to five years following the publication of the work in private, lockable locations. Once the five-year period has ended, any electronic files will be deleted and paper copies will be shredded.

The only information collected specific to the CMCs was to ensure eligibility in the study. This information was included in the transcription of the interviews, however, as much confidential information as possible was removed from the transcriptions while trying not to impact the raw data collected for analysis. The transcripts were all stored either in a lockable location or on a secure, password protected, and encrypted computer that was only accessible to the researcher. In addition, participant identification was changed to a numeric identifier to maintain confidentiality. The master list of participant identification and the corresponding study identification number were kept in a lockable location.

3.8 Budget and Timeline

Data collection and processing costs were minimal and covered by existing equipment and university computing services. A total of \$100 was spent on gift cards for participants which were covered by the researcher's scholarship funds.

The timeline for this research project began with the research proposal which was approved by the researcher's graduate thesis committee in March of 2020. The initial ethics application through RISE was approved in February 2020 by the University of British Columbia Okanagan Behavioural Research Ethics Board and Interior Health Authority Research Ethics Board. Revisions to the study were required due to the COVID-19 pandemic and the subsequent amendments to the original ethics application were approved in January 2020. Annual ethics application renewal was approved in February of 2021 as well. Recruitment began in August of 2020 and finished in March 2021. The participants were all identified and interviewed between January and March of 2021, with data analysis occurring concurrently and being completed in April 2021. The final results were written up from April 2021 to September 2021. This included sending the report out for feedback as well as incorporating and completing edits from the study committee as they were received. The submission for the defense of this graduate thesis is scheduled for November of 2021 with completion by December 2021.

Chapter 4. Results

In this chapter, the demographic characteristics of participants and their children living with chronic, complex medical conditions will be discussed first, followed by information regarding the type and number of health care interactions that parents described. After, the main themes and sub-themes for each research question will be presented.

4.1 Demographic Information

This study included five participants, all mothers of a child diagnosed with a chronic complex medical condition living within the interior of British Columbia. Participant age ranged from 38-50 years of age and all had at least one other child. All participants were married and had completed some form of education after high school, with the majority (three participants) having completed a diploma from a trade or college institution. Within the previous twelve months, all participants considered at least one of their main activities to be working part and/or full time. The main activities of the other parents to the children for the same time frame were reported as either working full or part time, being a student, or being unemployed due to the COVID-19 pandemic. All participants were Caucasian. Total household income over the previous twelve-month period ranged from less than \$40,000 to over \$100,000, with one participant declining to answer. Table 1 below provides a summary of the demographic information of participants.

All participants in the study met eligibility criteria based on experiencing one or more medical interaction(s) related to their child's complex medical condition between March of 2020 and March 2021. Examples of these types of interactions included outpatient appointments for medical treatments or assessments, follow-up appointments, emergency room visits (not resulting in admission to that facility), and/or urgent care clinic visits. None

of the participant's children experienced an admission or an in-patient hospital discharge from an Interior Health acute care facility within that same timeframe. The interactions participants discussed in the interviews ranged from a single interaction to multiple or repeated interactions within the timeframe. In instances when participants had experienced a single interaction, the interview was focused on that one experience; whereas, when participants had experienced multiple interactions within the timeframe, they discussed the collective interactions. Participants who experienced multiple interactions were asked to estimate the number of interactions their child had experienced. At the time of their interviews, these participants estimated the number of interactions over a span of approximately one year to stay within the study's timeline. Participants reported the number of interactions their child experienced during this time ranged between 6-70. Participants described the types of interactions as including in-person visits, telephone appointments, and/or virtual appointments via various videoconferencing platforms. Most of the interactions were either in-person or virtual, versus telephone appointments, especially for the participants who had experienced multiple interactions. The majority of the interactions were with health care professionals who were considered to be a regular provider for the child, with a small number being with providers the parent or child had never worked with before. Health care professionals who parents and their children had interacted with included physicians, specialists, and registered nurses.

Table 1 Demographic Information for Participants

Demographic	Number	Percentage (%)
<i>Gender</i>		
Female	5	100
Male	0	0
<i>Age</i>		
35-40	2	40
41-45	1	20
46-50	2	40
<i>Number of other children</i>		
1	3	60
2	1	20
3	1	20
<i>Marital status</i>		
Single/never married	0	0
Common-Law	0	0
Married	5	100
<i>High level of education completed</i>		
Some (trade school, college, or university)	1	20
Diploma from trade or college	3	60
University degree (Bachelors/undergraduate degree)	1	20
<i>Participant's main activity over previous 12 months</i>		
Working full time	1	20
Working part time	3	60
Other: combination (working part time, full time, and student)	1	20
<i>Other parent's main activity over previous 12 months</i>		
Working full time	2	40
Working part time	1	20
Student	1	20
Unemployed	1	20
<i>Ethnicity</i>		
Caucasian	5	100
<i>Total household income over previous 12 months</i>		
Less than \$39,000	1	20
Between \$40,000 and \$79,000	2	40
Between \$80,000 and \$99,999	0	0
Over \$100,000	1	20
Choose not to respond	1	20

The participants' children living with a chronic, complex medical condition ranged in age from four to seventeen. There were three male and two female children. Specific diagnosis information will not be shared in the report to maintain the confidentiality of participants and their families. However, the primary diagnosis of each participant's child met eligibility criteria for the study including the following: the presence of one or more chronic, complex medical condition(s); at least one functional limitation; high care needs; and frequent access to health care services. All five children had at least one primary medical diagnosis that was chronic and complex in nature and involved one or more body system(s). Functional limitations included impacts to any or all of the following functions: performance of activities of daily living; attendance or participation in school; mobilization; vision; hearing; and/or nutritional requirements. All the children required some form of intervention on a daily basis to manage their conditions; some requiring more care than others. Examples of interventions included medications, enteral nutrition, oral nutrition support, monitoring, and/or various medical treatments. All the children were accessing some form of health care service on a weekly to monthly basis, depending on their condition and the presence of any complications from their condition at the time of the study. In three of the five households, the child living with medical complexity lived full time with both parents. In one household, the child lived full time with the parent participant without the other biological parent in the same household, and the last child lived half-time with each of his/her parents. Table 2 below provides a summary of the demographic information of participants' children.

Table 2 Demographic Information for Participants' Children

Demographic	Number	Percentage (%)
<i>Gender</i>		
Female	2	40
Male	3	60
<i>Age</i>		
1-5	1	20
6-10	0	0
11-15	2	40
16-18	2	40
<i>Where child lives</i>		
Full time with both parents	3	60
Full time with participant only	1	20
Half time with both parents	1	20

This study aimed to answer two research questions. The first was, ‘What are the experiences of parents of children with medical complexity during in-patient hospital discharge or medical interaction via any delivery method (i.e. in person, virtual, telephone, etc.) that was required for more than routine care purposes?’. The second question was, ‘How can clinicians effectively support parents and families of CMC during the in-patient hospital discharge or medical interaction process?’. The aim of these questions was to gain a better understanding of parent experiences during medical interactions or an in-patient hospital discharge and provide recommendations from parents about how clinicians can help provide supportive care for parents and families during these events. The results from this study have therefore been sorted into two sections to provide answers to the two research questions. The first section contains the following five main themes and the associated sub-themes: parents’ emotional responses to interactions; being acknowledged as an expert; providers building connections with children; accessibility to health care services; and COVID-19 pandemic-related challenges. The second section contains the following six main

themes: the importance of forming connections with the child; the importance of clear and effective communication; individualized approaches to care; creating and communicating a plan of care; including parents and children as part of the health care team; and the importance of clustering care.

4.2 Parents' Experiences

Under the first research question, five main themes were identified: parents' emotional responses to interactions; being acknowledged as an expert; providers building connections with children; accessibility to health care services; and COVID-19 pandemic-related challenges. Further, within the theme of being acknowledged as an expert, two sub-themes were identified: active acknowledgment and acting as an advocate. In addition, within the theme of accessibility to health care services, two sub-themes were identified: flexibility in care provision and access to specialized resources. The themes and sub-themes will be described below in detail.

4.2.1 Parents' Emotional Responses to Interactions

During the interviews, parents described the emotional responses they experienced during and after their child's medical interactions. All of the participants reported feeling a wide, complex range of emotions as a result of the medical interaction(s). One parent (P1) estimated her son experienced nearly 50 medical interactions during the study timeframe and discussed her emotional responses to these interactions. She stated that at points during or after these interactions she felt discouraged, frustrated, confused, angry, depressed, and stagnant. But, she also reported at times feeling positive, happy, relieved, satisfied, comforted, secure, and with a sense of promise. She stated, "it was just a good mix". Another parent (P5) described experiencing feelings of concern, frustration, panic, worry, fear, and

being overwhelmed as well as feeling safe and comfortable at times during her son's estimated six medical interactions. She also discussed that while she felt the interactions could have gone better overall, she was "not dissatisfied" with some of her son's regular providers they worked with during these interactions. Of note is the variation in the number of medical interactions reported by participant 1 (estimated at 50) and participant 9 (estimated six). One mother (P4) discussed the approximately 70 medical interactions her daughter had experienced during the study timeline as predominantly positive experiences. She stated she "always felt heard and respected" during the interactions and attributed that to having a consistent provider for her daughter for most of these recurring medical interactions.

In some cases, parents recalled medical interactions that were highly charged events that had long-lasting emotional impacts. One mother (P2) recalled her daughter's only medical interaction that occurred during the study timeline and stated that at varied points during and following the interaction she felt frustrated, supported, happy, anxious, guilty, annoyed, desperate, overwhelmed, and positive. She described how her feelings of frustration continued for a few days after the interaction had occurred and explained it was a result of what happened during the interaction. She stated she was disappointed in the care her daughter received from one of the providers during the interaction and as a result of this provider's treatment plan, she had to closely monitor her daughter for any negative side effects which caused her to feel frustrated. In addition, she expressed feeling regret after the interaction. She stated that she did "replay some of those events a lot sometimes and go, 'I should have done something different, or I should have advocated a different way'. Because I guess I didn't feel good about how it went down". Another parent (P3) spoke about some of

her son's recurring medical interactions, estimating they had experienced approximately twelve interactions at one facility where they had just started attending appointments. During the initial interactions at this new facility, she stated she felt "incredible frustration" which continued until a plan was created to ensure her son had a consistent provider and routine during his regular interactions.

The one emotional response that was reported multiple times in four of the interviews (P1, P2, P3, and P5) was frustration. One situation that evoked frustration for parents was when providers had not acknowledged them as an expert in their child's care. For example, as one parent (P2) stated, "it's super frustrating. And um, I think that some don't want to listen to parents". Frustration was also reported when parents felt it had been difficult to access health care services for their child or if they felt there had been a lack of flexibility in health care service delivery. One participant (P2) explained, "and it's frustrating because it felt like it was a time-sensitive thing and there was not, like we waited a long time". Additionally, parents reported they had felt frustration and anxiety when working with providers who did not have a connection with their children. For example, one parent (P3) stated she experienced frustration because she felt "a lack of trust when some of the other people who haven't...got that rhythm because then things are done wrong and it leads to more poking or more this or that", reflecting this mother's concern for extra or unnecessary interventions for her son. The COVID-19 pandemic and the associated public health restrictions added to parent's frustration as well. One parent (P1) stated:

Because of COVID there was no way to have in-person visits. Which in his case would, I think, be more beneficial, and I felt frustrated because it seemed like because they couldn't get to know him on that level, that things maybe moved a little slower.

In summary, all the participants reported experiencing a wide range of emotional responses during and after their child's medical interactions. In all but one of the interviews, participants recounted feeling both positive and negatively associated emotions during and after each interaction, with frustration being parents most frequently reported emotional response. These findings suggest that parents' emotional responses to interactions are a complex and dynamic aspect of their experience during and after medical interactions and can be influenced by many factors during the medical interaction. In addition, these results also indicate that one of the factors influencing parents' emotional responses during and after medical interactions was the continuity and consistency of providers working with their child.

4.2.2 Being Acknowledged as an Expert

Participants repeatedly voiced the importance of parents being acknowledged as an expert in their child's health and care needs. This reflected parents' intimate knowledge of their children and their needs, both medical and non-medical. For example, as one parent (P2) described, "when I go in, I know that I am the most trained person, I'm the most understanding of what's going on person that's available to me" (P2). Two sub-themes were identified within this theme to further describe parents' experiences: active acknowledgment and acting as an advocate.

Active Acknowledgement. Parents discussed the importance they placed on working with providers who actively acknowledged and recognized parents' extensive understanding of their children's' complex medical needs during health care interactions. Specifically, parents voiced the great value they placed on interactions with providers who accepted, validated, and/or utilized their input and expertise in assessing their children's status or care

needs. This helped parents feel their children were receiving the most appropriate care during that interaction. Four of the parents (P1, P2, P3, and P5) described this acknowledgement as “being heard” or “listened to” by the provider(s) during the interaction and reported their appreciation of providers’ engagement in this practice. For example, one parent (P4) spoke of interactions with their provider where she was “given the opportunity to express and discuss my [her] concerns” which then contributed to her feeling heard and respected. Parents voiced that “being heard” was very important because healthcare interactions typically only allowed providers to see a quick glimpse of the children which meant they were not always able to truly understand the complexity of the children, the gravity of the particular situation, or the intricacies of the care needs. As one parent (P2) stated:

I’ve seen my daughter being examined by a physician who thought she was super sick and needing ICU and then fifteen minutes later she’s awake and playing and they come in and a different provider’s like, ‘oh, her chest is clear, she looks fantastic’. And it’s just interesting how moments in time people will see your kid and they can look totally different and different impressions get made about what they are and how they are.

Parents described the importance of this active recognition by providers as being vital for their children to receive the most appropriate care. As one parent (P2) noted:

Because you need to go in there and feel heard and you don’t want, like you can go off this crazy path if the wrong thing, like if they misinterpret what you’re saying... You just want to make sure that the right things are being done.

This mother (P2) further explained that when providers did not engage in active recognition, it could negatively affect her child’s care. She stated:

Sometimes I get emerg physicians that don't listen to what you're actually saying about your child. And then they'll order tests that are unnecessary or then you have a nurse that doesn't quite understand the severity of how sick your kid is and isn't really paying attention to them.

In another instance, a parent (P1) explained how after discussing her son's care with a new provider who "took the time" so that she "felt listened to", they were able to create a plan together for her son's care that they both agreed "was a good plan of action".

Acting as an Advocate. Interactions, where parents felt the provider was not engaging in active recognition, were described by parents as undermining their feelings of credibility and that their opinions and ideas about their children's care didn't matter. One parent, (P3) for example, described this lack of active recognition as being "met with some resistance on the other end" and stated in one instance, "they think I'm over-exaggerating". In these interactions, when providers did not acknowledge the parent as an expert or convey that they viewed their ideas as credible, parents described how they were then required to step into the role of advocate for their child. In this regard, one parent (P2) stated, "it requires strong advocacy from parents so that people can do what needs to get done". Another parent (P3) explained:

I've become very firm in saying no. Like that's great you have your plan but no that's not how this is going to go. This is going to go this way because we've done that either way before and that doesn't work. So, it sounds really harsh but I'm telling them how to do their job so that we can be successful because we've done the other end and it doesn't work.

These parent descriptions reflected how they believed that this advocacy was necessary in order to protect their children but also spoke of the subsequent emotional toll it could take. As one parent (P2) reflected, “because I do feel like my daughter’s life could be a whole lot different if the advocacy was different. Because it’s exhausting. I know how much of my life I spend doing it. And...it’s crazy and mentally exhausting”. Another parent, (P5) spoke of the challenge of knowing advocacy was needed at times but being unable to speak up. She stated, “I kind of had that huh feeling, like I should actually say something, I should do more but I didn’t act on it”. She went on to explain that upon reflection of her experience, even when she was able to speak up during the interaction, she did not always feel heard. She stated, “looking back on it, maybe I wasn’t heard completely”.

In summary, parents reported they felt it was important that providers recognized, valued, and/or utilized their input to better understand and care for their children during healthcare interactions. Without active recognition during interactions, parents reported they felt the need to advocate for their children in order to ensure they received the most appropriate care and that engaging in these advocacy efforts was, at times, challenging.

4.2.3 Providers Building Connections with Children

The quality of connection between the provider and the child was a recurring aspect of parents’ healthcare interaction experiences. Participants discussed whether or not they and their children were able to form strong connections and positive relationships with providers that, in turn, they believed affected the care their children received during interactions. Parents spoke of providers who actually took “the time to get to know the kids” (P5) and how that connection helped to make the child and parent both feel more comfortable. For example, one parent (P5) stated she felt it was important that providers “connected with him

[her son] and spoke to him in the appointments” because then her son “feels like he’s got a voice in it as well”. Another parent (P4) stated that her “daughter always appeared calm before a medical intervention but had a volcano erupting inside of her. Many nurses and doctors were able to sense that. This is something that makes human interaction human”. While another mother (P3) explained that when providers interacted “on a much more personal connection versus a medical connection” those “personal connections helped to make that person easier” for her son, and therefore, her to deal with. When talking about being able to form those connections with providers in acute care settings, one parent (P2) reported, “you connect with them and they become your favourites and you hope they’re working the next time you come in”. She also felt that “there’s only certain health care individuals that do that though. My experience has been that that’s not the norm” (P2). She went on to state, “it’s not across the board, I think that there’s something integral in the training that we’re missing in the humanness of medicine” (P2).

When parents spoke about the importance of connection they often described how much time the provider spent with them and/or their children during the interaction. When providers took time to get to know the children during the interaction, parents reported feeling more connected to that provider and felt that the provider cared about their children. One parent (P1) explained that she responded positively to providers who got to know her son as a person and not just a patient they were caring for. She stated, “because it just means that they’re taking the time, that they care enough about what it is my son is going through that they’re taking the time” (P1). She went on to further explain the importance of time stating she felt “really good support” from one of her son’s regular providers because she knew “that she is taking that time”. She also stated it was important to her as her son’s parent

to have time with the provider to ask any questions she had to ensure “everything is understood by them as well as by me [her]”. Another mother (P2) explained that during her daughter’s interaction, the provider in charge did not give her the time she needed to adequately explain the situation and voice her daughter’s needs for that interaction. She stated, “he just walked away and then I didn’t see him again for a long time. And I never really got a chance to explain the urgency of the situation and that it needed to get done quite quickly”. She recounted this interaction was with a provider with whom they had no previous relationship or connection with which she felt had made it difficult for her to explain what kind of health care service her daughter needed to access at that time. She reported, “I didn’t get a chance to really express what needed to happen”. She explained that these factors contributed to making this interaction “all kinds of frustrating” for her. She stated, “I was super annoyed”.

When participants were asked what they thought contributed to a negative interaction experience, one mother (P1) stated, “them not taking any time” and “not asking any questions of my son and actually speaking to him and how he feels”. She expressed ambivalence about certain interactions, stating one of her son’s providers “really listened” when they spoke to him, but the short length of the interactions left her wondering, “in fifteen minutes, how do you determine what he’s going through”. Another parent (P2) acknowledged that it wasn’t always the fault of the provider when they weren’t able to take time or form connections with their patients. She stated:

There’s definitely gems in health care, it’s just too bad that the system makes it really challenging for people...for good health care workers to do their job well. There’s the

time constraints and stuff, like I get why there's the disconnect but getting to know parents and how they know their kids, it's kind of invaluable.

Participants viewed the continuity and consistency of providers as another influence on the connection that was formed between providers and their children. Parents explained how being able to work consistently with the same providers created more opportunities for providers to get to know their children both on a personal and medical level that fostered trust between parents and providers. For example, one parent (P3) explained that they were able to form a strong connection with one of her son's consistent providers which led them to create a routine for his regular interventions. Having this routine in place then helped reduce her son's anxiety when they worked with new providers. She described how having this routine contributed to his interventions going well and the mother attributed that to "the level of trust that's been established" with their regular providers. In another instance, one parent (P4) spoke about her daughter's ongoing interactions with the same provider who consistently created an environment where she felt she was being "given the opportunity to express and discuss" her concerns which led to her feeling "heard and respected". She explained further that this in turn helped foster a strong, trusting relationship between the provider and herself where she felt she could "trust the medical assessments" and now does not feel the need to attend all of her daughter's interactions with this same provider. When asked whether her expectations were met during these interactions, this mother (P4) stated, "my expectations were exceeded". Another mother, (P5) confirmed how continuity and consistency with providers helped her to feel more supported during interactions, stating how she had a better rapport with those providers versus the "ER doc who doesn't know my son's

story”. Another parent (P1) spoke about some of her son’s ongoing medical interactions with a consistent provider. She stated:

I’m comfortable with who is looking after him, that I don’t feel like I have to be there. His nurse is very easy to communicate with and I’m comfortable with that.

There’s nothing left to be misinterpreted or anything like that.

In summary, parents reported feeling more comfortable working with providers who tried to create and maintain a connection with their children. Parents explained how they felt the amount of time spent with the children influenced the provider’s ability to form those connections with the children. In addition, parents felt the continuity and consistency of providers also impacted the connection the provider was able to form with the children, helped to establish routines for interactions, and contribute to the quality of the experiences.

4.2.4 Accessibility of Health Care Services

Ease in accessing health care services for their children was another important consideration for parents. Two sub-themes were identified within this theme to further explain parents’ experiences: flexibility in care provision and allocation of resources.

Flexibility in Care Provision. Parents identified flexibility as an important aspect of accessing care for their children. They described it as consisting of either the provider’s ability to deliver developmentally supportive care to their children regardless of their relationship or the willingness of providers to alter how they delivered their care to better meet the children’s unique needs. For example, one parent (P5) explained that providers changed how they approached her son while providing his care to better meet his medical and developmental needs. She stated, “they got softer because he’s a kid. So that’s great. But they still talk to him at a mature level which is fantastic”. Parents reported they appreciated

providers who acknowledged their children's uniqueness and approached their care with flexibility and understanding to best meet the children's needs. For example, another mother (P2), explained how parents often seek to minimize and reduce medical trauma for their medically complex children. This mother explained further how her daughter, and other medically complex children, "have been exposed to medical trauma for years of their lives, and thus they require very different interactions".

The other way the participants spoke about provider flexibility was how willing and able they were to adjust the delivery and access to health care services for the children. For example, one mother (P3) explained that her son needed a specific approach to access a common health care service to decrease his anxiety during his other medical interactions but found providers generally unwilling to adapt the timing and process of this medical care for her son. She stated, "a lot of people roll their eyes and say that's not how it works".

However, she described an exception where she "found this one provider that said she can do that and can see the value and merit behind doing that. So, we phone and if that provider isn't working that day then we don't go that day". Another parent (P2) recounted that during their interaction she knew the only way her daughter would get the specific care she needed at that time was to ask for help from providers they had a strong connection with. She stated she found "her people to help her get what needed to be done because what needed to get done wasn't going to get done the way it was supposed to".

Parents stated they felt it was also very helpful to have providers who understood the challenges they faced when trying to juggle all the interactions that their children require regularly, and worked with the parent to offer flexibility in accessing these services. One mother (P1) spoke about how their regular provider informed them of schedule changes that

altered which provider they worked with at her son's regular interactions. She said they appreciated being able to adjust her son's appointments to maintain continuity with their provider because "otherwise then it's somebody who changes the whole routine" which she felt negatively impacted the interaction for both her son and herself. Another parent (P2) spoke about the number of follow-up appointments they were asked to attend from all the providers they interacted with and described how frustrating it could be to take time out of their complex schedule to attend these appointments where parents felt providers just wanted to check-in. She stated, "I think some providers don't realize the amount of time it takes from your schedule to have all these like follow-up, just social visits, it takes over my life and my child's life". She also went on to explain how she appreciated providers who coordinated care with other services or didn't require follow up appointments if they felt it wouldn't change the care or treatment her daughter received at that time. This mother (P2) spoke about one particular provider who coordinated appointments with other services and stated, "he's had me in tears before because he's just been willing to be adaptable to make things easiest on my daughter, less traumatic, less appointments, less doctors".

Access to Specialized Resources. When discussing the accessibility to health care services, two participants also referred to ideas that reflected the allocation of health care resources. They discussed resource allocation by comparing the two facilities where they accessed health care services for their child on a regular basis: their local, non-speciality site that dealt with both adult and pediatric populations; and the tertiary pediatric center which specializes entirely in pediatric care in the province of British Columbia. Two parents (P3 and P2) had similar experiences where their local non-specialized facility lacked either a particular resource (e.g. specialized medication) or providers with the necessary training for

their children to access the most appropriate care. For example, one parent (P3) explained that when they first started accessing health care services regularly at their local facility, it was discovered that the local facility lacked a specialized medication that her son required for his medical interactions. The provider they were working with recognized the importance of having access to this medication for her son's care and was able to advocate to ensure the facility was able to supply the medication going forward. This parent stated she did not blame their local, non-specialized facility for not always having the same resources as specialized facilities do. She stated, "they don't know what they don't know. So, it's not like they've done anything wrong...they just don't know".

During her daughter's medical interaction, one mother (P2) spoke about the issues they experienced working with providers who did not have the specialized training needed in order to provide the care her daughter required during this interaction. She explained she had the knowledge and resources needed to help guide a provider through the procedure but she felt the provider in charge during her daughter's medical interaction "wasn't willing to do what needed to be done". She explained further, that instead, the provider in charge arranged for another, less experienced provider to perform the intervention for her daughter. This mother reported she only agreed to this alternative treatment plan because she felt there was no other option for her child at the time. She stated:

The only reason I did it was because I felt that I wasn't going to get out of there any other way. That's the only reason I agreed to letting her do it is because I knew the simplicity of the act of what needed to be done and I knew I could walk pretty much anybody through it.

However, despite agreeing to the alternative plan, this mother voiced her sense that the provider they worked with during the interaction did not have the appropriate education level needed. She stated this provider “wasn’t the right person to have done the job and it should have been somebody with a higher level of knowledge and skill”. She explained how in their case, the care her daughter needed was time-sensitive but basic and something she could do at home with the right equipment, and she was frustrated with the provider’s lack of experience during the medical interaction. Speaking about this experience, this mother conveyed her desire to see providers utilizing parents as a resource in this type of situation; leaning on the parent’s skill and knowledge of their child to ensure children are provided care by the ones who know them best. She elaborated, saying she felt many parents would be willing to bridge these resource gaps in their child’s care, especially in rural settings, because the parents who have been providing specialized care for their child in their home for extended periods of time have acquired the necessary knowledge and skills. She stated, “the mother...is going to know more about that and what needs to get done than anybody else in that town” (P2).

In summary, parents reported feeling appreciation when working with providers who were flexible in their delivery of care. Flexibility was described by parents as providers acknowledging and understanding their children’s unique care needs and working with parents to make accessing healthcare services more manageable. Participants also stated they were aware of resource gaps between specialized pediatric facilities and non-specialized facilities but did not blame the non-specialized sites for these gaps.

4.2.5 COVID-19 Pandemic-Related Challenges

The COVID-19 pandemic was reported as an influencing factor for some parents' experiences during their children's medical interactions. These parents felt that the pandemic negatively affected their experience and the care their children received. In some instances, COVID-19 restrictions utilized by institutions and provider offices were seen as having impacted the accessibility of health care services. For example, one parent (P3) spoke of the extra logistical challenges these restrictions placed on her family, requiring them to further juggle the care needs of their complex medical child during interactions in addition to the rest of the members of their family. She stated, "well it makes the family life tough. There's still a parent that's still trying to work. There's another child that can't be left alone. There's nobody else in our bubble that can look after him".

In addition, many health care services were changed from in-person to virtual appointments. Some parents felt that their children did not receive the care they needed because they felt virtual appointments removed the provider's ability to accurately assess the children's status. One mother, (P1) reported it was especially hard accessing care with new providers through virtual or telephone appointments as the providers "don't get to see her son face to face" and often had never met in person. She went on to explain that it was discouraging and she couldn't help but wonder if providers could "truly see what we're dealing with if they can't physically see him". This mother (P1) also mentioned experiencing frustration as a consequence of the COVID-19 restrictions her son's providers were under and felt that there was a negative link between COVID restrictions and her son's care. She explained her son's providers were only able to offer them virtual or telephone appointments which significantly restricted their ability to physically assess and monitor her son's

condition on an ongoing basis. For example, she recounted, “if it hadn’t been COVID, and we could have started doing personal visits, there’s more that could be explained, seeing things like that, there would be less frustration”. She also believed that being limited to only virtual or telephone appointments affected how fast her son responded to certain treatments. She stated, “all I want is to get him the quality of care and progress in a manner that...maybe he would be progressing a little bit more quickly if there was in-person things”.

Another parent, (P5) experienced something similar. During multiple interactions to address an acute illness her son was experiencing, she felt that the diagnosis of her son’s acute illness was delayed because providers were either restricted to offering virtual or telephone appointments instead of in-person appointments or were “so focused on COVID” that they “had blinders on”. She said she felt the providers “were working well within the parameters that they could” but still felt that her son’s acute illness “could have been caught [earlier] if it was just an in-person appointment”. She went on to explain that “it’s not their fault but it did cause me to keep seeking further medical help”.

In summary, some of the parents reported the COVID-19 pandemic was an influential factor when accessing health care services for their children during the pandemic. These parents believed the pandemic negatively impacted their children’s care and experience by changing how health care services were delivered. Examples of these health care service delivery changes included providers offering mainly virtual or telephone appointments, limiting in-person appointments, or influencing how children were assessed and diagnosed with illnesses. In addition, some parents felt there were extra logistical challenges associated with accessing health care services during the pandemic.

4.3 Recommendations for Providers

To answer the second research question of this study, “How can clinicians effectively support parents and families of CMC during the hospital discharge or completed medical interaction process?”, participants were asked if they had any recommendations for what providers could do to help parents feel supported during these processes. The recommendations discussed can be sorted into six main themes: the importance of forming connections with the child; the importance of clear and effective communication; individualized approaches to care; creating and communicating a plan of care; including parents and children as part of the health care team; and the importance of clustering care. These themes will be discussed below.

4.3.1 The Importance of Forming Connections with the Child

One theme that emerged from the parents’ recommendations was parents wanting to work with providers who strived to understand their children’s unique medical and non-medical needs, and attempted to create and maintain a connection with their children. Parents suggested providers attempt to connect with the children in some way during each interaction. For example, one parent (P4) reported she felt it was essential that providers were “compassionate and respectful” by not dismissing children or their families for experiencing difficult emotions, including anxiety, during medical interactions. Instead, she felt providers should “acknowledge them as very real” (P4). Another parent (P5) suggested providers “take a moment to get to know the kids where they’re at” during interactions to help create a connection between provider and children.

4.3.2 The Importance of Clear and Effective Communication

The second theme parents spoke about was regarding communication methods of providers. One mother (P2) stated, “miscommunication is the most common word I get told. Anytime anything doesn’t go right it was a miscommunication, and it is, that’s one hundred percent what it comes down to”. Parents reported that they wanted to work with clinicians who were able to communicate in a clear and honest way with parents. For participants, this included communication between provider and parent, between different providers caring for the children, and between different health authorities (if the child was accessing health services in more than one health authority on a regular basis). One parent (P4) recommended providers should “know their audience” during conversations with parents and listen effectively. She stated providers should “stop talking for a second and offer room for the other person to speak”. Another participant (P1) suggested providers be “proactive, don’t wait for a parent to ask”. She explained further reporting:

The more that the provider in any aspect can give an insight or a reason as to why they might be doing something as simple as the way they are putting the IV in or why they do what they do, it allows the parent to, because it’s their child, it allows the parent to understand more and feel more comfortable.

She stated this type of communication style made her feel reassured and explained it also helped her son to understand more. She stated that in her experience, children “don’t ask questions but they will listen, even if you don’t think they are, they will listen to what you’re having to say about the reason why you are doing something”.

4.3.3 Individualized Approaches to Care

The third theme identified was parents wanting providers to try to understand and accept that their children might require interventions that are different from the standard intervention. For example, one parent (P2) explained that providers working with her daughter need to “be patient and give her time” when they are providing care because of her extensive history and the number of interventions she has already experienced. Another mother (P3) explained how she and her son responded more positively to providers who followed her son’s preferred routine during his interactions instead of providers who did not consult her or her son on how they would like to proceed with his interventions. She stated, “when things aren’t done a certain way, it creates more...physical trauma”. She explained that following the same routine helped to make her son more comfortable, which in turn made her more comfortable. She stated:

At least if we can follow the same routine we’re not going to make this to a point where he’s so upset and doesn’t want to continue. This is a lifelong thing he’s going to have to deal with so let’s make it as positive as we can so that he’s going to feel happy about continuing his treatment for the long haul.

4.3.4 Creating and Communicating a Plan of Care

The fourth theme related to parent recommendations was that parents wanted to know the plan for their children’s care going forward from interactions so they had an idea of what to expect in terms of treatments, progress, and upcoming interactions. One mother (P1) explained how she wished for providers to explain the processes of her son’s care so she could see the whole picture and therefore understand where he was in the progression of that plan. She stated, “otherwise then you’re left wondering, ‘is this where we’re supposed to be

at? Is that all it is?”. Another parent (P5) reported that during her son’s health care interaction, having clear instructions for her son’s treatment plan made her feel supported by the providers they were working with. In addition, one mother (P3) reported she felt it was important for providers to create and communicate a plan for care with parents even in situations where providers do not necessarily have answers for an issue the child is experiencing. She explained, “I don’t need them to have all the answers but I need them to have a plan to figure out the answers”.

4.3.5 Including Parents and Children as Part of the Health Care Team

The fifth theme parents discussed in the interviews was wanting themselves and their children to be treated as members of the health care team. Parents felt this could be achieved by providers actively listening to them, asking for their opinion, and including parents and their children in the decision-making process. For example, one parent (P3) stated that at the beginning of an interaction, she would like the opportunity to settle her son so that he feels comfortable in the space they are using, and then speak to his providers away from her son to discuss the plan for the health care interaction. This was especially important to her when accessing a new facility or with new providers and she wanted to use that opportunity to work with the provider to outline “what works and doesn’t work for my [her] child”. She reported she felt this would give her a chance to take part as a team member with the provider and show her son how she supported the plan for the interaction. Another parent (P1) explained that she appreciated it when her son was asked about his care. She stated, “he’s been through this a lot, don’t think just because he’s a child or whatever he doesn’t know what’s going on.

4.3.6 The Importance of Clustering Care

The sixth theme identified was a desire for providers to work with parents and other team members to reduce the number of interactions occurring. This theme was only present in one of the five interviews with parents (P2), however, it was described as being incredibly important to this mother and her family as it frequently impacted their day-to-day life. For example, she (P2) stated her “biggest recommendations I think would be to try and work well with other groups and team members. My favourite people are the ones that like the patient-centered care, where they’re trying to group appointments with certain things”. She felt it was very important that providers recognized her daughter requires care from multiple providers on a regular basis, which often meant numerous appointments, and worked with her to try and cluster appointments to see multiple providers during the same visit or reduce the number of appointments altogether. She explained further that the providers who worked towards this goal with her were greatly appreciated because they were “willing to be adaptable to make things easiest on my daughter, less traumatic, less appointments, less doctors”. She also suggested providers try to be “mindful of how complicated it is to do these appointments” for families and try to be “flexible with people’s timelines and schedules”.

In summary, parents had six main recommendations for providers they felt would help parents of children living with chronic, complex medical conditions feel supported during an in-patient hospital discharge or medical interaction. The recommendations for providers included: the importance of forming connections with the child; the importance of clear and effective communication; individualized approaches to care; creating and communicating a plan of care; including parents and children as part of the health care team; and the importance of clustering care.

Chapter 5. Discussion

The aim of this research study was to increase understanding of parents' experiences and perspectives during an in-patient hospital discharge or medical interaction with their children living with a chronic, complex medical condition as well as provide clinicians with recommendations from parents on how to provide supportive care during in-patient hospital discharges or medical interactions. The study identified five main themes reflecting the experiences of parents during medical interactions. These included the following: parents' emotional responses to interactions; being acknowledged as an expert; providers building connections with children; accessibility to health care services; and COVID-19 pandemic-related challenges. Within the being acknowledged as expert theme, two additional sub-themes were identified: active acknowledgement and acting as an advocate. In addition, within the accessibility to health care services theme, two sub-themes were identified: flexibility in care provision and access to specialized resources.

The study also provided recommendations directly from parents for how they believed clinicians can better support parents during these in-patient hospital discharges and medical interactions. These included six main themes: the importance of forming connections with the child; the importance of clear and effective communication; individualized approaches to care; creating and communicating a plan of care; including parents and children as part of the health care team; and the importance of clustering care.

5.1 Key Findings of Parents Experiences

5.1.1 The Complexity of Emotional Responses to Interactions

One key finding from this study was that participants reported experiencing a wide range of complex emotions during and after their children's health care interaction. Parents

reported both positive and negative emotions and often reported experiencing both categories of emotions during the interaction. In addition, the emotions that parents reported experiencing were found to be in response to multiple factors within the medical interaction such as the length of interaction, the perceived quality of the interaction with the provider, and the accessibility and delivery of health care services. It is difficult to gauge if these findings are unique to this study or population as there is a significant literature gap concerning this topic, specifically with parents of children with complex conditions. One study was found that explored the experiences of parents of children without medical complexity who had been admitted to a pediatric intensive care unit (PICU) (Latour et al., 2011). The authors found that parents reported experiencing a relatively similar level in the strength of their emotional response to their children being admitted to a PICU and used the term ‘emotional intensity’ to describe this response (p. 322). Although Latour et al. interviewed parents of children without medical complexity, they did not delve into the types of emotions felt by parents but found as in the current study that their theme of emotional intensity appeared to have an influential relationship with their other identified themes from their study. This consistency with current study findings suggests that parents’ emotional responses to health care interactions comprise complex, mutually influential, and dynamic aspects of their care experiences.

In addition, a number of studies identified within the literature search specific to discharge experiences of parents of CMC for this project found that parents also reported a wide range of emotions during the various phases of hospital discharge (Brenner et al., 2015; Desai et al., 2016; Lerret et al., 2015; Leyenaar et al., 2017). Parents in the study conducted by Lerret et al. (2015) reported feelings of worry regarding the uncertainty of their children’s

future which persisted over the six months the study was conducted. Brenner et al. (2015) found similar results, with parents reporting worry over the burden their children's illness would cause in the future as well as reporting feeling isolated after discharge. These feelings of isolation were also reported by parents in the study conducted by Desai et al. (2016). Leyenaar et al. (2017) found parents reported experiencing a mix of emotions prior to discharge including excitement about going home and fear of readmission once home. While these studies were specifically examining parental experiences with discharge processes, the presence of results that emphasize the specific emotional experiences of parents suggests that their emotional responses are an important component of a parent's overall experience during discharge or medical interactions with their CMC.

5.1.2 The Importance of Active Recognition and Advocacy

Another important finding from this study was the idea that parents felt it was important to be actively recognized as an expert in their children's care. For parents, this meant working with providers who not only verbally acknowledged them as experts in their children's care but also valued and considered their opinion about their children's status and health care needs. The findings from this study suggest parents placed particular importance on whether or not providers used actions to help them feel acknowledged, such as acceptance, validation, and/or utilization of parent's input when assessing or creating treatment plans for the children. Similarly, Rennick et al. (2019) interviewed parents of children living with medical complexity about their experiences with their children's pediatric intensive care unit (PICU) admission. The authors found that parents in their study developed intimate and extensive knowledge of their children's care and needs as a result of being the primary caregiver for their children at home. The study participants reported

feelings of appreciation when this knowledge was valued and utilized by providers in the PICU and reported they experienced negative emotions when this acknowledgement was absent (Rennick et al., 2019).

When parents expressed feelings of not being heard, this was reported by some to trigger the need to advocate for their children. Parents in this study reported believing that advocacy was necessary in order to receive the most appropriate care for their children as they believed they knew their children's care and needs best. Other studies involving parents of children with chronic diseases or disabilities have reported similar findings (Conley Wright & Taylor, 2014; Krueger et al., 2019; Page et al., 2020; Rafferty & Sullivan, 2017). These studies all found that parents frequently expressed how they needed to advocate for their children in a variety of settings, including when accessing health care services. For example, Conley Wright and Taylor (2014) stated 73% of the parents in their study reported having to advocate for their children in a medical clinic setting. Another similarity across these studies and this current project were the advocacy behaviours described by parents. Parents in this study described employing persistent and assertive behaviours while they were advocating for their children. Conley Wright and Taylor (2014), Krueger et al. (2019), and Rafferty and Sullivan (2017) also reported persistence and assertiveness as behaviours utilized in some form by parents when advocating for their children. Further, when discussing advocacy, parents within this study spoke about the emotional burden they experienced when they felt required to advocate for their children. This was often linked to how frequently they felt the need to advocate as well as how successful they felt their efforts were. Interestingly, studies regarding parental advocacy report a mixture of burdens and benefits for parents. Some studies have found that parental advocacy is often associated with

a negative impact on parents as a result of the increased responsibility and care burden (Currie & Szabo, 2018; Page et al., 2020; Rafferty & Sullivan, 2017); while others have found benefits for parents who participate in advocacy, for example, increasing knowledge base, increasing self-reflection behaviours, and forming connections with other parents and families of children with similar diagnoses (Conley Wright & Taylor, 2014; Krueger et al., 2019). Other researchers have also described linkages between parental involvement in advocacy for their children and broader concepts of parental empowerment and self-efficacy (Conley Wright & Taylor, 2014).

Although the parents within this study did not discuss whether they associated advocacy with any benefits for their own physical, mental or emotional well-being, it was clear that they experienced the burden associated with this additional responsibility. It appears the burden of advocacy is often present due to the time and effort associated with the role of child advocate; however, parents often looked past the burden and focused on the potential benefits for their children as motivation to maintain this role.

5.1.3 Interconnection Between Themes

Another key finding from this study was the interconnection between some of the main themes. For example, one of the most apparent influential relationships was between parents' emotional responses to interactions and three of the remaining themes: providers building connections with children, accessibility to health care services, and access to specialized resources. It appeared that parents' emotional responses to an interaction were closely linked to whether they were acknowledged as the expert in their children's care, how connected they felt the provider was to their children, and/or how easily health care services were accessed. Generally, if a parent had an overall positive experience within most or all of

these themes, they expressed positive emotional responses to the interaction including feeling acknowledged, respected, satisfied, and/or comfortable. The results also suggest that the inverse was true as well; parents who reported feeling like they were not being heard, that their provider did not connect with their children, and/or had issues with accessing health care services for their children tended to report negative emotional responses to the interactions. These findings reflect how parents' emotional responses to medical interactions may be influenced by a number of factors. Similarly, Davies et al. (2017) studied how providers were delivering best-practice care to children with medical complexity and their parents. These authors reported medical interactions between parents and providers as dynamic situations that required multifaceted approaches from providers to achieve best-practice medical interactions. Furthermore, best-practice among health care professionals was found to be linked to their awareness of the impact their approach and provision of care had on parents' experiences during medical interactions. The authors also discovered that parents who were able to work with professionals who achieved best-practices during the interactions reported positive experiences (Davies et al., 2017).

Another interesting interconnection was between providers building connections with children and the accessibility to health care services themes. The findings suggest that the continuity and strength of the provider's connection with the children influenced the flexibility in care provision sub-theme. Specifically, when parents reported consistent continuity of care by providers there was often an associated strong connection between the provider and the children which then led to more flexibility in the delivery of health care services by that same provider. The parents in this study referred to flexibility in health care service delivery as providers' delivering developmentally supportive or individualized care

for their children, which parents believed allowed providers to better meet their children's unique care needs. Baird et al. (2016) reported similar findings when they interviewed parents of children with medical complexity in the pediatric intensive care unit (PICU) regarding continuity of care. In the study by Baird et al. participants explained how important provider continuity was in delivering individualized care for their child, explaining that continuity of care was linked with how often the provider cared for the child and therefore how well they knew the child and their needs. Additionally, a study conducted in British Columbia by Miller et al. (2009) found that parents of children with medical complexity believed continuity of care lead to a deeper, more personalized awareness of the children's care needs and characteristics, especially when the continuity was created through consistent in-person interactions between the children and the provider. As highlighted by this current study, the relationship between continuity of care and flexibility in health care service delivery is important to understand for providers working with this population as children with medical complexity have a high frequency of accessing health care services and could, therefore, benefit greatly if continuity of care is established as a valuable care delivery model.

5.1.4 Impact of the COVID-19 Pandemic

One key finding from this project was the impact the COVID-19 pandemic had on parents' experiences with their children's medical interactions. The study findings suggest that the COVID-19 pandemic created difficulties for parents trying to access timely and effective health care services for their children living with medical complexity. For a high-risk population such as children living with medical complexity, these results are concerning due to the frequency with which these children must access health care services. If services

are more difficult to access for these children and their families, there is potential for negative health effects on CMC. A recent survey with 156 parents drew attention to the significant impact of the pandemic on health care service delivery for children living with medical complexity in British Columbia and mirrors some of the findings of the current study (Baumbusch et al., 2020). The authors reported 63.8% of survey respondents stated their children had specialized pediatric medical service appointments changed to virtual/online platforms during the pandemic versus 17% reporting their children's appointments remained as in-person visits (Baumbusch et al., 2020). Further, 63.8% of parents in this survey reported their children's specialized pediatric medical services were cancelled or postponed by the clinic from which they were receiving care. The survey also found that during the first wave of COVID-19, the majority of parents reported their children's physiotherapy, occupational therapy, and/or speech and language therapy services were either decreased or stopped altogether (Baumbusch et al., 2020). While the survey did not examine if parents felt there were any benefits to having their children's appointments changed from in-person to virtual/online platforms, it does establish that drastic modifications in health care service delivery occurred for some children living with medical complexity and their parents during the COVID-19 pandemic. It is important for providers to be aware of these alterations in health care service delivery in order to help mitigate any damaging effects from these changes for children living with medical complexity and their parents.

5.1.5 Summary

These key findings reflect experiences of parents of CMC and in addition to the consistency of these findings with other studies, also reflect important connections to key

aspects of PFCC. For example, the complexity of emotional responses voiced by parents are closely linked to the core concepts of PFCC that include dignity and respect whereby providers are expected to honor the perspectives of family members (Institute for Patient- and Family-Centered Care, 2021). Findings around the need for active recognition and advocacy are also closely tied to this PFCC core concept as well as other core concepts such as participation and collaboration in that families should be included in decision-making processes and their knowledge and expertise should be incorporated into care delivery (Institute for Patient- and Family-Centered Care, 2021). The current study also highlighted the interconnection between themes identified, discussing how parents' experiences are influenced and impacted by each aspect of the medical interaction and the influential relationship between components of medical interactions, including how providers approach parents, families, and CMC during these interactions. These findings, again, share similarities with a core concepts of PFCC, collaboration, as well as the aim of PFCC to work together “‘with’ patients and families, rather than just doing ‘to’ or ‘for’ them” (Institute for Patient- and Family-Centered Care, 2021). In addition, since understanding of the influence of the pandemic on parents and families of CMC is such a new area, information from this current study and from others such as Baumbusch et al. (2020) can help to inform PFCC approaches regarding family perspectives on how collaboration and participation efforts can help to address the changing context of health care services and potential challenges that exist as a result of accessing these health care services during the COVID-19 pandemic.

5.2 Parent Recommendations for Patient- and Family-Centred Care

From participants' recommendations, six main themes were identified for providers to help foster patient- and family-centered care: the importance of forming connections with

the child; the importance of clear and effective communication; individualized approaches to care; creating and communicating a plan of care; including parents and children as part of the health care team; and the importance of clustering care. As these recommendations were gathered with the goal of providing tangible ideas for clinicians on how to evaluate, compare, and/or adapt current discharge or medical interaction processes, providers can apply the recommendations directly to their practice.

For example, the first recommendation parents discussed was how important they felt it was that providers attempted to form and maintain connections with their children during each interaction. Specific suggestions from parents on how providers can build a connection with their children included getting down on their level, speaking with the children during the interaction, including the children in the decision-making process (when able), and getting to know the children as people outside of their medical needs. These suggestions share some similarities with those shared in an opinion article in which parents of children living with medical complexity advised providers on how they should interact with their children living with medical complexity (Carosella et al., 2018). Additionally, parents in a study conducted by McNeilly et al. (2017) expressed their beliefs about the importance of providers getting to know their children outside of their medical needs and explained this helped to increase their trust in the provider's ability to contribute to health care decisions for their children as they felt these providers had their children's and their family's best interests in mind.

Another recommendation from parents was to ensure clear and effective communication with parents and other providers. Participants suggested providers ensure parents have moments during conversations to ask questions or provide more information as

well as offer explanations to parents and children about the care they are delivering in order to help increase parent and child understanding. Davies et al. (2017) found similar results regarding the communication styles of providers and the experiences of parents with chronic children. The authors discovered that parent satisfaction with interactions increased when providers participated in active listening, clarified topics, and were cognisant of the use of medical terminology when interacting with parents (Davies et al., 2017). In addition, Zanello et al. (2015) examined parents' perspectives on continuity of care of CMC after discharge from hospital and also found similar results regarding effective communication between clinicians and parents. Parents in this study spoke about providers using more accessible language (i.e. reducing the amount of jargon, etc.) when discussing their children's care and how that influenced their ability to comprehend and understand their children's care and status.

Another recommendation from parents was to approach providing care in an individualized way with each child. That is, acknowledge that children living with complex medical conditions will likely require different approaches during medical interactions than children without medical complexity. Participants suggested providers honour the children's preferred routine for their interactions and work with parents to learn how best to approach their children during the interaction and before interventions. Baird et al. (2016) found similar results when they interviewed parents of children with medical complexity about their experiences with continuity of care for their children during pediatric intensive care admissions. Parents in the study expressed their belief about the importance of individualized approaches to care for their children and explained they believed having continuity of care helped achieve this individualization of care (Baird et al., 2016).

The fourth recommendation from parents was the importance of creating and communicating a plan of care for the children going forward from medical interactions. Parents explained the importance of knowing what to expect in terms of future interactions, treatments, and signs of progress in order to understand the bigger picture of their children's illness and care. Adams et al. (2013) found similar results when they examined parents' and health care professionals' opinions about the effectiveness of care plan usage for children living with medical complexity. The authors found that both parents and health care professionals acknowledged care plans as beneficial, specifically reporting they believed care plans helped to organize care needs, acknowledge parents as experts in their children's care, and therefore reduce the power imbalance in the relationship between parents and health care professionals, increase communication amongst team members, promote parental empowerment, and reinforce relationships (Adams et al., 2013).

Another recommendation from participants was that they wanted themselves and their children to be included as members of the health care team. Specific suggestions on how providers could achieve this included listening to parents and children, asking for their opinion, and engaging with them during the decision-making process. This was seen as critical for parents because inclusion in the decision-making process helped them feel their children were receiving the most appropriate, individualized care possible. McNeilly et al. (2017) also found that parents placed great importance on working with providers who included them in the decision-making process for their children's health care decisions. In their study, 91% of parents reported feeling it was "extremely important" that they were included in making health care related decisions for their children with disabilities (McNeilly et al., 2017, p. 840). In addition, Allshouse et al. (2017) discuss the importance of the

involvement of children and parents as recognized members of the health care team. As discussed in their article, it is of vital importance that parents and children are included as members of the health care team because their knowledge, skills, and understanding of the children's health care needs can help providers to better recognize how to deliver individualized care. Further, in a study conducted by Leyenaar et al. in 2017 examining the discharge goals and priorities of parents of CMC, parents reported wanting to feel included in all the aspects of their children's care, including during discharge processes, as well as wanting to feel acknowledged and valued by the other members of the health care team.

The last recommendation from parents was the idea of clustering care as much as possible to reduce the overall number of interactions the children have to attend. Specific suggestions included providers coordinating visits for children if possible or reducing the number of follow-up appointments. Literature is limited when specifically discussing the reduction of duplicative health care services for children living with medical complexity; however, in a clinical report from the United States (Kuo & Houtrow, 2016), the authors also stated that families of children living with medical complexity in that study wished to see a reduction in the number of repeated services and unnecessary travel and/or interactions.

In addition, many of these recommendations from parents are also mirrored in an opinion article written by Carosella et al (2018). The article is a compilation of ten recommendations for physicians from parents of children living with medical complexity. The article's recommendations that shared similarities to the findings from this study included encouraging physicians to view the children as people outside of their medical needs, acknowledge parents as experts in their children's care, attempt to connect with the children, and reduce the number of medical interactions (Carosella et al., 2018).

Thus, recommendations for providers identified by parents in this current study and also mirrored by Carosella et al. (2018) highlight the relevance and importance of patient- and family-centered care (PFCC) approaches and offer insights on how PFCC can be applied and practiced by providers working with parents and families of CMC. The similarities that exist between the current study recommendations and those from the article written by Carosella et al. (2018) mentioned above provide a beginning understanding that parents of CMC share similar thoughts and desired ways for providers to interact with their children despite potential differences in sample characteristics of parents, CMC, and providers. While this insight is an important contribution to the understanding of how PFCC theory can be applied and utilized for parents and their CMC, it should also be noted that the underlying principles and core concepts of a PFCC approach encourages the inclusion and collaboration of patients and families in the health care team and decision-making processes (Institute for Patient- and Family-Centered Care, 2021). This also means that parents of CMC might have different interpretations of PFCC and hold unique or varied ideas about what a PFCC approach would consist of for them. This is an important area for further research about how PFCC approaches can best be tailored to meet needs of individual families or CMC.

5.3 Implications

5.3.1 Practice

The findings from this research study suggest that parents' experiences of medical interactions are varied and complex; however, there appear to be areas within the practices of providers, and with particular relevance to nursing practice, that could be addressed to better support parents during these experiences. In addition, the study findings can be utilized to provide more examples, suggestions, and evidence to support the use of PFCC models in

clinicians' practices. For example, the study findings related to parents' emotional responses to interactions suggest that parents generally do not experience only one type of emotional response to interactions and also that their emotional responses tend to be intensive. This has implications for clinicians working with this population as changes to their delivery of care and provider interactions with parents will likely need to be multifactorial and potentially individualized in order to address the complexity of parents' emotional responses to medical interactions. Nurses are ideally placed to address this during interactions with parents of children with medical complexity as they often work closely and frequently with these families, developing long-term provider relationships. Utilizing an empathetic approach during interactions, nurses can acknowledge the varied and intensive responses parents may experience and create space for parents to be able to discuss these responses. Nurses can also provide parents with further direction to access other supports that could help them to process these interactions or advocate for change, such as, mental health resources, quality or patient safety reporting systems or organizations, and/or community support programs. As highlighted by the core PFCC concepts of dignity, respect, and participation, it is critical for providers to listen to, acknowledge, and utilize family perspectives as they are influential components of parents' experiences during and after medical interactions. Thus, there may also be a need to ensure that nurses and other providers caring for families with CMC have communication skills training as well as cultural competency training to enhance their abilities to listen effectively and communicate with parents. Such training could occur as part of continuing professional development or incorporated into nursing curricula.

When addressing the findings related to the importance of active recognition, providers, including nurses, should strive to create a collaborative and inclusive relationship

with parents in which providers utilize parents' unique knowledge to better understand and care for children living with medical complexity. For example, nurses are uniquely positioned to work with parents of children with medical complexity during medical interactions to create, modify and implement collaborative care plans utilizing the knowledge and skills of parents in order to direct the child's care. In addition, nurses can utilize their position in health care to act as an intermediary between parents and other providers. For example, nurses could advocate for the creation of care coordination roles within their local organizations or health authorities whose responsibility it is to be the initial contact for families to connect with if they have concerns or questions as well as coordinate care between the different providers and services CMC access, update care plans and disseminate to families and providers. These nurses could also offer education and support for other providers learning how to increase collaboration between themselves and parents and families of CMC. Nurses can also facilitate parents' advocacy efforts by informing them about parental advocacy or support groups in the community that they could potentially become involved with. In addition, understanding how parents experience their advocacy role can help identify potential areas for service changes, support improvements, and practice changes aimed at creating better support for parents. Nurses are ideally situated to help support parents in their advocacy role as patient advocate is often a role that nurses know well and with which they have experience.

Another example of a practice implication arises from the study finding of interconnection between themes which is a significant finding for providers to consider when working with this population as connection and continuity often require time on the part of the provider as well as institutional/organizational support to ensure continuity of care.

Providers will likely need to work with their organizations and institutions to create care models that allow for provider continuity and flexibility of health care service delivery in collaboration with parents. For providers, this could also mean a need for creative and innovative problem-solving in order to meet the needs of parents within a health care system that typically struggles with flexibility. For example, Child Health BC released a report in 2016 discussing the challenges that exist in care continuation and continuity for CMC in BC; one of which included continuity of care issues between tertiary pediatric facilities and regional or community providers (Child Health BC, 2016). The report also identified ways to address continuity issues including recognizing the need for one member of the children's team to act as the care coordinator and first point of contact for the children and family to ensure adequate management and continuity of care (Child Health BC, 2016). The Government of British Columbia and the Provincial Health Services Authority are currently in the planning stage of addressing the gaps in continuity and transition care for children with medical complexity in the province by creating a children's complex care transition facility in BC (BC Gov News, 2020). The facility will provide children with medical complexity and their families access to health care services aimed at creating capacity to transition from acute care to community or home care as well as creating a provincial network of support programs for providers throughout BC (BC Gov News, 2020). Furthermore, the findings related to the impact of the COVID-19 pandemic have practice implications for providers working with CMC. Providers must be aware of the added difficulties for parents of CMC because of the drastic change in health care service delivery and strive to help mitigate the risks associated with difficulty accessing timely and effective health care services.

In addition, study participants provided six main recommendations for clinicians to help parents to feel better supported and these recommendations have implications for the way providers practice and deliver health care services with this population. When reviewing the recommendations, it is apparent that one significant implication for the practice of providers is that of time. Many, if not all, of the recommendations would require provider time to act on these recommendations. For example, clustering care for children would require time to organize and collaborate with other services and providers. Offering flexibility in the access to and delivery of health care services would require providers to alter aspects of their practice to meet the unique individual needs of each child and their family which would require time, collaboration with families, and thoughtful reflection. Further, providers, including nurses, would need to find ways to meet this request from families while working within a health care system that might not support flexibility as a concept in health care delivery which could prove to be challenging for providers. One potential strategy from Child Health BC (2016) that could help coordination of care and maximization of provider and parent time would be establishing the roles and responsibilities of all team members to ensure each member is aware of their function in relation to the team and service delivery and therefore potentially reduce duplicate interactions. Another potential strategy could be the use of shared care planning between parents and providers which might help to coordinate care and reduce duplicate interactions by allowing all members of the CMC care team to share insights and information thereby increasing collaboration.

5.3.2 Policy

The findings from this research project indicate that while parents of children living with medical complexity experience their children's medical interactions in very complex

and nuanced ways, there are also often similarities in parents' experiences. For example, consistency of providers was reported as being very important to parents in this study because parents believed it helped them to feel trust and comfort in their relationship with their children's provider. This finding has policy implications for institutions that offer health care services to this population. Institutional internal policies that enable providers to continually work with the same families would need to consider staffing, workload, or other issues that impact continuity. On a broader scale, policies to create and maintain care teams for children living with chronic, complex conditions would foster provider consistency within and across health authorities. These teams would require provincial support to be able to communicate and share information effectively across health authorities and electronic medical record systems. For example, Child Health BC (2016) recommends the identification of a most responsible practitioner as well as a care coordinator for children accessing care in BC to support continuity of care and collaboration across health services and geographical locations. These care team members would ensure children living with medical complexity and their parents had access to providers whose role it is to know the children's needs and be a resource for parents (Child Health BC, 2016).

Based on the six main recommendations from parents from the study, additional policy implications should be considered in a variety of areas. For example, one of the recommendations from parents was related to the importance of forming connections with the children. Similar to helping foster continuity and consistency of providers, enabling providers to form connections with the children they care for would likely require strong, supportive institutional policies that allow providers adequate time with patients. Likewise, the recommendation of individualized approaches to care would greatly benefit from

institutional policies that would support providers having access to adequate time with children living with medical complexity as well as policies that support provider education in developmentally supportive approaches to care. When addressing the parent recommendation regarding the importance of clear and effective communication and the findings of the substantial impact that provider approach can have on parent experiences with care, broader policy implications should be considered in terms of educational policies within the academic institutions which train providers as well as the various regulatory bodies of providers. Policies that place an emphasis on ongoing education related to communication practices with the pediatric population, families, and those living with chronic, complex conditions within and across provider academic institutions and regulatory bodies of professionals would help providers to have access to educational resources and support they need to learn appropriate communication skills. In addition, development of policies to ensure that nursing orientation programs in both hospitals and community settings are available for nurses new to pediatric settings would help to promote the development of nursing competencies for working with families with CMC at a health authority level.

Other recommendations of creating and communicating a plan of care and including parents and children as part of the health care team could be supported by policies across provincial health authorities that support provider and family access and use of innovative technology which allows for more streamlined communication processes between families and providers. For example, a computer-based application accessible to families and providers which allows for sharing of health records, creating and maintaining shared care plans, and easier connection between families and care team members, such as the Caremap, would enhance the communication process (Boston Children's Hospital and Duke Health,

2016). Further, Child Health BC suggests examining the use of the Care Connect program in BC to achieve the goal of a sharable and accessible care plan for providers; however, the functionality and access for parents would have to be examined and reviewed to ensure effective collaboration and inclusion (Child Health BC, 2016).

5.3.3 Research

This research study offered an initial view into the experiences of parents of children living with chronic, complex medical conditions which will help to bridge current research gaps and provide insights specifically relevant to the Canadian health care context. However, there is still much more to be learned from this population. For example, a topic to further explore would be to compare and contrast hospital discharge experiences from medical interaction experiences, which this study was unable to do based on the experiences of the sample and due to the study recruitment impacts from the COVID-19 pandemic. Institutional/organizational processes for hospital discharges and medical interactions vary greatly between facilities and health authorities, and it would be beneficial to compare and contrast these experiences to understand how the type of health care service being accessed affects the overall experience of parents. Ideally, families would be able to provide data after experiencing both situations.

Another potential research topic would be to expand the geographical catchment of the study to include discharges and/or medical interactions across provincial health authorities and not focused within the Interior Health boundaries only. Research examining the differences in parents' experiences across health authorities would help to identify gaps based on geographical location, between health authorities funding and service differences, and provide a more diverse sampling of this population to allow examination of cultural,

generational, and economical influences. For example, it would be fruitful to examine the differences between families' experiences living in rural versus urban settings and how geographical and economic factors impact the allocation of specialized resources needed for this population. In addition, the perspective of fathers are one that is often missing from studies involving children living with medical complexities. A study focused on understanding a father's perspective or at a minimum including both fathers and mothers would help to provide some valuable insights on the differences in experiences across the different caregiver roles. Other perspectives to consider for future research would also include parents who identify as LGBTQ+. Further, including the perspectives of Indigenous or immigrant families would help to build understanding about how the health care system approaches the care of children with complex medical needs and their families with different cultural backgrounds and beliefs.

Another area of further research could utilize a longitudinal look at parents' experiences over time. For example, a study that follows parents and families over a longer time frame could map their real-time interactions and discharges to determine how their experiences change over time. It could also inform researchers about how outside variables can influence the experience of parents. For example, a major influential variable throughout this study was the COVID-19 pandemic. One question to ask could include, 'if and how the experiences of parents differ during a pandemic versus non- pandemic times?'

Furthermore, future research should explore the individual themes reported by this study in more depth to gain a deeper understanding of parents' experiences. For example, parents' emotional responses to health care interactions appear to be an under-researched topic and should be explored further in order to determine if an influential relationship truly

exists between this concept and other aspects of the experiences of parents with children living with medical complexity. Future research should also focus on the relationship between continuity of care and the flexibility of health care services delivery to explore any positive or negative effects for children with medical complexity, their parents, and/or the health care system. Additional research on this topic would not only help providers to understand how to deliver optimal care for this population, but also equip providers with evidence and support to advocate for changes within health care systems that would support establishing and improving continuity of care as a care delivery model. For example, nurses often have the advantage of working closely with this population and could use their unique position to work with parents and health care administrators to create mutually beneficial service delivery models based on research regarding continuity and flexibility. Another theme from this study that would benefit from further research efforts is that of being acknowledged as an expert, including exploring the two subthemes of active acknowledgement and acting as an advocate in greater depth. Future research on this topic is needed to fully appreciate and explore the nature of the acknowledgement and advocacy experience for parents of children with complex conditions. It would also help to further conceptualize parental advocacy efforts and experiences for this population when engaging in health care interactions. In addition, exploring specific advocacy behaviours utilized by parents as well as any related burdens or benefits experienced as a result of those advocacy behaviours are important theoretical concepts that could be further explored in future studies with parents of children with complex conditions within the context of their health care interactions.

In addition, it would be beneficial for future research to explore each of the six parent recommendations presented in this study in order to identify if these recommendations are shared by other parents of children living with medical complexity. This would provide further evidence for clinicians to be able to understand the needs of parents in order to better support them during hospital discharge and/or medical interactions. For example, as stated earlier, the importance of clustering care was discussed by one parent in the study. While clustering care was voiced as incredibly important to this mother, future research would be required to help determine if this is shared by other parents of children living with medical complexity. In addition, research examining the impact of care plans on quality of care and parent satisfaction, specifically when used with this population, would help to provide further evidence regarding this recommendation and its relevance for other parents of children living with medical complexity. Additional research to develop and evaluate the implementation of innovative models of care that could serve to improve continuity of services across varied providers and settings would be beneficial. Such interventions should be based on a PFCC approach and could be tested across varied settings to assess effectiveness in different contexts.

Future research should also focus specifically on the impact of the COVID-19 pandemic on health care service accessibility and delivery for this population. For example, research could focus on examining changes in health care service delivery, especially the impact of utilizing virtual/online platforms for accessing health care services, in order to provide clinicians with information on the risks and benefits of the continual use of these service delivery models. Additionally, research should include exploring changes in practice that were prompted by the COVID-19 pandemic which parents have found beneficial in

order to continue with these practices and potentially enhance the delivery of the same services.

5.4 Limitations

There were a number of limitations of this study; primarily as a result of the COVID-19 pandemic and its associated provincial health restrictions. They included recruitment, study population, sample size, interview method, and applicability considerations. The limitations will be discussed below in detail.

5.4.1 COVID-19 Pandemic

There were a number of methodological aspects of this study that were impacted by the COVID-19 pandemic. Due to changing provincial health orders occurring during this study, certain aspects of the study required adaptations to accommodate the changing landscape of health care service delivery for the target population.

Recruitment. The recruitment efforts were impacted in multiple ways. As there were numerous provincial restrictions in place, there were no opportunities for in-person visits at recruitment sites to meet with providers and explain the research study. Instead, all recruitment sites were contacted either via email or telephone which caused delays while waiting for responses from sites; some sites were contacted multiple times before responses were received. In addition, many of the providers who were contacted for help with recruitment had changed from in-person office visits to offering virtual or telephone appointments to their patients. This meant there were no opportunities to place study information in waiting rooms which made it more challenging to reach potential participants. In addition, for providers working in clinical settings, there may have been increased general workload demands due to the pandemic which could have reduced their ability to take on

extra tasks such as assisting with research activities. Further, parents of children living with chronic, complex medical conditions are frequently the primary medical caregivers for their children in addition to their regular parenting role and responsibilities and this often places a large, additional demand on parents' time (Woodgate et al., 2015). This added demand on parents' time could have contributed in part to some of the difficulties experienced with recruitment and participation for this study. As a result, the mitigation strategies used to address these recruitment challenges included offering the study information in both paper and electronic versions for recruitment sites to aid in accessibility and ease of sharing as well as offering study participants the flexibility to determine their interview date and time with no restrictions.

Study Population. Initially, the research proposal was focused on interviewing parents of children living with chronic, complex medical conditions regarding hospital discharge experiences only. During the extensive recruitment efforts and ongoing conversations with recruitment sites, it was noted that admissions rates for chronic, complex medical children were low. One potential explanation for the decrease in admission rates was that providers were working diligently with families to avoid admissions to acute care facilities for this high-risk population during the COVID-19 pandemic. In consultation with the study committee, changes were made to the inclusion and exclusion criteria to adapt to the low admission rate, a change approved by the University of British Columbia Okanagan and Interior Health Authority ethics boards. It was decided to include any medical interactions a child experienced during the timeline that were for more than routine care purposes (ex. wellness check-ups). While this helped to recruit study participants, none of the participants' children had experienced an admission to an Interior Health acute care facility

during the study timeline. Therefore, although this study aimed to include the discharge experiences of parents of CMC, this was not possible and findings are not transferable to the discharge experience from an acute care facility. In addition, all participants identified as female, and therefore only the perspectives of mothers were included in this study because no males expressed their interest in participating in the study during recruitment. It is important to note that this study was unable to include the perspectives of male participants and therefore, caution should be taken if utilizing these results for any parents identifying as male.

Sample Size. Another potential limitation of this project was the smaller sample size of five participants. As discussed above, the COVID-19 pandemic created multiple challenges to recruitment for this study. Recruitment began at the beginning of August 2020 with the original proposal including only parents of children who had experienced a discharge from an Interior Health acute care facility. From August to November of 2020, 18 health care professionals were contacted, located at 15 different sites within the Interior Health Authority boundaries with no participants recruited during this time. At this point, amendments were made to recruitment strategies, inclusion and exclusion criteria, and the timeline to include parents of children who had experienced a medical interaction. Additional recruitment efforts were made from December 2020 until April 2021, including contacts with previous recruitment sites as well as five additional support organizations. Despite the exhaustive recruitment efforts, only five potential participants utilized the study contact information to voice their interest in partaking in the study. All five parents met the eligibility criteria and went on to participate.

Sample size and recruitment were discussed extensively with the study committee as data collection and analysis began. As the data collection and analysis stages of this project were identified as an iterative process, preliminary results were provided to the study committee as each participant was interviewed. After careful consideration and review of the preliminary results, the study committee decided to end active recruitment at five participants as the preliminary results showed rich data and some recurring themes. This decision was supported by the interpretive description methodology and its lack of prescriptive sample size. Thorne (2016) encourages researchers to focus not on specific sample sizes but rather on the number of cases they feel is required for the results to have value. Although there is no specific sample size associated with interpretive description, common sizes are often between five and thirty cases or participants (Trotter, 2012). While the results from this study shed light on parents' experiences during their children's medical interaction and help to bridge the current research gap associated with this topic, it should also be noted that with a smaller sample size caution should be taken when applying the results or utilizing the recommendations from parents as they might not be applicable to all medical interaction experiences for parents.

Interview Method. Another potential limitation of this study was the requirement that interviews take place over the phone instead of the previously planned in-person interviews due to the COVID-19 provincial health restrictions and the subsequent UBC Okanagan research guidelines. While telephone interviews are convenient, less expensive, can offer a safe space for participants, and, in this case, allowed provincial health orders to be followed while still conducting the study, they also have some limitations in terms of data collection (Tod, 2015). There is limited ability to observe the participants' non-verbal

communication and respond to certain physical emotional cues which have the potential to limit the discovery of comprehensive information (Tod, 2015). In this case, the benefits of utilizing telephone interviews outweighed the risks but it is still important to note the results could have been impacted by this interview method.

Applicability. As discussed above, this research project was conducted during the COVID-19 pandemic. All of the medical interactions that were discussed during the interviews with parents occurred during the pandemic. While the majority of each interview focused on the details of the interaction(s), there were two COVID-19 specific questions in the interview guide that all parents answered: ‘was your child ever diagnosed with COVID-19’ and ‘how did the COVID-19 pandemic affect your experience’. None of the children included in this study had been diagnosed with COVID-19 prior to their interview. Out of the five interviews, four parents reported feeling that the COVID-19 pandemic affected their experience during or after their children’s medical interaction(s). This is important to note as these findings occurred during the COVID-19 pandemic and the results from the non-specific COVID-19 questions could be influenced by various aspects of the pandemic and might be less applicable during non-pandemic periods.

In addition, the characteristics of the study sample should be considered when discussing the applicability of the findings to other populations. For example, the participants were all Caucasian females between the ages of 38 and 50 years old from a small geographical location within British Columbia. While there is the possibility that the findings or concepts from this study could hold relevance for populations with differing sample characteristics from this study, caution should be taken when attempting to apply these findings to other populations. However, as Thorne (2016) points out, even if results cannot

be applied to other contexts, valuable insights from the study can still be of interest for those working in other contexts or settings.

5.5 Strengths

5.5.1 Study Purpose

One strength of this study was the fulfillment of the study's purpose and objectives. The purpose of this research study was to gain a better understanding of the discharge and/or medical interaction experiences of parents of children living with chronic, complex medical conditions in order to provide clinicians with practice insights and recommendations for working with this population. To address this aim, the study utilized interpretive description (ID) methodology and had three objectives identified to guide the project. First, to expand insight into the experiences and perspectives of parents of CMC during discharge or medical interactions. Utilizing interpretive description allowed this objective to be met by the assembling of data from participants who have a detailed understanding of the study topic in order to provide a description of their experiences for clinicians, illuminating unique incidences while also identifying and explaining commonalities across experiences (Thorne et al., 2004). The second objective was to help address a gap in research within this topic in the Canadian health care system. This objective was met as the study was conducted within the interior of British Columbia with participants who had accessed health care services for their children within the Interior Health Authority boundaries thus providing insights from one region in Canada. The third objective was to offer providers recommendations from parents on how to better support them during a discharge or medical interaction. To meet this objective, the study gathered recommendations from participants to help providers to improve support for parents during these medical interactions. The participants were all

parents of children who had been diagnosed with a medically complex condition at least two or more years ago and consequently had had numerous and varied medical interactions to draw upon when providing these recommendations.

5.5.2 Previous Experience

Another strength of this study was my previous clinical experience working with this population in both acute and community settings. This unique insight provided me with a familiarity regarding language and terminology as well as common discharge and medical interaction processes which allowed me to understand the experiences of participants better and provide an accurate and comprehensive report for other clinicians to examine and consider. During and after the study, I was aware of the potential influencing effects of my previous clinical experiences with this population. In order to help mitigate the risk of influencing the data, I ensured participants were aware of my previous clinical experience and understood there would be no negative effects to their children's care from participating in this study. In addition, it was confirmed that all participants knew the study was not intended to be a review or critique of individual providers rather a discussion of their previous experiences within the health care system as a whole, encouraging participants to share both positive and negative experiences. Participants were informed that any information identifying providers that was discussed in the interviews would be removed. Further, I strove to foster and maintain an open environment for participants to feel safe and comfortable to share their stories. Confidentiality was reviewed with all participants prior to the interview starting and I was very aware of the potential for identification of participants from the specific experiences parents shared through to the final report. To help mitigate this risk, I went to great lengths to ensure that potentially identifying information was generalized

to the best of my ability while also attempting to provide enough context to allow understanding for clinicians utilizing this report. In addition, participants were informed they were not required to answer any of the questions asked during the interview to ensure they knew they had full control over what information they shared in the interviews.

5.5.3 Reflexivity

Another strength of this project was that I engaged in the practice of reflexivity, noting my own personal and professional assumptions and impressions throughout the project in order to help limit my influence on the representation of the data. Reflexivity was practiced during each stage of the research process in different ways. For example, during the creation of the interview guide, I reflected on the development and phrasing of questions to ensure neutrality and allow participants to honestly share their experiences. During participant interviews, I made every effort to ask for participant clarification using open-ended questions to avoid influencing answers. In the data analysis phase, after the first two readings of each transcript, I engaged in a reflective practice that included making notes of how my previous professional experience working with this population or any prior assumptions could influence the interpretation of the data. I also engaged in reflection during and after each stage of the coding process, allowing for adaptations and edits until the final themes and sub-themes were developed in order to ensure the authenticity of the findings. Finally, I also practiced reflection throughout the process of writing the final report which encouraged me to once again review the research process and results to try to remain authentic to parents' experiences.

5.5.4 Interpretive Description

A further strength of this project was the use of interpretive description (ID) methodology which allowed an exploration of the experiences of parents of children with medical complexity; a population with the most intimate knowledge and understanding of this concept under study. Further, ID methodology allowed recommendations for providers to be gathered straight from parents of children with medical complexity. This enabled me to present and organize these provider recommendations from the population with the most experience and understanding of medical interactions which could then be used by providers to make changes to their practice to better support parents. ID allowed me to act as a bridge between parents of children with medical complexity and the providers who work with this population with the intent to provide knowledge and understanding to help positively impact the care children with medical complexity receive.

5.5.5 Trustworthiness

Another strength of this research study was the adherence to the concept of trustworthiness; which is often used to determine the quality of qualitative research studies (Peterson, 2019). In following with characteristics of trustworthiness as outlined by Peterson (2019), I acknowledged potential researcher bias, conducted a final literature review, provided a detailed description of participants and sampling, included the interview guide within this report, provided a comprehensive account of the data collection and analysis strategies, explained the steps taken to ensure privacy and confidentiality of study participants, and included numerous participant quotations from the transcripts. By acknowledging prior professional experience working with this population, I highlighted any potential researcher bias as a result of this previous experience. Including a final literature

review prior to completing the report ensured any new research published during the completion of this project was considered and examined. Further, describing participant demographics, sampling strategies, and challenges with sample size, including the justification of the final sample size, allowed a rationale to be provided for the procedures used during the study. Including the interview guide within the report supplied readers with the ability to determine the quality of the inquiry used within the study. Presenting the strategies used to collect and analyze the data in an open way aided in providing justification and rationale for the decisions made throughout the project, therefore allowing readers to see the inductive processes used to determine the findings. Additionally, the steps taken to ensure that the confidentiality and privacy of study participants were upheld throughout the project were explained in detail. Finally, participant quotations were frequently supplied within the results section to demonstrate depth, meaning, and confirmation of the findings from the study. All of these strategies were utilized during the study to help establish and maintain transparency throughout the project, allowing potential readers of the report to determine the trustworthiness of the study and its findings.

6. Conclusion

This study explored the experiences of parents of children living with chronic, complex medical conditions during and after medical interactions in order to provide clinicians with practice insights and recommendations for working with this population. The study provides clinicians with a better understanding of factors that can influence the experiences of parents during medical interactions including communication and interpersonal skills of providers, accessibility to health care services, and COVID-19 related-pandemic challenges. In addition, the study offers recommendations from parents on how clinicians can better support parents during and after a medical interaction. Taken together, the findings from the study can be utilized by clinicians to make changes to their practices to better support parents, help advocate for alterations in policies that affect health care services for this population, guide future research endeavours to help further understanding and support for parents, and ultimately provide better, more supportive care to parents and their children living with a complex medical condition.

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Appendices

Appendix A

Information Poster

Health Care Interaction Experiences of Parents of Children with Medical Complexity During COVID-19

STUDY PURPOSE

To learn about the experiences of parents of medically complex children when they interact with the health care system. This will help us understand interaction processes from the perspective of parents and learn how to better support parents during these experiences.



ELIGIBILITY

Mothers, fathers, or legal guardians of children 19 years or younger who have chronic complex medical needs and have experienced a hospital discharge or non-routine completed medical interaction from the Interior Health Authority or a private company since March 2020. Parents of children with a primary diagnosis of a psychiatric condition are not eligible to participate in the study. Participants must also be comfortable speaking English. If you are interested and contact the researcher, you will be asked a few questions to help determine if your family meets the specific study criteria.

DETAILS

Participants will take part in a telephone interview approximately 45 minutes to 1 hour long. The date and time of the interview will be arranged between the researcher and each participant.

BENEFITS

- ❖ Increasing understanding of the perspectives of parents of complex children about their interactions with the health care system
- ❖ Opportunity to share your opinion and suggestions on what health care providers can do to support parents during these experiences

FOR MORE INFO

Please contact Kathryn Smith (Researcher) at UBC Okanagan, School of Nursing by email at ksmith10@mail.ubc.ca or Dr. Lise Olsen by phone at 250-807-9180

Parent Discharge Experiences Email: ksmith10@mail.ubc.ca Phone: 250-807-9180	Parent Discharge Experiences Email: ksmith10@mail.ubc.ca Phone: 250-807-9180	Parent Discharge Experiences Email: ksmith10@mail.ubc.ca Phone: 250-807-9180	Parent Discharge Experiences Email: ksmith10@mail.ubc.ca Phone: 250-807-9180	Parent Discharge Experiences Email: ksmith10@mail.ubc.ca Phone: 250-807-9180	Parent Discharge Experiences Email: ksmith10@mail.ubc.ca Phone: 250-807-9180	Parent Discharge Experiences Email: ksmith10@mail.ubc.ca Phone: 250-807-9180
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Appendix B

Parent Information and Consent Form – Interview

Study Title: Health Care Interaction Experiences of Parents of Children with Medical Complexity During COVID-19

Principle Investigator: Dr. Lise Olsen, Associate Professor, FHSD, School of Nursing
University of British Columbia, Okanagan
Email: lise.olsen@ubc.ca (Phone: 250-807-9180)

Co-Investigator: Kathryn Smith, RN, BScN, MSN Student, School of Nursing
University of British Columbia Okanagan
Email: ksmith10@mail.ubc.ca

AN INVITATION TO PARTICIPATE

You are being invited to take part in a telephone interview that will help us learn more about your experiences during and after a hospital discharge or interaction with a health care professional with your child who has a complex medical condition. Health care interactions can include doctors' appointments, hospital visits, specialty clinics or therapy appointments and can occur in person, over the phone or virtually. You will be asked questions related to your experience during and after this interaction. Approximately 10-15 parents will be invited to participate in this study.

WHO IS BEING INVITED TO PARTICIPATE

Parents of a child living with a complex medical condition under the age of 19 years who have experienced a hospital discharge or non-routine completed medical interaction from the Interior Health Authority or non-health authority entity since March 2020. Parents of children who have received health services from other health authorities (Provincial Health Authority, etc.) are not eligible to participate in the study. Further, the child must have the following: one or more chronic, complex medical conditions; high care needs; functional limitations; and frequent use of health care services. Parents of children with a primary diagnosis of a psychiatric condition are not eligible to participate in the study. Participants must live within the Interior Health Region and have a basic working knowledge of spoken English in order to participate in the interviews.

VOLUNTARY PARTICIPATION

Your participation in this study is voluntary and you are free to withdraw at any time. If you wish to withdraw from the study after the interview, please contact the researcher Kathryn Smith, and your information will be removed from the study and deleted. There will be no negative consequences to participating in the interview and the care your child receives will not be affected by this study.

WHAT THE STUDY INVOLVES

If you choose to participate in this study, it will include being interviewed over the phone by the researcher for approximately 45 minutes to one hour. During the interview, the researcher will ask you questions regarding your experiences with your medically complex child during and after the hospital discharge or medical interaction. You may also be asked if the COVID-19 pandemic affected your experience. You may choose what information you would like to share for the study. You can decline to answer any question you are asked, including the questions related to COVID-19. The meetings will be audio recorded so the researcher can focus on talking with you. Some notes may also be taken by the researcher throughout the meeting.

WHAT ARE THE POSSIBLE RISKS OF PARTICIPATION?

We do not think being in this study will be bad for you. Some of the questions are personal and could upset you. You will be provided with a list of resources you can access if you experience distress from participating in the study. You have the right to refuse to answer any questions that you want too without needing to give a reason. Please let the investigators know if you have any questions.

WHAT ARE THE BENEFITS OF PARTICIPATION?

Your participation in this study will help to increase our understanding of the unique perspective of parents with medically complex children when they interact with the health care system. This information could be used by health authorities to evaluate current discharge and medical interaction processes in place to make changes. Participants will receive a \$20 gift card as a small token of appreciation for their participation before the interview.

HOW WILL THIS INFORMATION BE USED?

The results from this study will be used in a masters student thesis and could also be published in academic journals or health care publications, or presented at an academic or health care conference. If you are interested in being sent a copy of the lay summary, condensed summary or the full thesis, please contact the researcher.

WILL THE INFORMATION I PROVIDE BE KEPT CONFIDENTIAL?

The identity of you and your child will be kept confidential. No personal identifiers for you or your child will be included in reports or articles. Research documents will be identified only by a code number. Only the research team will have access to the written information, recordings, and computer files which will be stored securely. The data will be stored for five years following publication of the results as per UBC policy. After this period, all data will be destroyed or deleted.

WHO DO I CONTACT IF I HAVE QUESTIONS ABOUT THE STUDY DURING MY PARTICIPATION?

If you have any questions about the study or would like more information during or after the study, please contact Kathryn Smith at ksmith10@mail.ubc.ca or Dr. Lise Olsen at 250-807-9180.

WHO DO I CONTACT IF I HAVE ANY QUESTIONS OR CONCERNS ABOUT MY RIGHTS AS A PARTICIPANT DURING THE STUDY?

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, please contact the Research Participant Complaint Line in the University of British Columbia Office of Research Services by email at RSIL@ors.ubc.ca or by phone at 250-807-8832 (Toll Free Number 1-877-822-8598). You may also contact the Chair of the Interior Health Research Ethics Board by phone at 250-870-4602 or by email to researchethics@interiorhealth.ca. Please reference the study number H19-03228 when calling so the complaint line staff can better assist you.

CONSENT TO PARTICIPATE

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study at any time without giving a reason and without any negative impact on your access to services for your child. Your signature below indicates that:

- You have read and understood the participant information and consent form
- You have had enough time to think about the information provided and to ask questions if necessary.
- You have read this form and freely consent to participate in this study.
- You have been told that you will receive a dated and signed copy of this consent form.

I give my consent for this interview to be audio-recorded.

Yes

No

Printed Name of Participant

Signature

Date

Printed Name of Researcher
obtaining consent

Signature

Date

Appendix C

Health Care Interaction Experiences of Parents of Children with Medical Complexity During COVID-19 - Eligibility Screening Questions

- Use the following script to help determine eligibility of potential participants:
 - “Thank you for contacting me for this study. We are looking to conduct this study with families who are experiencing certain conditions, so I have some questions to ask you to see if your family will be able to participate.”
- Ask the following questions. Further questions to clarify answers given or to find out more information may be required to properly determine eligibility.

1. Is the child under 19 years of age? *(If no, then not eligible)*

2. Are you the parent or legal guardian for a child that has the following:

a. One or more chronic medical conditions that the child is expected to have for their entire life? This condition can be diagnosed or unknown.

b. Requires medical care, educational support, or specialized therapies above what is expected for other children without complex conditions (i.e. daily medications, help with personal care and dressing, help with eating, support while at school in order to participate fully).

c. Frequently accesses health care services (i.e. at least two or more medical interactions)? Examples of health care services include: specialized therapies (physiotherapy, occupational therapy, dietician services, speech and language therapy, etc.); specialized health care providers or services (pediatricians or other specialized physicians, complex feeding team services, respiratory therapy clinics, specialized medical clinics, etc.); hospitalizations; and/or surgeries.

d. Limitations because of their chronic condition(s) that limit their ability to perform everyday tasks independently? Examples of functional limitations include: feeding tubes, wheelchairs, or medical technology equipment like a ventilator.

(If any of a, b, c, or d is a no, then not eligible). If primary diagnosis for ‘a’ is a psychiatric condition only, then not eligible.

3. Is the child’s primary diagnosis considered a psychiatric condition? *(If yes, then not eligible).*

4. Where do you and the child live? *(If not in Interior health, then not eligible).*

5. Has the child experienced a hospital discharge or non-routine medical interaction from Interior Health Authority or a non-health authority entity since March 2020? Examples of medical interactions can include but are not limited to: hospital visits (inpatient or outpatient); speciality clinics; doctor’s offices; or diagnostic services. These interactions could have occurred in person, over the phone or virtually. *(If no, then not eligible. If health services were received from another health authority (i.e. PHSA) then not eligible).*

6. Do you feel comfortable answering questions and talking to the researcher in English? *(if no, then not eligible).*

7. How did you hear about this study?

- If the criteria are met based on the answers of the potential participant, proceed to the script below:
 - *“Thank you for answering these questions. It appears you are eligible to participate. The next process would be for me to send you the consent form for you to look over. Once you have reviewed the consent form, I would ask you to contact me so we can discuss any questions or concerns you may have before you decide if you wish to participate in the study. At that time, we can schedule the time and place for the interview. Do you have any questions or concerns at this time? Would you like to proceed and have me send you the consent form?”*

- If any of the criteria for questions 1-5 are not met based on the answers of the potential participant, proceed to the script below:
 - *“Thank you for answering these questions. At this time, we are limited to speaking with families that meet specific criteria and unfortunately, it appears your family does not meet all of our criteria so we are unable to arrange for the interview at this time. I really appreciate you contacting us for this study and for your time today to answer these questions.”*

Appendix D

Discharge Experiences of Parents of Children with Medical Complexity Demographic Information Form – Parents

1. Are you the child's legal guardian? Please circle one: Mother Father Other Caregiver
If other, please indicate relationship _____
2. What is your age? _____
3. What is your child's age and gender? _____
4. Do you have any other children? Please circle one. Yes No
If yes, please list their ages: _____
5. What is your marital status? Please circle the most appropriate answer:

Single/never married	Separated	Separated Common-Law
Married	Divorced	Widowed Common-Law
Common-Law	Widowed	Prefer not to answer
6. Does your child live full time with both parents? ____
If no, which household do they live the most with?
7. What is your highest level of education you have completed? Please circle one:

Some high school	Graduated high school
Some – trade school, college or university	Diploma from trade or college
University degree (Bachelor's or undergraduate degree)	
University degree (Master's and/or Doctoral degree)	
8. Over the last 12 months, which of the following would you consider your main activity? Please circle one.

Working full time	Working part time
Looking for work	Student
Retired	Stay-at-home parent
Other: _____	
9. Over the last 12 months, which of the following was your child's other parent's main activity?
Please circle one.

Working full time

Working part time

Looking for work

Student

Retired

Stay-at-home parent

Other: _____

10. How would you describe your ethnicity?

11. What is your best estimate of your total household income over the last 12 months (before taxes or deductions)? Please circle one.

Less than \$19,999

Between \$20,000 and \$39,999

Between \$40,000 and \$59,999

Between \$60,000 and \$79,999

Between \$80,000 and \$99,999

Over \$100,000

Choose not to respond

Other: _____

12. What is the name of the community you live in? _____

Appendix E

Interview Guide

Review:

- Purpose of study
- Consent to participate
 - Confidentiality
 - Ability to withdraw consent at any time
 - Ability to decline to answer any of the questions
- Questions or concerns
- Establish a safe place for participants and acknowledge the sensitivity and personal nature of the topic

Ask questions one to three for every participant first to get background information. While the remaining questions are numbered, they do not need to be asked in order. Not all questions have to be asked. The idea is to focus on obtaining comprehensive data, not focusing on ticking all the questions off.

Review the following with all participants prior to initiating the interview:

We are going to begin the interview now. I will be asking you questions related to your discharge/completed medical interaction experiences with your child since March 2020. We may also speak about how the COVID-19 pandemic has affected your experience. Please remember that you do not have to answer any of these questions. Just let me know if you would like to skip a question and we will move on.

Draft Interview Questions:

1. Tell me about your child please:
 - a. diagnosis
 - b. type of health care needs
 - c. functional limitations
 - d. how frequently health care services are accessed
2. How many discharges/completed medical interactions have you and your child experience since March 2020?
3. What types of interactions were they?
 - i.e. hospital discharge, ER visit, doctor's appointments, specialty clinics or therapies, etc.
4. How did you access these interactions?
 - i.e. in person, over the phone or virtually, etc.
5. If your child experiences a hospital discharge, can you describe any assistance you received from health care professionals to coordinate the discharge from hospital?
 - a. Was it clear to you if there was a professional whose role it was to help you with the discharge process?

6. How would you describe your overall experiences of the discharge/completed medical interaction process(es)?
7. What kinds of emotions did you experience during the discharge/completed medical interaction and how long did they last?
8. What were your expectations of the last discharge/medical interaction process? Were you given an opportunity to express and discuss your expectations with the health care professional or team?
 - a. Would you say that your expectations in general were met? If not, how could they have been better met?
9. Looking back, how ready did you feel to manage your child's care on your own after the discharge/completed medical interaction? What factors influenced this feeling for you? Was this a topic that was discussed openly between your family and the members of the health care team?
10. How did the discharge/medical interaction affect the health care services your child received or accessed after the interaction?
11. What made you feel supported during the discharge/completed medical interaction?
12. What made you feel less supported during the discharge/completed medical interaction?
13. What do you think creates a positive discharge/medical interaction experience?
14. What do you think creates a more negative discharge/medical interaction experience?
15. This next question is related to COVID-19. You can choose to skip this questions if you prefer. How did the COVID-19 pandemic affect your experience?
 - i.e. were there positive aspects, were there negative aspects?
16. This next question is related to COVID-19. You can also skip this question if you prefer. Was your child every diagnosed with COVID-19?
 - a. If yes, how did this diagnosis impact your experience with interactions?
17. Do you have any suggestions for how clinicians can support families with medically complex children during discharge/medical interactions?
 - a. If yes, what are the suggestions?

Appendix F

Health Care Interaction Experiences of Parents of Children with Medical Complexity During COVID-19 – Resources for Participants

- 310Mental Health Support (for emotional support, information and resources specific to mental health)
 - 310-6789 (area code not needed)
- Health Link BC
 - 811
- Interior Crisis Line Network (24 hours)
 - 1-888-353-2273
- For Mental Health Services within Interior Health:
 - To find counselling and treatment services near you visit:
 - https://www.interiorhealth.ca/FindUs/_layouts/FindUs/info.aspx?type=Service&loc=&svc=Counselling%20and%20Treatment%20Services&ploc=
- Central Patient Care Quality Office
 - 1-877-442-2001 or patient.concerns@interiorhealth.ca
 - If you wish to provide a compliment or register a complaint
- Canadian Mental Health Association (Kamloops Branch)
 - <https://kamloops.cmha.bc.ca/find-help-now/>