Children with medical complexity in the emergency department: Parent experiences and information needs

by

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Abstract

When your child needs emergency health care, as a parent, you typically drop what you are doing and drive to the hospital or call 911. For parents of children with medical complexity, an emergency department visit is more often a calculated decision after exhausting all other options- it has been described as “the last resort”. Children with complex medical needs constitute a growing number of pediatric patients that utilize the emergency department, disproportionately more than children outside of this category. Parents of these children are often the key source of information, lead care coordinators for their child, and best understand their specific clinical signs predictive of decompensation. The unique challenges these parents face when accessing emergency healthcare are highlighted in this study and their expertise in their child reinforced. The objective of this patient-oriented study is to explore information needs and experiences of parents accessing emergency health care for their child with medical complexity. The first chapter of this paper-based thesis provides context as to why further exploration into experiences of parents of this pediatric population is warranted. The second chapter houses the manuscript that will be prepared for consideration for journal publication, post-defense. The final chapter presents a general discussion of the study and its implications for nursing and future study. Our findings from the parent interviews yielded valuable insight to inform a future knowledge translation tool to improve outcomes for these children and their parents accessing the emergency department healthcare. A qualitative approach to understanding the experiences and information needs of this population successfully demonstrated the priorities and perspectives of the families who access our healthcare system the most.

Keywords: Children with Medical Complexity; Emergency Department; Parent

Preface

This thesis is an original work by Danielle Lysak. No part of this thesis has been previously published. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name "Experiences and Information Needs of Parents of Children with Medical Complexity accessing Emergency Department Healthcare", Pro00124646, January 04, 2023.

Chapter 2 of this thesis is ready for submission for publication. I was responsible for the data collection and analysis as well as the manuscript composition. Dr. Shannon Scott co-designed the study, assisted with the study recruitment, data collection and contributed to manuscript development. Dr. Scott was the supervisory author and was involved with concept formation and manuscript composition.

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Chapter 1: Introduction

Background

Children with Medical Complexity

In Canada, 948 out of every 100,000 children are classified as medically complex (1). Children with Special Health Care Needs (CSHCN) is a broader term present in the literature that describes a child who requires any additional health care services whether that be for behavioral, psychiatric, or medical needs that is expected to last more than 12 months (2, 3, 4, 5). CSHCN are a larger percentage of children and vary in complexity and diagnoses and can include children with intellectual and developmental disability (2, 3, 4). Within CSHCN, the most complex children are further specified in a subgroup described as medically complex and make up around one third of the CSHCN population (2, 4, 6, 7, 8). Children with medical complexity (CMC) meet all four following criteria: (1) one or more chronic, multisystem conditions, (2) functional limitations, (3) frequently utilize healthcare services, and (4) significant home healthcare service needs (3, 4, 5, 9, 10, 11). Combining these four characteristics creates challenges when navigating a healthcare system ill equipped to support these children and families. Many primary care providers provide referrals to specialists but may not always have experience managing complex pediatric needs (2, 5, 12). There is not one defining diagnosis or medication that will classify a child as having complex medical needs in the literature. Rather, it is the intersection of care needs, developmental abilities, functional limitations, and socioeconomic circumstances that complicate a child's medical experience.

As medical technology improves, complex pediatric patients are living longer in their communities and therefore, this subset population is growing (4, 5, 8, 10). They are a high-cost sub-population in the health care system that require multiple specialty services including home care and subspecialty follow up (5, 9, 10, 13). In Canada, 39% of children within this group will use five or more prescription medications in one year and this varies higher or lower based on relative complexity of health needs (1). In 2012, Cohen and their colleagues described that, between the years of 2005-2007, this specialized pediatric population admitted to hospital made up less than 1% of children in Ontario but accounted for one third of the province's total child health expenditures (9). Their frequency of inpatient acute care admissions is higher, and the complex nature of their condition means families often must visit a range of specialty clinics after a hospital visit to meet their entire health needs (9, 13, 14). Due to multisystem involvement in their diagnoses, complications develop quickly, require swift intervention and thus, more emergency department (ED) visits to stabilize acute events (10, 15, 16).

Emergency Department Use and CMC

CMC and CSHCN disproportionately require care in an ED in comparison with other children (16, 17, 18, 19, 20). From 2015-2016, within Alberta, Ontario, and Yukon, 17% of all pediatric ED visits were for CMC (1, 19). The Canadian Institute of Health Information (CIHI) reported that CMC in Ontario, Alberta, and Yukon had an average number of 4.3 ED visits within a two-year study period (1). A Seattle-based study at a tertiary level pediatric ED that 20% of their visits in one year consisted of children with chronic conditions (4). The most medically complex children in their sample comprised 2.4% of the 77,748 pediatric ED visits however they had an admission rate of 57% (4). Quantifying the exact prevalence of this population is difficult as many studies use administrative data to identify CMC and CSHCN. The level of specialist health care needs, functional limitations, and home health needs are not adequately assessed to best identify the CMC and CSHCN within a population through these methods (4, 8, 9, 19).

Nonetheless, available data in Canada and the United States demonstrates the significant presence of CMC in our EDs and hospitals.

Emergency Department Challenges for CMC

CSHCN and CMC have a longer length of stay (LOS) in EDs and have high admission rates to an inpatient unit or pediatric intensive care unit (1, 4, 19). Extended LOS is related, in part, to the increased time needed for practitioners to review available medical records (16, 18, 21, 22). ED staff are tasked with understanding their baseline versus presenting concern in relation to their past medical history and then often consult the various specialties involved in a patient's care team (15, 16, 18, 21, 22). Physicians in one study exploring ED visits for CMC identified that the best health history is the one recounted by the parent, as electronic medical records are lengthy, may be out of date and may be difficult to interpret (15). Transfer of key information related to a CMC is critical to providing optimal care but is challenged due to lack of centralized health records and the complex and lengthy health histories of CMC (15, 16, 18).

CMC and CSHCN may often have verbal or cognitive impairments in addition to their other diagnoses that make it difficult for them to express their needs in ways health care professionals (HCPs) can understand (17, 20, 23, 24). Many CMC concurrently experience intellectual or developmental challenges that require special consideration in clinical settings like the ED (17, 20). Sensory overload from bright lights and loud environments further exacerbates stress in the ED for CMC and their parents (24). CMC who also have neurodevelopmental challenges often are unable to communicate their needs effectively to their care team. In some cases, subtle behavior changes can express serious symptoms for CMC (17, 20, 24). There is limited staff training and understanding of how to best serve these children and their families in the ED. Often the encounter is further delayed by HCP's inability to recognize and reduce stimulation which can increase stress and agitation in a patient during assessment and care (17, 23). These factors all contribute to negative experiences associated with accessing the ED for CMC and their parents.

Challenges Faced by Parents- Care Coordination of CMC

Parents are care coordinators, advocates, and experts on their child's health history. We recognize not all primary caregivers of CMC are parents and may be foster parents, group home workers or other family members. However, we will refer to the individuals managing care at home for CMC as "parents" within this paper. The data from a national profile of more complex CSHCN in the United States found that parents and families spent a median two hours a week on coordinating care in addition to the 11-20 hours providing direct care to their child (3). The extensive time and cost parents face organizing their child's care among multiple specialists, centers and programs is a well identified issue (3, 5, 12, 13, 25, 26, 27). Creating a complex care model is a hotly debated topic in terms of how the healthcare system organizes care for complex pediatric patients and supports families (12, 26, 27). In Canada, SickKids Hospital in Toronto has been a leader in trialing development of complex care coordination for CMC in Ontario. Their model includes using tertiary care pediatric sites as hubs, and community health centers as spokes to connect wider communities in caring for CMC (12). Implementation of these strategies remains a challenge as there is still lack of consistency in provider perspectives across care areas, limited funding and staff retention who can specialize in pediatric complex care (12). However, these efforts remain important to streamline care for CMC and reduce emergency department visits with a stronger community care model.

Challenges Faced by Parents- The Emergency Department

Despite ongoing care coordination efforts mentioned above, many regions do not have the infrastructure for complex care clinics and experts nearby. Thus, parents must decide to bring their child to the ED due to their increased risk of clinical deterioration without intervention (16). Parents are most familiar with their child's communication tools to assess and manage overstimulation in a busy ED and understand their child's signs of deterioration (16, 17, 23). Lack of consistency in ED staff experience with children requiring complex medical care supports the troubling statistic that this group is more likely to experience medication errors and have worse outcomes in the ED and hospital settings (16).

In an ED visit, despite being frequent consumers of care, providers may not be familiar with the child or their diagnoses. This contributes to stressful scenarios where parents must relay their child's extensive health history in acute situations. With parents being the key informant of their child's most up to date history, errors and inconsistencies can arise as the parent's attention is divided. Parents are looked to be expert in their child's care and concurrently manage their own plethora of emotions related to their child's change in clinical status (3, 10, 16). Caregiver burden is therefore a major concern regarding parents of CMC. How we understand the parent experience in the ED is important to understanding how HCPs can improve the outcomes of their children while supporting parents through each encounter.

Purpose

The objective of this patient-oriented study is to explore the information needs and experiences of parents accessing emergency health care for their medically complex child.

Research Question

What are the experiences and the information needs for parents of children with medical complexity when accessing ED healthcare?

Significance of the study

The impetus for this study emerged from priorities identified through a Pediatric Parent Advisory Group in the ECHO research lab (28, 29) and Translating Emergency Knowledge for Kids (TREKK). TREKK is a nationally funded knowledge mobilization initiative aimed at improving children's emergency care in Canada that she co-leads (30). Varying inequities these children and their families face in the ED have been identified, including longer wait times, increased incidence of medical errors in the ED and HCP reliance on parents for health histories (16). While many American studies have examined the care of CMC, Canadian literature in this area remains limited. It is important to continue building Canadian literature around this topic as American health systems are structured differently. Basing data of CMC from the lens of an American health care system reduces transferability to the Canadian context (11).

The literature is scarce on the specific experiences in Canada of parents' needs during ED encounters and leaves a gap in understanding how to better support these parents. Analyzing the unique experiences of parents highlights the intersecting factors that create barriers to accessing health care services for these families. Moreover, amplifying perspectives of parents of medically complex children is a vital first step to understanding and addressing the challenges faced when accessing the ED.

Manuscript Overview

The following manuscript details a qualitative, patient-oriented study following principles of qualitative description from Sandelowski's seminal work on this methodology in 1995 and 2000 (31, 32). Parents were recruited and then interviewed using a semi-structured interview guide (Appendix A). Iterative data collection and analysis occurred. Inductive content analysis was conducted to code data and group findings. A detailed study log was kept detailing recruitment and memos to capture insights throughout the analytic process. The manuscript will be submitted for publication after the thesis defense.

Chapter 2: Manuscript: Children with medical complexity in the emergency department: Parent experiences and information needs

Abstract

Background: Children with medical complexities are a cohort of pediatric patients that visit the emergency department on a more frequent basis than most children related to one or more diagnoses that often require coordination of multiple specialties. As medical technology improves, complex pediatric patients are living longer in their communities. Clinical decompensation may happen quickly and requires swift intervention, often in an emergency department setting. Parents are often the key source of information, lead care coordinators for their child, and best understand their specific clinical signs predicative of decompensation. Given these critical roles, caregiver burden is a major concern regarding these parents. Understanding the parent experience in emergency rooms can inform how health care staff can improve the outcomes of children with medical complexity while supporting parents through each encounter. This patient-oriented study explored the information needs and experiences of parents accessing emergency health care for their medically complex child.

Methods: This qualitative study utilized patient-oriented principles and followed Qualitative Description methodology. Data collection and analysis were concurrent and iterative. Parents were purposively sampled from a nurse practitioner led clinic to participate in semi-structured interviews via Zoom. Purposive sampling of participants allowed us to meet the following eligibility criteria: 1) parent who is 18 years of age or older of a child less than 18 years of age 2) parent presented to the emergency department pursuing care for their medically complex child in the past twelve months from start of data collection; 3) the child is defined as medically complex by their health care provider and/or parent; 4) the parent is fluent in spoken and written English 5) participants must have access to telephone or Zoom software. Conventional, inductive, content analysis was used remain close to the data.

Results: Nine interviews were completed with ten parents. One male and nine female parents participated. Four overarching categories were identified through analysis of the transcripts: How the Emergency Department is Different for Children with Medical Complexity; Emergency Department Experience and Resilience; Parents as Key Contributors to Care Coordination; Communication and Learning Preferences.

Conclusion: Amplifying the perspectives of parents of children with medical complexity is a vital step to understand and address the challenges when accessing emergency healthcare. This population of pediatric patients access emergency care disproportionately more than other children thus, their families have a wealth of knowledge and experience with pediatric emergency care. Interviews with parents provided key insights to inform and improve the care provided in the emergency department for this growing population of children.

Introduction

Quality pediatric emergency care of children with complex health care needs relies on collaboration between health care providers and family units. In an ED visit, despite being frequent consumers of care, providers may not be familiar with the child or their diagnoses. This contributes to stressful scenarios where parents must relay their child's extensive health history in acute situations. Parents are experts in their child's care and concurrently manage their own plethora of emotions related to their child's change in status (3, 10, 16). Caregiver burden is therefore a major concern regarding parents of CMC. Factors such as chronic illness, prescription medication use, functional limitations, specialized therapies, or treatments contribute to a child's complexity of health needs (1, 5, 6, 10). These needs are emphasized when accessing emergency department (ED) care and pose challenges to parents and health care professionals in the case of medical emergencies for a child. This study highlights parent voices and the intersectional factors creating barriers to quality ED care for children with medical complexity (CMC) and their families.

Methods

Patient-oriented principles guided this study and aligned with Qualitative Description (QD) methodology (31, 32, 33). Parents of children with medical complexity were purposefully sampled to participate in semi-structured interviews online via Zoom and phone collecting data following principles of QD. Purposeful sampling was used to recruit parents with a child with medical complexity who could provide in-depth and detailed information about accessing ED care. Ethical approval was obtained in January 2023 under the Research Ethics Board at the University of Alberta (Pro00124646). Written consent was requested prior to each interview and the form can be found at the end of the "Interview Information Letter" (Appendix B). A consent infographic was additionally created to create a visual poster with consent information to improve participant's understanding of the study when signing consent (Appendix C). Verbal consent was obtained and recorded with each participant in addition to the request for written consent.

Population and Setting

The parent sample was based from a pediatric specialty outpatient clinic at the Stollery Children's Hospital (SCH), one of the most specialized children's hospitals in Canada (34). SCH is a Western Canadian tertiary care center that serves the largest geographical area of any children's hospital in Canada; 39% of inpatient admissions are patients from outside the city of Edmonton (34). Thus, the sample was selected among a diverse population of varying diagnoses, geographical location, race, age, and income status.

Sampling and Inclusion Criteria

Nine parents were purposefully sampled from the SCH nurse practitioner-led outpatient non-invasive ventilation clinic. Twelve to fifteen parent participants were anticipated for sample adequacy however data saturation was achieved at nine interviews where no new content was identified (33, 35, 36). In keeping with guidelines for qualitative research, we maintained recruitment until data redundancy was achieved, a thick description of the phenomena of interest existed, and our research question was answered (31, 33, 35, 36, 37).

Inclusion for participation in this study was based on meeting the following criteria: 1) parent who is 18 years of age or older of a child less than 18years of age 2) parent presented to the ED pursuing care for their medically complex child in the past twelve months from point of data collection; 3) the child is identified as medically complex by their health care provider and/or parent; 4) the parent is fluent in written and spoken English 5) participants have access to a telephone or Zoom software. Persons were excluded from participation if participating in any legal proceedings in relation to their child's medical care, their child had passed away, or was expected to pass imminently.

Purposive sampling was used to select participants best suited to fit the objectives of the study and as per QD (32, 36). Patients in clinic were notified about this study by the nurse practitioner and affirmed their interest in hearing from a research assistant about a study they may be eligible for. Interested parents gave their verbal consent to receive a call from DL (Masters student) who provided the details of the study and confirmed eligibility. Parents who expressed interest on the call were emailed the recruitment poster (Appendix D), the consent infographic (Appendix C), and the interview information letter with the consent form (Appendix B).

The research team only contacted families that expressed interest in the study to the third-party staff member in the clinic. Parents were thus provided with the opportunity to invite our team to discuss the study rather than approach them without prior permission. This format of sampling and recruitment offers parents the opportunity to participate through trusted individuals in their clinic. Parents prefer not be approached for research opportunities in settings where their child is in the ED and receiving care (30). Thus, our team opted to interview parents in a non-emergent setting due to the stress and competing priorities the ED involves for parents of CMC.

Data Collection

Recruitment for this study began in May 2023 and data collection commenced in July 2023. Zoom interview times were scheduled by DL with parents who agreed to be a participant after having the study explained and written consent collected. Verbal consent was also confirmed at the beginning of each interview call. The semi-structured interviews were conducted remotely on Zoom and consisted of open-ended and close ended questions and a demographic survey. The iterative interview guide can be found in Appendix A. Data collection concluded in November 2023 when no new ideas were yielded in the interviews and analysis, thus signaling saturation (31, 32, 33, 37).

This study is supported by my supervisor's well established research lab, "Translating Evidence in Child Health to Enhance Outcomes," henceforth referred to as "ECHO"(28, 29, 38, 39, 40, 41, 42, 43, 44, 45, 46, 47, 48, 49, 50, 51, 52). Membership in ECHO research affirms that the data collection, storage, and management processes were standardized to ensure participant confidentiality and ethical principles are upheld. Standard demographic data regarding their child and their diagnosis was additionally collected from parents as part of the ECHO research processes to facilitate opportunities for secondary analysis of data.

Data Management and Cleaning

The interview data was recorded via Zoom recording software. Interviews were conducted remotely on a device that has been given access to the ECHO research local area network (LAN) drive that is encrypted, and password protected. This drive is backed up once daily and only available to ECHO research members given access to the LAN. By completing a preliminary data mapping process, audio files from the recording were saved directly to this secure LAN upon the end of each interview. Upon completion of recordings, the audio files were sent to a professional transcription service for transcript development. Once transcripts were returned, data preparation and cleaning commenced.

Transcripts were compared to original audio recordings by DL and transcript data was cleaned of any errors in speech or disruptions. Names of people, hospitals, and cities were de-identified to uphold anonymity of each participant. This data preparation served as a preliminary analysis because interviews were reviewed repeatedly and thus providing the research team with initial understandings of ideas and themes (33).

Data Analysis

Data analysis aligned with Sandelowski's (31, 32) guidelines for QD and aimed to describe findings with low inference through conventional content analysis (53). QD encourages researchers to create a descriptive summary of parent experiences and responses without high level interpretation (32). Analysis occurred simultaneously with data collection, preparation, and interpretation (31, 37, 54). Quantitative, demographic data were entered and analyzed in Microsoft Excel. Descriptive statistics and frequencies were conducted. Analysis of this interview data was complicated by mixed individual interviews and one dyad interview when both parents for a child were present for the interview. Dyadic or paired interviews are an emerging mode of interviewing within qualitative research and possess strengths and challenges (55, 56, 57). As parents have shared experience caring for a child with complex medical needs, a joined interview can uncover relational aspects of a topic, deepening interview conversation (56, 57). However, this mode of interview presents challenges as it can limit a participant's self-reflection when in the presence of their partner (56, 57). Heightened researcher reflexivity was necessary to consider the two perspectives in relation to the interview questions and towards each other as emphasized in this recent study examining dyadic interviewing (56).

Cleaned, anonymized transcripts were entered to NVIVO software for qualitative analysis. The QD data analysis strategies can be further categorized as a conventional inductive content analysis of the interview data (53, 54). Our data analysis strategy closely followed steps to inductive content analysis as summarized by Vears and Gillam (54) and Hsieh and Shannon (53) to code and categorize data from the interview transcripts. A low inference, inductive method of qualitative analysis ensured congruence to the data set. Keeping with QD, analysis did not seek a novel interpretation of parent experiences but rather described the interview data through iterative coding (31, 32, 53, 54).

First, transcripts were repeatedly read with the intent of obtaining a broad view of the interview (31, 53, 54). This preliminary analysis built an overall impression of a data set. The text was summarized into main ideas only after the data set was fully understood and reviewed comprehensively (31, 53, 54).

Next, the researchers DL and SS grouped data based on the initial content categories within the text (53, 54). Data were analyzed line by line in to create data units (phrases, paragraphs, pages) relevant to the research question and then broadly grouped. Annotations in transcripts, memo notes through the interview and coding, and meetings with my supervisor supported the inductive development of categories (31, 53, 54). By the end of this phase, text was organized into large and overarching categories (53, 54).

In this third stage of coding, subcategories within the large content categories were created by assessing each line within a broad category. By combing through the larger categories, new descriptions were developed to deepen the analysis and create subcategories (53).

The final stage of analysis was refining current codes which included collapsing similar codes into one, grouping similar codes into larger categories or further developing codes. In this step, data across transcripts was compared for similarities in codes and the result was a finalized coding tree for the data set (53, 54). By re-reading texts, comparing data sets and the subcategories created, findings were effectively organized to demonstrate a thorough, low inference description of the interview data. This analytic approach ensured iterative data collection and analysis and further ensured that the analysis remained close to the data (36, 53, 54, 55).

Study Rigor

Study rigor for this project was guided by credibility, transferability, dependability, and confirmability (58, 59). Throughout data collection and analysis, memo notes were recorded as a form of reflexive journalling to enhance rigor of the study (36, 59). Further, all coding decisions and comparisons are depicted in detailed memo notes (study log) then reviewed with my supervisor (36, 37). This process perpetuated researcher reflexivity in the interviews and ensured any researcher reading the memo notes could see how analyses and decisions were made (36, 58).

Purposive sampling of parents of CMC, clear inclusion criteria and thick description facilitated transferability (31, 36, 58). Readers may independently determine whether the conclusions from this study can be transferrable to their own settings due to the thick description of participant context, data and findings (36, 58).

Dependability relies on the ability to compare findings and themes with experts in the study area (58, 59). This study is created with the support of my supervisor's well established research program focusing on patient oriented approaches in improving emergency care for children and families (38, 39, 40, 41, 42, 43, 44, 45, 46, 47, 48, 49, 50, 51, 52). In addition, committee members are experts in the fields of pediatric emergency care and the care of medically complex children respectively. My committee members were key informants to confirm the dependability of findings and processes through the course of the study.

Study confirmability was augmented by a detailed study log, memo notes, and debriefing with my supervisor through the data collection process (58). The above efforts to establish and maintain rigor were key to developing useful and trustworthy qualitative research.

Results

Demographics

Nine interviews were completed with ten parents that primarily were between the ages of 31-40 who identified as female and one as male. Table 1 demonstrates demographics of the parent participants. 50% (n=5) of parents reported visiting the emergency department (ED) in the last twelve months between 1-3 times for their child. Two parents reported 4-6 ED visits in the last 12 months and two parents reported requiring over six ED visits in the last 12 months for their child. All parents but one reported their child had multiple diagnosed health conditions and all but one parent reported their child being admitted to hospital because of their diagnoses. Table 2 displays basic demographic data of the ten children with complex medical needs as reported by parents. All the participants' children were patients of a specialty outpatient pediatric clinic specializing in non-invasive ventilation requiring technology support in the way of continuous positive airway pressure (CPAP) or bilevel positive airway pressure (BiPAP). Interview participants were all primary caregivers and parents of children with variable diagnosis between ages one through fifteen. Diagnoses of their children included prematurity with associated conditions, genetic trisomy disorders, genetic neurological malformations, bronchopulmonary dysplasia, achondroplasia, and other rare diagnoses. In the nine interviews, ten children with complex medical needs were discussed as one of the parent participants had two children they reported as medically complex.

Content Categories Identified in Parent Interviews

The interviews with parents were 60-90 minutes in duration. Through conventional, inductive content analysis, the four categories were identified as: How the ED is Different for Children with Medical Complexity; Parents as Key Contributors to Care Coordination; Emergency Department Experience and Resilience; Communication and Learning Preferences.

How the Emergency Department is Different for Children with Medical Complexity

When asked about recent experiences in the ED parents describe the record of ED visits prior to their most recent one which better contextualizes what happened at their latest visit. Some parents were unable to recall a time spent in an ED waiting room as each time they have gone has been by ambulance and rushed through, *"A lot of the times that we've ended at emerg [emergency department] it's been with an ambulance. So I don't have direct like sitting there waiting, you know" (Interview 005).* Other parents, even when having to wait, understood their child may not be the sickest and can acknowledge that *"I've seen the other side" (Interview 001).* Still the waiting room brings on anxiety: *"Once I'm in the back [in a room], I don't care if you see me. I'm not surrounded by getting coughed on. I don't feel like my kid's picking up anything worse" (Interview 002).* Many parents echoed this sentiment and called for separate waiting areas or options to wait in their vehicle instead to avoid compounding viruses as their children's immune systems are weaker. For families with non-invasive ventilation support for their child when sick, the wait rooms often don't have a plug in for their bilevel positive airway pressure (Bi-PAP) machine and this parent notes that waiting in the general waiting room is even *“unrealistic” (Interview 004)* for them.

Parents characterized the acuity of their child and the life-threatening episodes they have survived during their life. This was important to explain why any trip to the ED for these families is longer in duration and loaded with their history of past ED encounters. *“When we go to the emergency, it has to be emergent. We don’t go there for a potential issue, it is an issue at that point” (Interview 002)* explains one parent discussing how they acknowledge an ED visit usually means admission to hospital. For these parents, the most common reasons for ED visits were escalating respiratory concerns related to a virus or aspiration. This was explained by one parent who shared that a *“cold hits her harder than just a cold for anyone else” (Interview 001).* Parents with access to home oxygen have a threshold of how much oxygen they can provide at home before reaching out for additional healthcare support and report that their child *“gets sick with something respiratory related for sure once a month. And sometimes we can manage at home and sometimes not” (Interview 004).*

In addition, parents reported feeling hesitant to go to general EDs versus the pediatric tertiary care hospital where they typically receive their child’s healthcare. Many participants noted they *“don’t go anywhere else” (Interview 005).* than the pediatric tertiary care hospital. Unfamiliar EDs may not have access to their child’s electronic medical record (EMR) and may not have the resources to support their child when in rural settings. Their child’s specialists are concentrated in one center and many non-pediatric specific hospital sites cannot provide the level of care needed when their child is in distress. Therefore, parents report that any emergency often means transfer to the pediatric hospital.

Parents as Key Contributors to Care Coordination

This category captures the knowledge and expertise of parents and their care coordination efforts in collaboration with their pediatrician and child's specialists. Hospital processes, managing medication schedules, and navigating dynamic levels of acuity for their child are part of the specialized knowledge participants have developed. Parents of CMC have expertise in their child's unique care needs and act as care coordinators often doing what they can to avoid the ED, *"I had to learn…at what point to take him and what point to keep him at home…if there's any possible way we can manage it at home we will" (Interview 004)*. A few parents report their child requiring some level of home oxygen support and this is especially helpful when their child becomes sick. Parents trained on home oxygen can save emergency visits and shorten hospital stays as parents learn to titrate oxygen needs until their child recovers or requires more advanced respiratory support in a hospital. While these added skills can be a large responsibility for parents, support from their child's care teams is a key factor to confidently caring for their child at home. Parents value the connection with a pediatrician experienced in caring for complex pediatric patients:

> *On top of that, Dr. (Name), he's the specialist pediatrician. So, he's very knowledgeable and, you know, he gave us his phone number after hours. He worked with us on specific things to make our potential ER [emergency room] trips easier. Like I was trained to pull sputum samples. He gave me a requisition for a year. If she started getting sick, I could pull it in the early stages, have it off to the lab so if we had to go into the ER [emergency room] or see him, they already had the cultures already. (Interview 002)*

Early and close connections with specialty teams and complex care pediatricians were key to mitigating their emergency visits but brought on new responsibilities for parents to learn key assessments and skills to assist in managing their child at home. If parents were concerned about their child, they could be assessed urgently during clinic hours in person or by phone. Some parents could call their pediatrician directly. With these consultation options, a plan could be put in place to ensure an ED trip remained the last resort. A parent participant describes how they are the ones that see the whole picture of care for their child. They note that with their child being under many health teams, *"specialists tend to singularly think of solely their one specialty and not how it is going to affect a, b, c"* and that as the parent they *"need to look at all of it because we live with all of it" (Interview 002).*

Parents described their repeated experiences in the ED and built a knowledge base to feel confident and give advice for other parents and health care professionals. In one recollection of the previous ED encounter, a parent called an ambulance and the paramedics verbalized that they were not used to *"dealing with kids like this" (Interview 009)* and asked for the parent's suggestions during the ride to the hospital. The parent provided instructions to apply their child's continuous positive airway pressure (CPAP) machine and connect an increased oxygen supply until they got to the ED. Another parent described their collaboration with nurses in the ED and that they *"often make a game plan together" (Interview 006).* Despite the parents' familiarity of their child's care needs, "*sometimes I feel super heard and super validated, and sometimes I don't" (Interview 006)* when discussing their child's care in the ED with staff. Participants strongly advised other parents of CMC to plan for ED encounters and pack a *"go bag" (Interview 005)* for prolonged admissions including their child's medications for administration in the ED. In addition, other participants encouraged parents to ask questions and to advocate for their child. Many of the participants discussed advocacy in the ED and urged parents to trust themselves when something doesn't seem right.

> *And I think that's one of the biggest things I've learnt is that if I'm noticing something, I need to advocate and use my voice so that, you know, I can be my son's voice because while for maybe a typical child these little changes might not be a big deal and that it will go away and recover on its own, for someone with a complex disease that's not the case. Those little changes often mean something bigger is coming. (Interview 003)*

Some participants recommended that ED staff have enhanced education in terms of the special behavioral needs in CMC, clear expectations of wait times and updates, and validating the parent concerns for presenting to ED.

> *…in these cases when it's special kiddos and just to kind of validate like hey, you're here for a reason good that you brought her in and we're gonna get her checked. You know, like we're gonna get to the bottom of this. (Interview 005)*

Emergency Department Experience and Resilience

The results grouped into ED experience and resilience include subcategories about advocacy, medical trauma experienced by parents and children, the impact of ED tests and procedures on children with complex medical needs, parent support in the ED and quality of life.

Advocacy for their children was a prominent point of discussion regarding experiences in the ED and one parent discussed how their parenting values are challenged in an ED setting: *"I think one of the things that I struggle with as a parent is teaching my kid advocacy, body boundaries, all of those things but then being like, okay, but not at the hospital. You don't get a choice" (Interview 002).* More experienced parents were vocal about the need to advocate for certain tests, assessments, and processes in the ED. Parents new to a diagnosis or who spoke English as a second language described moments when staff in various health care settings advocated for them and their child’s care. One example is described in this parent’s account of a staff member walking them to the ED from a clinic appointment: *“She say if it takes time you have to call me. You can’t wait at the waiting room…They have to bring you inside. If they say one hour, call me she tells me. I said thank you” (Interview 007).*

Parents observed when their child was reactive and agitated with procedures like venipunctures for blood work.

> *I think at the beginning of this journey, he was very good. He was really good with things, and he wasn’t very fearful or anything like that. But as things have escalated a little bit, he’s much more fearful now. And so, I do find that when we do have to go, he’s very, very scared. He will cry sometimes which he never used to do. (Interview 003)*

For parents of CMC with additional behavioral challenges, parents are key advocates and translators. Some participants explained how their child cannot communicate in ways other staff can always understand and may not respond to typical distraction techniques in the ED for procedures. Medical trauma can contribute to behavioral outbursts with procedures but for children who have an additional behavioral diagnosis, sensory experiences of the ED can easily contribute to the stress of the ED for CMC and their families:

> *“I would say initially the hardest part about going to the emergency was actually the autism factor of being in those situations would cause severe behavioural challenges. And I think, you know, as much as people talk about autism nowadays and even back then, you know, a lot of people don’t understand it.” (Interview 003)*

Parents encouraged staff to continue to be aware that not all children can communicate the same. Stressful circumstances, as in the ED, may further impair a child’s ability to fully communicate in their own capacity.

Parents also experienced traumas related to their child’s ED encounters and require social support in ED settings as well. Having a social worker or extra staff explaining what was happening was mentioned as positively influencing particularly traumatic visits. One parent discussed how going to emergency brings up intense feelings of fear for their child:

> *I feel like every time we go there it’s life or death and not that it has been, but for me it feels like it because we know these kiddos could pass away from big seizures, any respiratory illness. So, when she’s intubated, I’m gonna think she’s gonna die. (Interview 005)*

Participants described that their children were either agitated with venipunctures and painful procedures or indifferent to these tests. One parent described this alternative reaction in this quote:

> *So, often by the time we're taking him in, he's going to be very, very lethargic likely. He is not a crier. And that can fool some people sometimes, though as he's gotten older that's been better. When he was little, they were like, 'well, he's not crying.' I feel like that doesn't mean it's not hurting. (Interview 006)*

Repeated painful procedures for these children may lead to them becoming more fearful of these events moving forward as reported by participants. Parents described either their child becoming *“used to it” (Interview 009)* or increasingly traumatized by these painful experiences and tests. Multiple parents described the benefits of having a child life therapist during painful procedures to ease fears of both the child and the parent.

> *Child Life has been amazing at the [home pediatric hospital] for us. distracting her, helping me, talking to her, even, you know, holding my things while I have to hold her down. You know, things like that. They’ve been, you know, telling her she’s brave.*

> *Distracting her. Giving her a toy afterwards. Doing all the things to help kind of make it as positive as it can be. (Interview 002)*

The resilience of the children through repeated emergency healthcare encounters and hospital visits was described by parents. Discussion about a child's resilience through painful procedures in the ED often brought up parents discussing quality of life for their child. Quality of life for their child remains a consistent priority for participants and parents had variable interpretations of their child's quality of life. Parents described many traumatic instances in the ED for their child and seek to reduce traumatic experiences, like painful procedures, and caring for their child at home when possible. Although these encounters can be incredibly distressing for parents and children, these families build a unique resilience that is palpable among those who care for their children as well:

> *But we also want to have as much time with her as possible while she's feeling good, so. But then in the last few years, I think probably, you know, she's just proven like how tough she is, so I think that it's very easy now. Like they do sort of understand that she's gonna make it through this. (Interview 009)*

Resilience in the children is described thoroughly. Participants emphasize that despite the acuity, the medical trauma, and repeated ED visits, their child continue to grow and be a positive presence:

> *I always tell my husband; I don't know at the end of this how he can smile and be so happy. Like he – it's just it's actually inspiring to have him because he shows you what's truly important in life. (Interview 004)*

Communication and Learning Preferences

Information exchange between family and providers and learning needs of parents were two sub-categories identified within this overarching category. These findings discussed overall communication in the ED in terms of ED expectations, learning for parents, use of the electronic medical record (EMR), and parents feeling heard by ED staff.

Participants depicted communicating their child's presenting concern and health history to ED staff to be repetitive at times, but overall parents understood why providers were asking questions. Parents understand their child's history is documented in the EMR but still are asked many questions in the ED to clarify points. One parent stated, *"I do appreciate like their attention to detail…I would rather somebody ask me all the questions that they wanna ask so that they can better help" (Interview 003)*. Discussion about their child's normal or baseline versus their current presentation was appreciated by parents as it provided a clear way to communicate their current presenting concern. Despite this, parents reported challenges with succinctly explaining health histories for their child as evidenced in this quote:

> *Basically, I just said well he has something called [name of syndrome] and I'm trying to explain what happens when he's breathing and that, you know, he's high risk. Like they're gonna have to call his doctors before just deciding oh he has to go for surgery... And it is also really hard to try to explain a complex diagnosis and I'm still trying to figure that out. (laughs). (Interview 003)*

Other parents described some frustration with repetition of questions especially in the context of an EMR being available at their ED.

> *I find every time I go, I'm essentially repeating his whole life story because although it is written in the chart, it's like they still want to hear it from your mouth and that can be a*

> *little bit frustrating too because it's like right – it's in the chart, but I guess maybe for them, you know, they read it but they don't quite understand it so they wanna get more information from you. Yeah. I'm, always repeating myself for sure. (Interview 003)*

The efficacy of the EMR for communicating health history was varied between parents. One parent describes their child's EMR as a key tool to communicate their child's needs to ED staff:

> *So, at the (pediatric tertiary care center), they pull up her file. It's well documented. Everything that – like there are huge notes right at the top by [specialist doctor] intubation issues, former trach patient, you know, that kind of stuff. So, there are big, red flags when we walk in that are flagged on our file which [specialist doctor] has very lovely put that on for us. We're very blessed to have that. (Interview 002)*

A summary tool to aid in communicating key info about their child with complex medical needs was not consistently used across this parent sample. Some parents report using a pamphlet, discharge summary from the hospital or binder with a health history based on templates they created or inspired from parent peer social media groups. However, the parents who currently are not using one stated that they would be interested in creating one and endorse its use in ED settings.

As they present to the ED so frequently, fear of not being heard or validated for presenting was reported between various parents. Some parents discuss how using medical terms helps prove their knowledge with their child and experience in the hospital. One parent stated *"I'm still learning like what do you say to be taken fully seriously like you're not just, you know, my kid's a snowflake where you know what you're talking about" (Interview 002).* Parents expressed the value of finally receiving a diagnosis in how they feel when talking to teams as well. Prior to having a diagnosis for their child while awaiting testing or diagnostics, the ED trips were reported as very difficult as parents knew something was wrong but were not able to label it yet or understand their child's care needs.

Learning needs and preferences for parents were variable as described in this second subcategory. Parents reported many self-directed strategies to find information on the internet about their child's condition or the ED as well as utilizing parent online forums and using multimedia sites specifically, *"YouTube" (Interview 007).* Some participants expressed a preference for print resources and others preferred online resources. However, overall online was preferred for updates about ED process or for educational material related to their child. Participants shared that receiving information in one teaching session or verbally was not effective and this approach did not allow for returning to examine the material again to consolidate what they were hearing. This parent preferred an online resource to provide multiple opportunities to refer to that information at a different time, *"because the thing about, it's doctors or verbally from anyone is great, but how, am I actually going to take it in at that time" (Interview 001).* Learning needs for parents of CMC in the ED included expectations of the ED process and wait time. As most parents learned this over time and experience in the ED, having a way to understand expectations, things to bring, and how to prepare for an ED visit would be beneficial earlier in their child's journey. One parent endorsed this experience in their quote:

> *I didn't know how emergency works, you know, in the same capacity. But now I'm like okay, they might not come to us right away but we're not getting neglected, you know…or like I've been able to give them information so it's easier hopefully for them to understand what's going on. (Interview 005)*

Because this pediatric group includes a diverse population and diverse diagnoses, parent learning needs are individualized. However, providing information about basic ED processes, expectations and general guidance would be welcomed by parents especially those new in the journey of their child's diagnosis and care.

Discussion

The findings from this study provide insight into Canadian parents' information needs and experiences of some of the most medically complex children as they seek emergency care. As most of the previous literature on CMC is within the American context, many of the findings illuminate a key Canadian perspective on ED use from high care consumers. This study recruited parents whose children all had EMRs that are shared among care providers in their region. Not all participants live near a pediatric tertiary care center. This provided diversity in experience as some of the findings vary based on what resources, staff and pediatric expertise is available at the hospital the families sought emergency healthcare. Key topics discussed from results include the nuances of the ED for CMC, care coordination gaps, the resilience required from parents and their children, and information needs of parents.

How the Emergency Department is Different for Children with Medical Complexity

For parents of children with medical complexity, the ED is a place that many parents have become familiar with over repeated encounters in their child's health journey. Parents recount their pattern of ED visits in the parent interviews and have built a wealth of knowledge from these frequent encounters. The high acuity of these pediatric patients is a key aspect to understand when considering their ED experience. Our findings parallel the literature reiterating how quickly clinical decompensation can occur in these children resulting in high stakes, advanced ED care being required (3, 5, 7, 10, 11, 16, 60). Participants described vivid experiences calling ambulances, admission to ICU within the hour of getting to the hospital, and details of high-level interventions that are required when presenting to ED. When other options within specialty clinics are exhausted or their pediatrician is not available after hours, parents may have to determine management of an illness at home and when to come into the ED. If care cannot continue to be managed outpatient or at home and the decision is the ED, parents described the extra preparation they go through for an ED trip. Many parents discuss packing necessary supplies for care in the ED, medications, special feeds and preparing for a lengthy trip.

Parents in a 2021, American, single pediatric site study exploring parent and ED provider perspectives of CMC care in the ED affirm the challenge with caring for CMC in the ED (16). Parents described lengthy triage times, delays in admission, and ineffective communication with ED staff and specialists despite their child being well known at the hospital (16). Our findings demonstrate variable parent experience of waiting in a busy waiting room, being rushed through triage for stabilization, or waiting long periods for admission to a bed in hospital. Notably this study further parallels with ours in that parents also affirmed challenges with repeating their child's health history, navigating communication between specialists and suggesting a summary tool to aid communication with teams (16).

CMC have been described in literature as highly challenging to care for in the ED due to their medical fragility and the time constraints in the ED (18). In a recent multi-institutional study from the United States, 97.4% of pediatric ED physicians reported that this population was challenging to care for in the ED (18). These physicians point to challenges for caring for CMC in the ED such as lack of communication with the child's known specialists, lack of accessibility of pertinent data and lack of personal understanding of the medical condition. Participants in our study as well as the parents in the 2021 Pulcini study (16) support these findings of a need for improved communication. Parents rely heavily on specialists who know their child and must seek care almost exclusively at a pediatric tertiary care center to ensure advanced resources and interventions are readily available.

Emergency information forms (EIF), communication with known providers/specialists, and advanced staff training for caring for CMC were preferred strategies to improve their care in the ED and these strategies are supported in other literature from parent perspectives as well as physician (3, 5, 7, 10, 15, 16, 18, 21). These strategies are not well studied in the Canadian context however the findings from our study demonstrate the unique experience of seeking emergency care for CMC in Canada and highlight that CMC in the ED require a specialized approach collaborative with specialist physicians, parents, and ED staff.

Care Coordination and Parent Expertise

A strong emphasis is placed on acknowledging the expertise of parents in relation to their child's care as well as their care coordination efforts to manage a medically complex child at home. Parents' knowledge about their child's specialized care needs was richly described by our participants. Medical decision making for their child is a relentless task the parent of a CMC has to consider (5, 61, 62). Participants shared how they have had to learn when to seek emergency care, when to seek outpatient care and when their child's health needs could be managed at home. Making these care decisions requires them to learn how to assess their child's symptoms, how the symptoms have changed and their response to treatments/interventions. Parents describe how they are involved in all the specialist visits and juggling the advice from multiple care teams. The responsibility caregivers hold to coordinate follow up, treatment, and relaying information with care teams for their child resonated with the extant literature studying support needs and experience of parents of children with complex illness (3, 5, 16, 61, 62, 63, 64). Based on the parent sentiments, collaboration with their pediatricians and specialist clinics, going to the ED is a decision made after exhausting options with their outpatient clinics to manage at home. Their role as a key care team member is thus well known and further described in the current literature about CMC and their parents (3, 18, 20, 62, 65, 66, 67). It is important for health care professionals in the ED to acknowledge this unique expertise when caring for this niche pediatric population seeking emergency care.

There is no handbook for becoming a parent of a child with complex medical needs. Parents obtain knowledge and skills through their child's multiple care teams, self-research online, parent forums and experience (63, 66). This learning and experience combine to form a unique, comprehensive expertise on their child's condition and care needs. Advice from participants for other parents of CMC was a mix of practical advice about ED trips and more subjective advice about asking questions and having faith in their caregivers. Other literature examining advice giving in parents of children with complex chronic illness echo similar findings in their parent interviews and noted that advice sharing is often done within social media parent forums (63). A few participants recount parent forums that they are a part of that share advice and information for their child's unique diagnoses. Parents in our interviews noted that their confidence and knowledge about ED processes was developed through experience as there was no formal education from care teams about ED preparations. Knowing that most of this information is shared with experience, it may be important to ensure new parents are given opportunity for peer support in other parents of CMC early on. This support could be found in a supportive parent forum or through a structured format in collaboration with their specialty clinic.

Care coordination efforts to reduce and improve emergency encounters will best be determined through a collaborative approach with the child's specialists, pediatrician, and parent.

Need for improved care coordination strategies between the child's care team is well discussed in current literature for CMC and pediatric chronic illness (5, 12, 61, 62, 68, 69, 70, 71, 72, 73, 74, 75). There are emerging programs in Canada that look to address some of the challenges of care coordination including the Complex Care for Kids Ontario Hub and Spoke Model (12). Facilitators of this care coordination initiative to spread expert care for CMC beyond the pediatric tertiary sites included inter-organizational partnerships, knowledge sharing between tertiary hub sites and complex care clinics, family engagement in care delivery, program design and governance (12). In the site participants were recruited from, no pediatric complex care program exists as in the above example. Some parents were connected to a complex care pediatrician and this expertise of a central leader in their child's care team proves not only valuable for easing care burden from parents but also may reduce ED visits according to parents and results from a study examining complex care coordination for children (76). Parents enrolled in this tertiary care based complex care coordination program reported positive results and the ability to focus on being a parent rather than healthcare expert for their child(76). Complex care coordination is a well-studied topic in North American literature (12, 61, 62, 70, 71, 73, 76). As the population of complex pediatric patients continues to grow, creating networks between hospital sites, utilizing advanced practice nursing roles and knowledge sharing can reduce barriers to quality care for these children and their parents in the ED (12, 61, 62, 70, 71, 73, 76). By having proactive measures in place with specialists and their pediatricians, early connections with teams positively impact a parents' experience when accessing ED care.

Emergency Department Resilience

The caregiver burden, medical trauma and resilience of parents of CMC in the ED was well documented by the participants. Treatment and testing in the ED was a prominent topic, specifically for venipunctures in the ED. Parents of CMC discussed how common procedures in the pediatric ED can be more stressful as their child may communicate differently than what staff may understand. A recent American study examining parents' perspectives of pain in CMC (specifically children without verbal abilities) noted that parents must learn to recognize their child's unique pain signals over time and are tasked with explaining them to other staff and caregivers (77). Extant literature emphasizes the need for enhanced complex care exposure and staff training for child psychology and communication when mitigating children's stress and pain perception in health care settings (21, 78).

Parents had variable support in the ED for painful procedures such as child life specialists based on their ED site or specific recollection. Even so, some parents' first point of care is in a general ED where child life is not readily available as when they are at a pediatric tertiary care center. Until their child is transported to the tertiary care site, there are limited resources to supporting complex pediatric patients in their local general EDs. The parents who reported having child life therapists available were appreciative of their presence and that it had a positive impact on their child's experience. However, a 2020 American study examining painful procedures in a pediatric ED found that increased caregiver satisfaction of an ED encounter was associated with a child life specialist coming in prior to painful procedures to explain things to the child and parent as opposed to just being present during the procedure (79).

Parents in our study understood the need for tests but some of the parents describe intense distress that venipunctures cause for their child resulting in physical restraint to get blood tests done. In these cases where the child has intense medical trauma to procedures, recent Canadian literature suggests considering and combining interventions like inhaled nitrous oxide and local topical anesthetic to reduce anxiety and pain. This may allow painful procedures to be more positive for the child and caregivers (80, 81). Including parents and children in the conversation with staff regarding painful procedures in the ED is important to ensuring parents feel heard, patients are supported, and that ED staff can provide the necessary care safely.

Caregiver burden in parents of CMC is compounded with care coordination responsibilities, their child's home care needs and also in the medical trauma they have experienced with their child (61). The prevalence of pediatric medical traumatic stress (PMTS) or post-traumatic stress symptoms (PTSS) in parents of children with chronic illness and CMC has led to many studies examining its effects on families and how to provide trauma informed care (78, 82, 83, 84, 85, 86, 87, 88). It has been shown that specific illness group does not determine a parent's scoring on measures of PTSS however there are unique psychosocial risk factors that can influence parents' ability to cope based on parent past experiences and current supports among other factors (87). While this study did not specifically examine medical trauma in CMC or parents of CMC, events described by parents in interviews aligned with definitions and examples of medical trauma studied elsewhere in the literature (61, 78, 84, 88, 89). A recent Western Canadian study recruited parents of CMC to participate in interviews specifically about PMTS and their findings confirm that recurrent exposure to PMTS through individual experience, interactions with staff and lacking systematic support influence hospital experiences with their child and can induce significant mental health consequences as a caregiver to CMC (88). The sentiments and suggestions from parents in the above study (88) parallel our interviewed parents' experience accessing emergency care for their child as being traumatic in nature. This brings into question how our EDs are practicing widespread trauma informed care and what we can do to better screen and support parents and children experiencing stress and trauma related to their diagnoses and health journey.

Parents and their children are resilient in all that they have overcome and learned through their child's health journey and ED history. Connections with various staff and positive supports in the emergency setting contribute to a better experience in the ED (88). Parents appreciate the humanization of the staff in the ED, when the authenticity between staff and patients is palpable, and when their child can remain smiling despite the things they have endured.

Communication and Learning Preferences

Participants in this study described challenges in effective information transfer in the ED and identified key learning needs. The specific learning needs of parents varied as there were diverse levels of experience among parent participants. Some parents had older children with complex medical needs where they have been managing care for over a decade while others are still newer in their journey with their child's diagnoses. The newer parents report using varying self-research strategies through Google, YouTube and other internet sources to try and find out more about their child's diagnosis. Learning needs surrounding emergency care were based on expectations of the ED process and visit including projected wait times. This can be variable but perhaps providing guidance for newer parents of a child with complex care needs to expect to stay longer in the ED with their child, to plan childcare, supplies or care equipment needed for your child to be in the ED for a full day may be helpful. Overall parents endorsed online websites or resources to learn about their child and ED care over print sources.

Across participants, a learning need was identified in how to communicate their child's diagnosis, health history and presenting concern in a succinct, effective way. Ensuring parents can communicate health information confidently is a crucial part of empowering them in their child's care. Health care professionals learn in their schooling how to succinctly give a handover report with practical instructions through a situation, background, assessment, recommendation

(SBAR) format (90, 91). SBAR is a validated communication tool to effectively communicate the pertinent information about a patient event (90, 91) that could be helpful to parents of CMC communicating to ED teams. Parents of CMC are recognized in the literature and care settings as key members of their child's care with expert knowledge about their child's specific condition (3, 18, 20, 62, 65, 66, 67). Teaching parents these communication strategies may ensure they can be heard in emergency settings with their child and speak the language of the health care professionals.

Some parents expressed in the interviews that they bring a summary tool or EIF to emergency visits to aid communication between them and their provider so that most pertinent information can be found quickly in the form of a pamphlet or binder that they created. Surprisingly, most parents from this sample did not report a current method to facilitate communication of their child's condition and health history in emergent settings. This was also found in a 2022 mixed methods study that surveyed the pediatric ED physicians' perspectives caring for CMC. Physicians in that survey reported that families of CMC often do not present to the ED with an emergency information form (EIF) but that they find this a key strategy to assist with providing care for a child with medical complexities in the ED (92). The American Academy of Pediatrics have a policy statement from 2010 that recommended CMC use an EIF to enhance efficiency in providing quality emergency care (15). This statement reinforces use of an electronic version so that it can be easily updated and between hospital networks and systems as necessary (15). In the pediatric tertiary care hospital these participants were recruited from, parents reported the electronic medical records are utilized to flag certain warnings or details that every provider encountering the child must know. Some of these instructions are simply to call their specialist prior to any further intervention. However, from these interviews, we know this is not consistent across patients or clinics. There is a great opportunity to utilize the EMR to create up to date, accessible summary pages or EIFs for CMC in collaboration with their pediatrician and specialists. Overall, strategies to mitigate parents repeating and explaining their child's detailed health history need to be considered in the emergency setting. Findings from these parent interviews can provide valuable guidance in creating a future knowledge translation tool aimed at improving their child's outcomes and the overall experience when accessing the ED for their medically complex child.

Limitations

Participants were recruited from nurse practitioner led specialty clinic in a leading pediatric tertiary care center that serves a large and diverse population in Western Canada. While some may see the diversity across our participants as a limitation, this diversity was purposefully sought. Through rich and detailed interviews, a diversity of perspectives allowed us to explore the range of experiences and information needs in ways that a homogenous sample would be unable to. It is important to highlight that our participants sought ED care in a variety of sites (e.g., urban, rural) with varying levels of acuity. There are inter-provincial variations in care practices and service delivery which further add to the diversity of parental experiences. Participants all had children with medical complexity and there was diversity in the diagnoses of each child. Furthermore, some families who are in frequent contact with their primary care provider or specialists regarding their medically complex child were able to bypass the emergency room through direct admissions to inpatient wards and have different ED experiences as a result. This direct admission process requires initial patient assessment to occur in outpatient settings and the primary care provider having admitting privileges in the pediatric tertiary care center. Therefore, patient experience may vary based on what admitting privileges their child's primary care provider has.

Conclusion

Parents of children with medical complexity have unique experiences and knowledge needs when accessing emergency department (ED) healthcare for their child. After many encounters in the ED and having a child with complex conditions, they quickly become an expert member of their child's care team. With this responsibility, parents are at risk for caregiver burden with being a care coordinator and key advocate for their child in stressful situations like an ED visit while also still being a parent. Four key categories emerged in our study: How the ED is different for children with medical complexity, ED experience and resilience, Parents as Key Members of the Care Team, and Communication and Learning Preferences.

Our findings highlight that it is important for ED managers and health care professionals to review the current care delivery processes and evaluate opportunities to collaborate with parents and streamline care for children with more complex medical needs. Strategies to consider include implementing EIFs with specialty clinics and pediatricians, considering communication tools to assist parents in communicating pertinent information about their child and complex care networks. This study highlights the voice of parents of CMC in the ED and can inform areas of further study about this growing Canadian population. These parents have a unique set of skills and knowledge base as frequent care consumers in the Canadian healthcare system. Including parents of CMC in research and seeking opportunities to streamline complex care for children is key to understanding how we can continue to empower and strengthen families accessing emergency healthcare.

Chapter 3: General Discussion and Conclusions

Implications for Future Study

The findings from this study can inform the creation of a future knowledge translation tool to support families of children with medical complexities (CMC) accessing emergency care. The findings within these interviews could be leveraged to facilitate the development of tools to improve information transfer between parents and health care professionals in emergency settings. Exploring trauma informed care in the emergency department (ED) for CMC is another branch of study that can be expanded on to inform ED staff on how to recognize and mitigate the medical trauma that many children experience when brought to the ED.

Implications for Nursing

The categories identified highlight key areas to focus quality improvement endeavors in the ED. As this pediatric population continues to grow it is important to remember that these parents are a strata of care consumers with unique information needs and experiences. The qualitative findings highlight challenges parents have in communicating their child's needs succinctly and in a way that expresses their concerns. Triage nurses are in direct communication with these parents at this key time and have a great opportunity to provide reassurance and validation to parents bringing their child in. These interviews emphasize the expertise that these parents possess. Nursing can directly support patient and family centered care by recognizing parents' expertise.

Recommendations

There is a great opportunity for advanced practice nursing roles in care coordination for these complex patients. Enhancing communication between specialty clinics, pediatricians and acute care can improve overall care for these patients and alleviate some care coordination responsibilities from parents. Outpatient and specialty programs are implored to explore how advanced practice nursing roles can improve care coordination for families managing a child with complex medical needs.

Information needs of parents of CMC emphasize a need for a communication tool to support handover of their child's health information in emergency department settings. EIFs can be developed in collaboration with pediatricians, specialists and parents to ensure the most pertinent information is communicated during stressful emergency encounters. In addition, educating parents of children with complex medical needs on handover communication tools such as SBAR (situation, background, assessment, and recommendations), may empower parents in these settings and facilitate clear communication with emergency room staff. Families reiterating information that is available in the patient's chart and explaining complicated health histories should be avoided in emergency settings. Strategies to mitigate the onus on parents to articulate their child's health history in emergency settings should be explored to ensure consistency of information amongst care teams and support family centered care in emergency department settings.

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Tables

Table 1

Demographic Data for Parents (n=10)

Variable	n (%)
Gender	
Female	9 (90)
Male	1 (10)
Race/Ethnicity	
White	5 (50)
Black	2 (20)
Middle Eastern or North African	1 (10)
South Asian	1 (10)
Other	1 (10)
Age	
20-30 years	1 (10)
31-40 years	5 (50)
41-50 years	3 (30)
51 years and over	1 (10)
Supportive adult in daily life (e.g. spouse, partner, common law)	
Yes	9 (90)
No	1 (10)
Yearly Household Income	
Less than $25,000	1 (10)
$25,000-$49,000	1 (10)
$50,000-$74,000	1 (10)
$75,000-$99,000	2 (20)
$100,000-$149,000	3 (30)
$150,000 and over	1 (10)
Prefer to not answer	1 (10)
Highest Level of Formal Education	
Some Highschool	1 (10)
High school diploma	1 (10)
Post-secondary certificate/diploma	3 (30)
Post-secondary degree	4 (40)
Graduate degree	1 (10)
Location of Household	
Inner City	4 (40)
Suburb	3 (30)

Town	2 (20)
Farm/Rural	1 (10)
Relationship to Child with Medical Complexity	
Parent	10 (100)

Table 2

Basic Demographic Data of the Children with Medical Complexity (n=10)

Variable	n (%)
Gender	
Female	5 *(50)*
Male	5 (50)
Age	
0-3 years	3 (30)
4-9 years	5 (50)
10-15 years	2 (20)
16 years and over	0
Emergency Visits in Last 12 mos	
1-3 times	5 (50)
4-6 times	2 (20)
6+ times	2 (20)
None	1 (10) *
Admission to Hospital as a Result of their Diagnosis	
Yes	9 (90)
No	1 (10)

Notes: *One of the children did not have a recent ED visit reported by their parent but their sibling, who was also labelled medically complex by the parent, did have an ED visit in the past 12 months. Both child's experiences were discussed with the parent as they had reported two CMC in their family.

Appendix A

Interview Guide

Demographic data

1) a. Which gender do you identify with most?
- ☐ Man
- ☐ Woman
- ☐ Non-binary
- ☐ Gender fluid
- ☐ Not sure or Questioning
- ☐ Another preferred term: __________
- ☐ Prefer not to answer

1) b. Would you describe yourself as transgender?
- ☐ Yes
- ☐ No
- ☐ Prefer not to answer

2) a. Which of the following race and ethnicity groups best describes you? *Please select all that apply.*
- ☐ Black (includes African, Afro-Caribbean, African Canadian descent)
- ☐ East Asian (includes Chinese, Korean, Japanese, Taiwanese descent)
- ☐ Indigenous (includes First Nations, Métis, Inuk/Inuit descent)
- ☐ Latino (includes Latin American, Hispanic descent)
- ☐ Middle Eastern or North African (includes Arab, Persian, Afghan, Egyptian, Iranian, Lebanese, Turkish, Kurdish, and other West Asian descent)
- ☐ South Asian (includes East Indian, Pakistani, Bangladeshi, Sri Lankan, Indo-Caribbean, and other South Asian descent)
- ☐ Southeast Asian (includes Filipino, Vietnamese, Cambodian, Thai, Indonesia, and other Southeast Asian descent)
- ☐ White (includes European descent)
- ☐ Not listed or other: __________
- ☐ Do not know: __________
- ☐ Prefer not to answer

2) b. If you selected Indigenous, would you describe yourself as Two-Spirit?
- ☐ Yes
- ☐ No
- ☐ Prefer not to answer

3) What is your Age?

- ☐ Less than 20 years old
- ☐ 20-30 years
- ☐ 31-40 years
- ☐ 41-50 years
- ☐ 51 years and older

4) Do you have a supportive adult in your everyday life (e.g., spouse, common-law partner, other partner/relationship)?

- ☐ Yes
- ☐ No
- ☐ Prefer not to answer

5) What is your yearly household income?

- ☐ Less than $25,000
- ☐ $25,000-$49,999
- ☐ $50,000-$74,999
- ☐ $75,000-$99,999
- ☐ $100,000-$149,999
- ☐ $150,000 and over
- ☐ Prefer not to answer

6) What is your highest level of formal education completed?

- ☐ Some high school
- ☐ High school diploma
- ☐ Some post-secondary
- ☐ Post-secondary certificate/diploma
- ☐ Post-secondary degree
- ☐ Graduate degree
- ☐ Other
- ☐ Prefer not to answer

7) Where does your household live?

- ☐ Inner City
- ☐ Suburb
- ☐ Town
- ☐ Farm/Rural
- ☐ Other: _______

8) What is your relationship to the child that you brought to the emergency department?

- ☐ Parent
- ☐ Grandparent
- ☐ Other family member
- ☐ Guardian

9) How many children do you have? _______

10) What is the age of the child defined as medically complex? ______

11) a. Does the child with medical complexity have multiple diagnosed health conditions?
☐ Yes
☐ No

11) b. If yes, what are they? ________________

12) How many times has this child visited an emergency department in the last 12 months?
☐ 1-3 times ☐ 4-6 times ☐ 6+times

13) a. Has this child ever been admitted to the hospital as a result of [condition]?
☐ Yes
☐ No

13) b. If yes, how many times? ________________

Open Ended

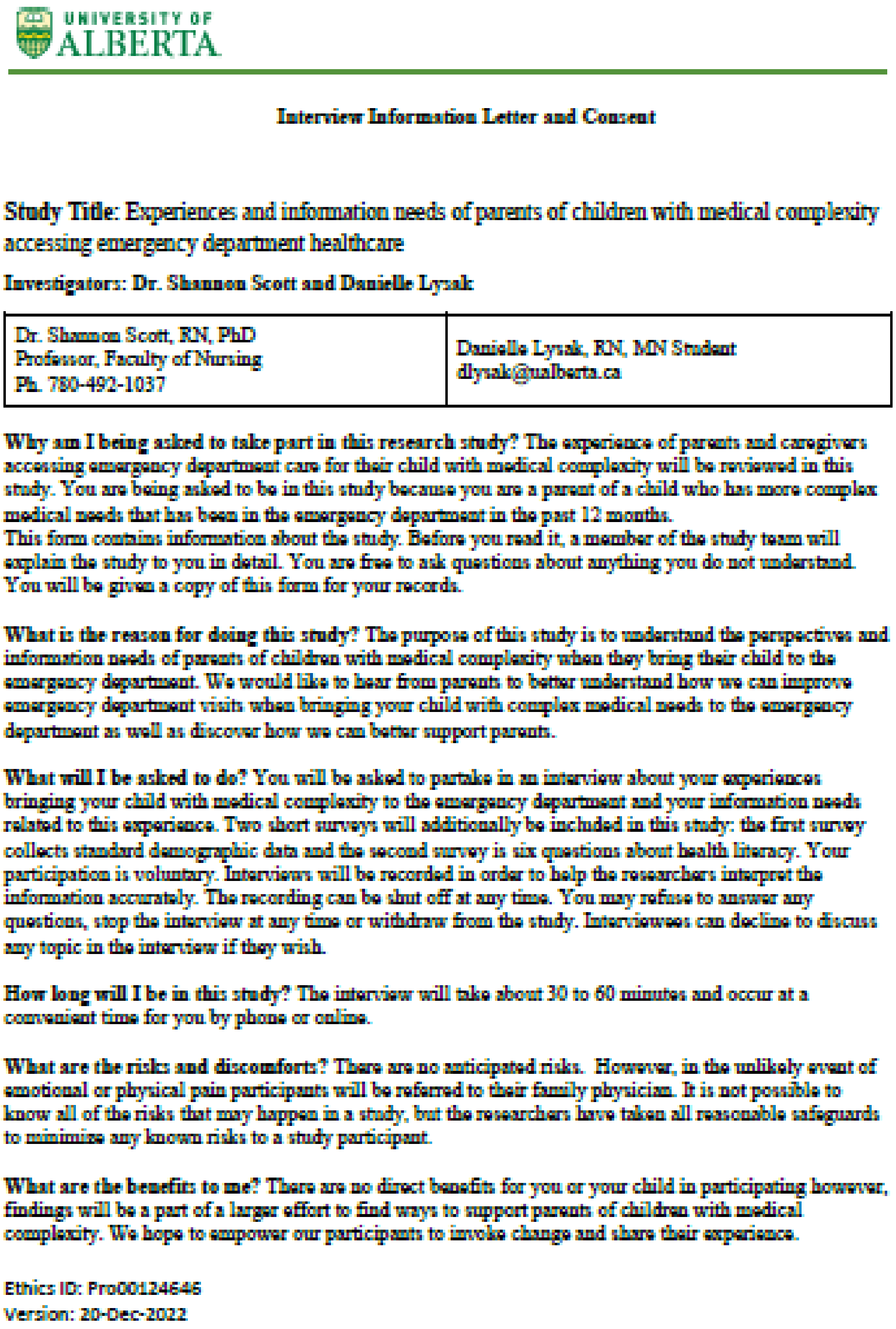
1. Tell me about your experiences of having a medically complex child?
2. When did you first realize/were told that your child is medically complex?
3. What information were you provided with regarding taking your child to the emergency room? What, if anything, was helpful about this information?
    a. When were you told this information?
    b. How were you told this information?
4. You mentioned seeking emergency department care ___ times in the last year, what is the most common reason you must seek emergency care for your CMC?
5. When was your last encounter at an emergency department (ED) seeking treatment for your child with medical complexity (CMC) and can you describe your experience?
    a. What was your experience in the waiting room and the length of time spent waiting?
    b. Can you describe your interactions with the first nurse you saw and registration? What about the first interaction with a doctor?
    c. What has been your experience with any required medical procedures such as blood tests, IVs, tests, treatments once you left the waiting room and entered a treatment room?
    d. Can you describe the process or delay in getting admitted?
    e. Length of stay?
6. What factors of an ED visit can improve or worsen the encounter for you and your child?
7. Are there any ways you and your child’s team work together to prevent emergency room visits?
8. Can you describe how you communicate pertinent information about [child] in the ED?

9. Today, do you feel you have enough information to get through an emergency visit for your child with medical complexity?
    a. If not, what would you like more information about?
10. Over time, has your preference for learning strategies changed? What ways do you prefer to learn about emergency department processes when regarding your CMC?
11. What would you identify as key information that parents of a CMC should know when going to the ED?
12. What was/has been the hardest part of accessing emergency care for a medically complex child? How has that changed over time?
    a. What is one thing they are doing well at in the emergency department?
13. What would you like emergency room staff to know about your experiences of caring for a child who is medically complex?
14. If you could change one thing about the current emergency department process, what would it be and why?

We are at the final stage of the interview and we will finish with a short demographic survey. This part of the interview is important because it gives a picture of who our parents are that we are interviewing. None of these answers will be tied to your identity and just like the rest of the interview will be anonymous. You are allowed to skip any question you would like and can stop at any time. Can we move ahead?

Appendix B

Interview Information Letter



UNIVERSITY OF ALBERTA

Interview Information Letter and Consent

Study Title: Experiences and information needs of parents of children with medical complexity accessing emergency department healthcare

Investigators: Dr. Shannon Scott and Danielle Lysak

Dr. Shannon Scott, RN, PhD Professor, Faculty of Nursing Ph. 780-492-1037	Danielle Lysak, RN, MN Student dlysak@ualberta.ca

Why am I being asked to take part in this research study? The experience of parents and caregivers accessing emergency department care for their child with medical complexity will be reviewed in this study. You are being asked to be in this study because you are a parent of a child who has more complex medical needs that has been in the emergency department in the past 12 months.
This form contains information about the study. Before you read it, a member of the study team will explain the study to you in detail. You are free to ask questions about anything you do not understand. You will be given a copy of this form for your records.

What is the reason for doing this study? The purpose of this study is to understand the perspectives and information needs of parents of children with medical complexity when they bring their child to the emergency department. We would like to hear from parents to better understand how we can improve emergency department visits when bringing your child with complex medical needs to the emergency department as well as discover how we can better support parents.

What will I be asked to do? You will be asked to partake in an interview about your experiences bringing your child with medical complexity to the emergency department and your information needs related to this experience. Two short surveys will additionally be included in this study: the first survey collects standard demographic data and the second survey is six questions about health literacy. Your participation is voluntary. Interviews will be recorded in order to help the researchers interpret the information accurately. The recording can be shut off at any time. You may refuse to answer any questions, stop the interview at any time or withdraw from the study. Interviewees can decline to discuss any topic in the interview if they wish.

How long will I be in this study? The interview will take about 30 to 60 minutes and occur at a convenient time for you by phone or online.

What are the risks and discomforts? There are no anticipated risks. However, in the unlikely event of emotional or physical pain participants will be referred to their family physician. It is not possible to know all of the risks that may happen in a study, but the researchers have taken all reasonable safeguards to minimize any known risks to a study participant.

What are the benefits to me? There are no direct benefits for you or your child in participating however, findings will be a part of a larger effort to find ways to support parents of children with medical complexity. We hope to empower our participants to invoke change and share their experience.

Ethics ID: Pro00124646
Version: 20-Dec-2022

Do I have to take part in this study? Being in this study is your choice. If you decide to be in this study, you can change your mind and stop being in the study at any time, and it will in no way affect the care or treatment you are entitled to.

Will I be paid to be in the research? To thank you for your time, you will receive a $25 electronic gift card after the interview. If you should choose to withdraw midway through the interview, you will still be eligible for this gift.

Will my information be kept private? All information will be held confidential (or private). The information that you provide will be kept in a secure, password protected local area network (LAN) only accessible to the study team for a minimum of five years. Your name or any other information identifying you will not be attached to the information you gave. Your name will also never be used in any presentations or publications of the study results. The data gathered from this study will be aggregated so as not to identify any person. Direct quotations may be used in the stories and/or publications; however the quotations will be presented in a manner that removes any identifiable information. Sometimes, by law, we may have to release your information with your name so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your information is kept private.

At the University of Alberta, we keep data stored for a minimum of 5 years after the end of the study. The information gathered for this study may be looked at again in the future to help us answer other study questions. If so, the ethics board will first review the study to ensure the information is used ethically. After the study is done, study data will be stored in the research team's secure local area network (LAN), to facilitate re-use of the data by approved researchers. Any personal information (i.e. your name, address, telephone number) that could identify you will be removed or changed prior to sharing study data with other researchers. Any researcher who wants to use this data must have the new project reviewed by an ethics board and sign an agreement ensuring your confidentiality and restricting data use only to the approved project. Your data may be linked with other data for research purposes only to increase the usefulness of the data, as subject to scientific and ethical oversight as mentioned above.

During research studies it is important that the data we get is accurate. For this reason, your data, including your name, may be looked at by people from the University of Alberta or the Health Research Ethics Board.

What if I have questions: If you have questions or concerns about this study at any time, you may contact: Dr. Shannon Scott, 780-492-1037 or shannon.scott@ualberta.ca. You may also contact the University of Alberta Research Ethics Office for questions regarding one's rights as a research participant. Ph: 780-492-2615. This office has no affiliation with the study investigators.

This study has been funded as part of Dr. Scott's Stollery Distinguished Researcher WCHRI grant.

How do I indicate my agreement to be in this study?

By signing below, you understand:

- That you have read the above information and have had anything that you do not understand explained to you to your satisfaction
- That you will be taking part in a research study
- That you may freely leave the research study at any time
- That you do not waive your legal rights by being in the study

- That the legal and professional obligations of the investigators and involved institutions are not changed by your taking part in this study.

SIGNATURE OF STUDY PARTICIPANT

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Name of Participant

____________________________ __________________

Signature of Participant **Date**

SIGNATURE OF PERSON OBTAINING CONSENT

____________________________ __________________

Name of Person Obtaining Consent **Contact Number**

SIGNATURE OF THE WITNESS

____

Name of Witness

____________________________ __________________

Signature of Witness **Date**

Appendix C

Consent Infographic

PARENTS OF CHILDREN WITH MEDICAL COMPLEXITY IN THE EMERGENCY DEPARTMENT STUDY

The purpose of this study is to understand experiences and information needs of parents/caregivers of children who have complex medical needs when accessing emergency department (ED) care. Understanding perspectives of parents can help us improve the care provided in the emergency department.

WHY AM I BEING ASKED TO TAKE PART IN THIS STUDY?

You are invited to take part in this study because you are a parent or caregiver of a child under 18 years old who has complex medical needs and has visited the emergency department in the last 12 months.

WHAT WILL I BE ASKED TO DO?

You will complete one, 30-60-minute interview by Zoom call or phone and this will include a short survey.

The interview will ask questions about your ED experience with your child and a short survey about health literacy.

1. The interview will show us where we can improve emergency care for children with medical complexity and their parents.
2. The health literacy survey will help healthcare professionals provide important medical information more clearly.

CAN I CHOOSE TO QUIT?

Yes. You may refuse to answer any questions, stop the interview or withdraw from the study at any time.

DO I HAVE TO TAKE PART?

No. Your participation is completely voluntary.

WILL I BE PAID TO BE IN THE RESEARCH?

Parents who choose to participate will be offered a $25 gift card.

WILL MY INFORMATION BE KEPT PRIVATE?

Interviews will be audio recorded and assigned a number. We will not use your name.

Your details will be kept confidential and will be stored in a secure, password protected computer at the University of Alberta for 5 years.

Results of the study will be presented, published and written in a summary format that does not describe any identifiable details of participants. Direct quotes may be used, but any identifying details will be removed.
Your name will not appear anywhere in the study.

Are there any benefits?

Participants may not experience any direct benefits. However, the interviews will help us learn how to improve care for families in the emergency department.

Are there any risks?

There are no anticipated risks. Participants may feel different emotions that may make them feel distressed discussing their experiences.

This study has been reviewed by a Research Ethics Board at the **University of Alberta (Pro00124646)**. If you have any questions regarding your rights as a research participant or how the research is being conducted, you may contact the Research Ethics Office at 780-492-2615

Questions? Contact Danielle Lysak at dlysak@ualberta.ca

Appendix D

Recruitment Poster

Has your child received care at the **Emergency Department** in the past 12 months?

DOES YOUR CHILD HAVE SPECIALIZED OR COMPLEX MEDICAL NEEDS?

We invite you to participate in a new research study at the University of Alberta!

WE WANT TO HEAR FROM YOU!

We are recruiting parents of children under 18 years old who have complex medical needs. We want to learn about their experiences in the emergency department within the last 12 months.

WHAT IS THIS RESEARCH ABOUT?

We want to learn about **parent needs and experiences** when they visit the **emergency department** for their **child with complex healthcare needs.**

WHAT IS MY ROLE?

Parents will be asked to meet virtually for a 30–60-minute Zoom call or phone call where they will complete an interview and short survey.

This study is being completed at
the University of Alberta
Pro00124646

Parents will be offered a $25 Gift Card for their participation

echo
translating evidence in child health
to enhance outcomes

UNIVERSITY OF
ALBERTA

For more information contact Danielle Lysak at dlysak@ualberta.ca