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Exploring Informational Needs of Parents of Children with Intestinal Failure: A Thematic Analysis

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Exploring Informational Needs of Parents of Children with Intestinal Failure: A Thematic
Analysis

by

Lily Anne Ragan

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES
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Abstract

Information seeking has been observed to be important for the coping and empowerment of parents of children with rare diseases. This study was conducted to better understand the education needs of families of children with pediatric intestinal failure (IF) and how technology might be effectively leveraged to address these needs. We hypothesized families would benefit from an electronic education platform encompassing the aspects of medical and management knowledge required by parents. A qualitative methodology using thematic analysis (Braun & Clarke, 2006) was utilized. Purposeful sampling was adopted to recruit 10 parents/caregivers of children with IF who then participated in a 1:1 semi-structured interview. Interviews were recorded, transcribed and themes identified through open and focused coding. Four qualitative themes emerged: (1) reliable electronic or printed information resources relevant to their child's unique needs are lacking; (2) educational program with in-person and hands-on learning is preferred for transition to home; (3) practical and relatable information was valued over medical knowledge as children's needs evolved; and (4) creation of electronic resources would be useful for information seeking and sharing. This study revealed that parents of children with IF have high informational and educational needs and sought information beyond what they received. Participants stressed the importance of their informational needs related to practical day-to-day management rather than medical knowledge. Although digital resources were considered valuable, a blended approach of care team discussions and electronic tools was preferred for receiving knowledge and skills. Parents' connections with other caregivers was also noted as important for practical day-to-day management information, as well as supporting their well-being. Gaining an understanding of parents' informational needs will assist in the creation of a digital education tool that is accessible, user-friendly, and emphasizes practical information.

Other practice implications include developing additional strategies to enhance parental coping and resiliency to reduce the stress associated with the uncertainty of their child's diagnosis.

Keywords: intestinal failure, parent information, information needs, electronic resources, qualitative research, thematic analysis

Preface

This thesis is a combination of chapters and a manuscript written to fulfill University of Calgary graduate studies thesis requirements. It includes an introduction to the research (Chapter 1), one manuscript submitted for publication (Chapter 2), as well as a concluding chapter (Chapter 3). The manuscript was developed by the first author, Lily A. Ragan, with guidance from her supervisor and supervisory committee members. All authors participated in the final manuscript review and provided intellectual contributions.

- Chapter 1 (Introduction): Overview of the study background, purpose, methodology, and significance, and contribution to research.
- Chapter 2 (Manuscript 1): Ragan, L. A., Duffett-Leger, L., Laing, C. M., & Boctor, D. L. (2020) Exploring informational needs of parents of children with intestinal failure: A thematic analysis. Prepared for submission. Target journal: *Journal of Pediatric Nursing*.
- Chapter 3 (Conclusion): Overall discussion of results, recommendations for the educational tool, and future topics of research in this population. It will also include implications for nursing policy, education practice, and research.

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Dedication

This study is dedicated to all the families and children who are impacted by Intestinal Failure.

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List of Abbreviations

CAC	Community Advisory Committee
CHIRP	Children’s Hospital Intestinal Rehabilitation Program
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CMC	Children with Medical Complexities
ICT	Information Communication Technology
IF	Intestinal Failure
PN	Parenteral Nutrition

Chapter 1: Introduction

This introductory chapter includes a summary of the background, objectives of this research, and current body of literature in the topic area. The following chapter contains the publishable manuscript. Finally, the concluding chapter provides a summary of the research findings, recommendations for the educational tool, and future topics of research in this population.

Background

Advancements in medical knowledge, technology, and treatment have given rise to a new subset of pediatric patients with chronic and complex conditions who require significant medical support (Opreescu et al., 2013; Peter et al., 2011). Patients with pediatric intestinal failure (IF) represent one of these emerging populations. Intestinal failure is defined as reduced functional gut mass resulting in a dependence on parenteral nutrition to meet fluid and nutritional needs for adequate growth and development (Dore et al., 2017; Duggan & Jaksic, 2017; Murray & Mahoney, 2012). Etiologies of IF can vary including surgical cause related to short bowel syndrome, gastrointestinal dysmotility, and other rare cases. Only 50 years ago, infants and children with diagnoses leading to IF did not survive (Murray & Mahoney, 2012). Improved treatment options with the advent and further development of parenteral nutrition (PN), advanced surgical procedures, and development of multidisciplinary programs have dramatically increased the survival of children affected by IF (Bines, 2009; Cohran et al., 2017; Dehmer et al., 2011).

The management of children with IF is complex and challenging for both families and healthcare professionals. This population of children have complex, multi-system diseases requiring the long-term use of medical devices including enterostomy tubes, indwelling central venous catheters, and ostomy appliances (Cohran et al., 2017; Murray & Mahoney, 2012; Nelson

et al., 2015). The goals of medical management are to optimize growth, stimulate intestinal adaptation, enhance nutritional intake, minimize hepatotoxicity and sepsis, and over time reduce dependency on parenteral nutrition and ultimately, when possible, to achieve enteral autonomy (Culkin et al., 2009; Dore et al., 2017; Duggan & Jaksic, 2017). However, intestinal adaptation takes time and resources. The progression of each child with IF is unique based on their anatomy, length, and quality of the intestinal bowel (Dore et al., 2017, Squires et al., 2012). Similar to children with rare genetic diseases, manifestations can present differently with every child (Oprescu, et al., 2013; Van den Bree, 2013) and in some cases IF may be irreversible. In many cases, pediatric IF is a lifelong disease with many stages of transition throughout the illness.

The cost to the medical system is substantial for this population as the medical charges for each child with IF is estimated to exceed \$500 000 US in the first year of life (Squires et al., 2012). Cost is a major contributing factor in the growing shift from acute care to community care, increasing expectations on families to provide ongoing medical care and support at home (Berry et al., 2011; Cohran et al., 2017). However, the volume and complexity of managing a child with IF at home can be overwhelming and requires advanced skills. Families caring for children with IF manage a list of complexities including stoma (ileostomy, jejunostomy, or colostomy) or fistula care, aseptic central venous access, infusion of PN, monitoring nutritional intake, and daily stoma/stool/urine outputs (Culkin et al., 2009; Murray & Mahoney, 2012). Families must also learn about an extensive list of potential complications including: IF associated liver disease, catheter-associated bloodstream infections, metabolic bone disease, dehydration, metabolic disturbances, small intestinal bacterial overgrowth, D-lactic acidosis, cholelithiasis, and nephrolithiasis (Cohran et al., 2017; Duggan & Jaksic, 2017; Fullerton et al.,

2017). Treatment complications often result in high rates of hospital readmissions related to their chronic conditions (Anderson et al., 2013), specialized care needs (Culkin et al., 2009; Visschers, et al., 2011), and medical technology use (Drews et al., 2017).

Parents of children with chronic complex conditions may become overburdened with the demands of their children's care and increased parental stress may lead to decreased medical compliance and poor patient outcomes (Edelstein et al., 2017). As a result, families often experience a variety of stressors such as social isolation, financial difficulty, increased anxiety, and marital problems (Dehmer et al., 2011; Edelstein et al., 2016; Zamvar et.al, 2014).

Central to family and patient empowerment, education has been shown to decrease parental anxiety and increase patient outcomes (D'Alessandro & Dosa, 2001; Woodgate et al., 2015). However patient education resources for complex or rare diseases are insufficient as there is little evidence-based literature regarding management options (Hummelinck & Pollock, 2006; Pelentsov et al., 2015; Spring, 2014; Van den Bree, 2013). In the field of pediatric IF, limited evidence prevails for many treatments and clinical factors related to enteral autonomy due to heterogeneity of the disease, varying cases of severity, and low prevalence rates (Duggan & Jaksic, 2017). Additionally, the information needs of parents with children with chronic illnesses may change over time as they become experts in their child's day-to-day management (Hummelinck & Pollock, 2006). With unmet informational needs, families increasingly seek out other sources of information, such as the Internet, to fill gaps in knowledge; however, parents often become frustrated by the lack of reliable and trustworthy informational resources (Dol et al., 2017; Lewis et al., 2005).

Statement of the Problem

While evidence suggests that multidisciplinary intestinal rehabilitation programs improve the management of pediatric IF (Bines, 2009; Culkin et al; 2009; Merritt et al., 2017, Squires et al; 2012), limited knowledge exists on which types of educational methods delivered by the team would be most effective in meeting the informational needs of parents. Thus, an opportunity exists for researches and healthcare providers to design reliable Internet-based interventions to address this gap (Lewis et al, 2005; Nicholl et al., 2017; Powell et al., 2011). Given the unique and evolving needs of IF children, a better understanding of informational needs of caregivers would help healthcare professionals provide families with optimal tailored educational support. To our knowledge, no other research to date has qualitatively explored the informational needs of parents with IF. A qualitative examination may offer important insights about the evolving informational needs of parents during the stages of their children's illness, and how technologies such as the Internet could be leveraged to help bridge gaps in their educational needs.

Purpose of the Study

This study was designed to address this gap and help inform the future development of educational tools to better equip healthcare providers support families in the ongoing care and management of children with IF. Specifically, focus of this research aimed to answer the following questions:

1. What are the informational needs of parents/ caregivers of children with IF during: (a) initial diagnosis and hospitalization; (b) preparation to go home; (c) throughout their ongoing care and management thereafter?
2. How can the use of technology be effective in supporting and meeting the informational needs of families of children with IF?

Theoretical Foundations

A qualitative methodology was utilized to examine the research questions. Qualitative research is grounded in the inquiry and interpretation of human experience (Streubert & Carpenter, 2011). Thematic analysis was the chosen method as it seeks to describe repeated patterns across qualitative data that is under-researched (Braun & Clarke, 2006). Influenced by an essentialist/ realist epistemology, analysis was data-driven and used an inductive and semantic approach to uncover the truth or essence of the identified themes (Braun & Clarke, 2006). Inductive thematic analysis method as described by Braun and Clarke (2006) is used for identifying, describing, organizing, analyzing, and reporting rich, complex, and detailed accounts of data. This method has been compared to other qualitative methods such as grounded theory or interpretative phenomenological analysis, however thematic analysis provides more flexibility with data analysis as it is not linked to a particular theoretical framework (Braun & Clarke 2006). Thematic analysis was deemed the most appropriate approach in investigating the proposed research questions as the focus was to uncover themes related to the meanings and experiences of parents caring for children with IF and how they influence their informational needs, rather than generating a theory of the phenomenon.

Community-based research methods were also used in this study. A Community Advisory Committee (CAC), consisting of stakeholders from both inpatient and outpatient care areas (patient care managers, pediatric gastroenterologist, and the Alberta Children's Hospital Intestinal Rehabilitation Program (CHIRP) clinic team), was established to help guide the research. Partnership with the CAC helped to identify possible participants as purposeful sampling was used to identify and select participants for the study. Identified parents or caregivers were approached by a clinic nurse (not affiliated with this study) at an appointment

and given a poster (Appendix A) introducing the study. If they voiced interest, potential participants were then contacted by the first author for consent (see Appendix B). Participants were deliberately selected to acquire a varied representation from families at different years and stages of living with pediatric IF. This ensured a sample of participants with diverse perspectives and backgrounds to gain rich and in-depth data (Polit & Beck, 2017). CAC members identified were also given the opportunity to review and provide feedback on the protocol and research methods.

Semi-structured interviews were used to collect study data. Interviews were completed over the phone with the participants and were audio-recorded, ranging in length from 45 minutes to 80 minutes. Demographic characteristics of participants and children of participants were collected using a researcher-designed survey (Appendix C). Questions for the interview guide (Appendix D) were informed by study aims, current literature, and developed in discussion with the local intestinal rehabilitation clinic team to ensure face validity. The interview guide consisted of open-ended questions to elicit genuine participant responses and was divided into two sections: experiences with IF while admitted in the hospital and experiences with IF after discharge home. Interview questions were refined with sequential participant interviews as emerging concepts and themes unfolded.

Data analysis occurred simultaneously with data collection and followed the six-phase guide to performing thematic analysis outlined by Braun and Clarke (2006). Phases included: (a) familiarizing yourself with your data; (b) generating initial codes; (c) searching for themes; (d) reviewing themes; (e) defining and naming themes; (f) producing the report (Braun & Clarke, 2006). This process was integral to engaging, identifying, coding, and reporting themes reflective of the entire data set. Phases were conducted as followed:

1. Phase one: transcripts were read repeatedly to ensure familiarization with the entire data set. Initial thoughts and ideas were written down through memo-writing or field notes after each participant session; the act of reflexivity is encouraged to document gained insights, build codes, and record personal accounts of the researcher's own values in the process of discovery (Nowell et al., 2017).
2. Phase two: line-by-line coding was completed by hand to generate initial codes based on specific interest, characteristics, and frequency. Relevant codes were grouped together and compiled into meaningful statements.
3. Phase three: code extracts were inductively explored with local experts and clinical staff caring for this population of children to develop preliminary themes.
4. Phase four: potential themes were reviewed and refined for fit and emerging patterns. Evolving themes were generated, reworked, evaluated and discarded based on their appropriateness in relation to the research aims (Braun & Clarke, 2006).
5. Phase five: themes were named and defined with a detailed analysis and corresponding code extracts.
6. Phase six: validity of themes was evaluated. Identified themes and descriptions were confirmed and discussed with my supervisor Dr. Linda Duffett-Leger and then further reviewed and verified with members of the CAC.

Rigor

Establishing trustworthiness is a way to enhance rigor and acceptability of qualitative inquiry (Nowell et al., 2017; Polit & Beck, 2017). Lincoln and Guba (1985) suggested a framework for developing trustworthiness through criteria of credibility, dependability, confirmability, and transferability (Connelly, 2016; Nowell et al., 2017; Polit & Beck, 2017).

Formal and informal methods of reflexivity such as memo writing and member checking with local experts and clinicians was utilized to enhance the credibility and dependability of the study. Data collection and analysis was completed using a systematic and consistent approach. An audit trail that included reflexive memos and notes was utilized to document decisions, rationales, and personal insights with interviews, transcriptions, coding sessions, and discussions with my supervisor and members of the CAC. This process allowed for peer debriefing and helped examine evolving thoughts and ideas. Transferability and confirmability were addressed by presenting research findings to other pediatric intestinal rehabilitation programs in western Canada in June 2020. Research findings were also presented in a poster presentation at the 11th International Pediatric Intestinal Failure and Rehabilitation Symposium in June 2020.

Significance

To our knowledge, no previous study has investigated the informational needs of families in this patient population. With improved survival rates of patients with pediatric IF, it is imperative that healthcare teams have appropriate and available resources to help guide and support the caregivers to provide safe and effective care in the home and community settings. Despite evidence indicating the Internet is a main source for parents to seek out medical health information (Brazy et al., 2001; Nicholl et al., 2017), information about IF care is provided to families by the CHIRP team in person and through printed materials such as pamphlets and booklets. Increasingly, it has been demonstrated that there is an opportunity for healthcare providers to design reliable Internet-based interventions to meet the informational needs of parents (Lewis et al, 2005; Nicholl et al., 2017; Powell et al., 2011). Currently, the CHIRP team is interested in developing an online educational tool to better help support families in their ongoing care and management. The outcomes from this study may provide a better

understanding of what and when information is needed, and how an online educational tool may help support parents/ caregivers to obtain information during the different stages of their child's illness.

Review of Literature

Searches were conducted using the electronic databases Cumulative Index to Nursing and Allied Health Literature (CINAHL), MEDLINE (Ovid), as well as the search engine Google Scholar for literature related to intestinal failure, parental information needs, and online or Internet education. A combination of keywords was used to search each of the terms. Initial searches revealed no articles. The search was expanded to include children with medical complexity and children with rare or orphan diseases as there are overlap in characteristics between groups and needs of parents. Key words included: *Medically complexity, complex child, chronic illness, medically fragile, child with rare disease, and child with orphan disease*. Abstracts were reviewed, and relevant articles selected. Articles were also hand selected through reference lists of relevant articles. Finally, in addition to the database search, a literature search was conducted with the aid of Dr. Alix Hayden, nursing librarian at the University of Calgary. Inclusion criteria used to select relevant articles included a sample of parents or caregivers who care for children with IF, complex medical needs, rare diseases, premature infants, and chronic disabilities. Exclusion criteria included educational programs on parenting or programs that did not explicitly address care needs of the same population of children listed in the inclusion criteria. All relevant articles were included in the literature review. Reviewed articles were limited to peer-reviewed and English language. As there were a limited number of articles generated, no limitations on dates were applied.

Intestinal Failure Complexity

Intestinal Failure (IF) is considered a rare disease (Duggan & Jaksic, 2017; Visschers et al., 2011) presenting with similar challenges as children with medical complexities. In children, the etiology can be congenital or acquired postnatally through other conditions such as necrotizing enterocolitis, or motility disorders (Bines, 2009; Dehmer et al., 2011). This population of children often present with complex, multi-system diseases that are often dependent on the use of long term medical technology including enterostomy tubes and indwelling central venous catheters (Cohran et al., 2017; Murray & Mahoney, 2012; Nelson et al., 2016). Families caring for children with IF manage a list of complexities related to stoma (ileostomy, jejunostomy, or colostomy) or fistula care, maintaining aseptic management of a central venous line, daily infusions of parenteral nutrition, documentation of nutritional intake, and stoma/stool/urine outputs (Culkin et al., 2009; Murray & Mahoney, 2012).

There is an expectation for families to learn about an extensive list of potential complications from the diagnosis and treatments. Patients can develop IF associated liver disease, catheter-associated bloodstream infections, metabolic bone disease, dehydration, metabolic disturbances, and cholelithiasis (Cohran et al., 2017; Duggan & Jaksic, 2017; Fullerton et al., 2017). Treatment complications often result in higher rates of hospital readmissions related to their chronic conditions (Anderson et al., 2013), specialized care needs (Culkin et al., 2009; Visschers, et al., 2011), and medical technology use (Drews et al., 2017). Parents of children with chronic complex conditions may become overburdened with the demands of their children's care and increased parental stress may lead to decreased medical compliance and poor patient outcomes (Edelstein et al., 2017). Despite the fact children with IF represent a small portion of the pediatric population, the average estimated cost of care to the health care system is

approximated \$300,000 per patient per year for treatments and care related to home parenteral nutritional needs (Kosar et al., 2016).

Identifying Information Needs

The goal of medical management of IF is to optimize growth and minimize complications. This involves stimulating intestinal adaptation, enhancing nutritional intake, and minimizing hepatotoxicity and sepsis to possibly reduce dependency on parenteral nutrition and achieve enteral autonomy (Culkin et al., 2009; Dore et al., 2017; Duggan & Jaksic, 2017).

However, intestinal adaptation takes time, and the progression of each child with IF may be different depending on their anatomy, and the length and quality of the intestinal bowel (Dore et al., 2017). Similar to children with rare genetic diseases, manifestations can present differently with every child (Oprescu, et al., 2013; Van den Bree, 2013) and in some cases IF may be irreversible. Treatment options are challenging as enteral tolerance may fluctuate over time and requires individual tailoring. Given the unique and evolving needs of IF children, identifying and meeting the informational needs for impacted families is challenging.

Researchers studying patient education for complex or rare diseases, found healthcare providers lacked sufficient resources to provide adequate information as there is little evidence-based literature regarding management options (Hummelinck & Pollock, 2006; Pelentsov et al., 2015; Spring, 2014; Van den Bree, 2013). Healthcare providers have limited evidence for many treatments and clinical factors related to achieving enteral autonomy; issues include lack of consensus related to the definition of the disease due to heterogeneity, varying cases of severity, and low prevalence of pediatric IF (Duggan & Jaksic, 2017). Only recently has the first textbook on pediatric IF been developed and published for healthcare professionals (Duggan et al., 2011). Ambiguous and non-specific information provided by healthcare providers have been deemed

inadequate by many parents, forcing them to seek out alternative sources of information and education, in an effort to gain control and independently troubleshoot management of their children's illness (Brazy et al., 2001; De Rouck & Leys, 2012; Jachimiec et al., 2015; Opreescu, et al., 2013; Pain, 1999).

This behaviour of information seeking has also been identified as important for parents of children in the neonatal intensive care unit (De Rouck & Leys, 2012), and with chronic conditions (Hummelinck & Pollock, 2006). De Rock and Leys (2012) observed that parents sought information at the event of the diagnosis, before visiting a care provider, before or after introduction of a medical treatment, and with any new symptoms. Similarly, Pain (1999) found that the informational needs of parents of children with disabilities were motivated by their desires to: (a) facilitate decision-making regarding illness management; (b) better cope with caregiver stress; and (c) access benefits and services.

Information helps families in the process of coping with their child's health condition through increasing confidence and a sense of empowerment (D'Alessandro & Dosa, 2001; Pelentsov et al., 2015; Spring, 2014). Accessing information about their child's condition, prognosis, and potential complications enables parents to feel involved in the management of their child's care and help them prepare for the future (Hummelinck & Pollock, 2006; Jachimiec et al., 201; Pelentsov et al., 2015). Parents of children with IF experience similar challenges as parents with other pediatric chronic and complex conditions, and the evidence suggests that their informational needs may also be similar. Future research is needed to explore the unique information needs of parents impacted by pediatric IF and how best to support them in meeting those needs, potentially through the use of technology.

Timing of Information

Informational needs of parents of children with complex chronic illnesses vary greatly over the course of their children's illness trajectory (De Rouck & Leys, 2012; Hummelinck & Pollock, 2006). During the early and acute stages, many parents experience difficulty processing information provided to them about their children's condition. Not only may the diagnosis overwhelm parents, they are given large amounts of medical information leading to poor understanding and retention (Hummelinck & Pollock, 2006; Van den Bree et al., 2013). Rogers et al., (2016) reported that many families faced a large learning curve within the first month of their children's diagnosis. However, if information is not made available to parents, they can experience increased stress and anxiety trying to interpret, understand, and cope with the challenges of their children's condition (Van den Bree et al., 2013). In a systematic review of parent education programs for special health care needs of children, researchers found that early intervention and timely information was important for positive parent-child relationships throughout treatment and into the future (Jackson et al., 2016).

Over time, parents develop an increased level of confidence regarding their child's condition and day-to-day management (Hummelinck & Pollock, 2006). As such, the nature of their informational needs change as they become expert partners in the medical decision-making process of their child (Powell et al., 2011). This was also observed among parents with children in the neonatal care unit as information and communication needs changed during the hospital stay compared to after discharge (De Rouck & Leys, 2012). Initially, parents of children with complex healthcare needs reported being reluctant to perform technical nursing type care management, yet when faced with chronic illness parents were willing to learn these skills and continue necessary care (Coyne & Cowley, 2007). While there is growing evidence that

education and partnership with families is important for management of pediatric chronic illness (Coyne & Cowley, 2007; Harrison, 2010), there is a deficit of research in how best to support ongoing care needs of families of children with IF. Although a gap exists in the literature related to specific timing of delivery of information, it is important for healthcare professionals to consider the timing of educational programs for families to facilitate their transition to home. Timing and amount of information provided may need to be tailored for each family to ensure it is effective and appropriate. Future research is needed to demonstrate the impact of timing on learning and retention of skills required for parents to care for their children with IF at the time of diagnosis, preparation for discharge, and transition home.

Education and Information Methods

There is evidence to suggest that multidisciplinary intestinal rehabilitation programs improve the management of pediatric IF (Bines, 2009; Culkin et al; 2009; Merritt et al., 2017). However, limited evidence exists on which types of educational methods delivered by the multidisciplinary team would be most effective in meeting the informational needs of parents. Two education programs have demonstrated improved IF patient outcomes. Drews et al. (2017) developed a program for parents and caregivers related to central line teaching, which included a didactic class component delivered by a program nurse educator, a take home DVD video, and hands on practice with a simulated manikin. Following implementation of this program with 80 families, catheter related infection days significantly decreased from 4.8 to 2.9 per 1,000 catheter days among IF patients (Drews et al., 2017). Culkin et al. (2009) provided adults with chronic IF individualized advice along with an information booklet on topics related to IF such as physiology and demonstrated significant improvements in patient knowledge and clinical outcomes, optimal nutritional intake, and appropriate use of medications (Culkin et al., 2009).

Although the educational methods and tools were not validated, both researchers demonstrated that using varying methods of education delivery may have an impact on patient health outcomes, such as decreased infection rates and increased enteral autonomy.

Despite the widespread dissemination of medical informational materials in recent years, patients and families have reported dissatisfaction about the quality and consistency of information provided to them by healthcare professionals (Hummelinck & Pollock, 2006; Van den Bree et al., 2013). Traditionally, information was acquired solely through consultation with healthcare professionals. More recently, however, parents and caregivers are increasingly looking to other methods of information delivery, such as the Internet, to meet their informational needs (Nicholl et al., 2017; Oprescu et al., 2013; Powell et al., 2011; Van den Bree et al., 2013). The Internet is recognized as a significant source of information for families of complex patients, to help clarify information they received from healthcare providers, or confirm a diagnosis (D'Alessandro & Dosa, 2001; Nicholl et al., 2017; Oprescu et al., 2013). This is supported by previous research which found that majority of parents used the Internet 44% of the time compared to other sources such as clinicians (28%), personal contacts (20%) and printed materials (7%) (Van de Bree et al., 2013).

While there is an increase usage with the Internet for information seeking, the quality of information can be questionable and parents continue to value interactions with a clinical professional (Jak et al., 2019; Van de Bree et al., 2013). Healthcare professionals represent a preferred and trusted source of medical information (Oprescu et al., 2013; Pain, 1999). While convenient, information on the Internet is often unregulated and may be inaccurate, making it difficult for parents to evaluate the quality and relevance of the information (D'Alessandro & Dosa, 2001; Nicholl et al, 2017). In a systematic review on eHealth interventions for parents in

neonatal intensive care, Dol et al. (2017) reported that 84% of parents found information on the Internet harder to understand than information provided by clinicians. Moreover, 73% of parents reported that the information they found online was inadequate (Dol et al., 2017). To date, there are no studies related to web-based education resources for the pediatric IF population.

Additional research is needed to determine optimal information delivery methods to address the learning and informational needs of parents caring for their children with IF.

Summary of the Literature

The management of children with chronic IF is complex and challenging for families who are expected to maintain ongoing care and management of their child at home. There is little evidence available on the informational and educational needs of parents and the methods of delivery to best support their learning and development of nursing type skills required to care for their children with IF. The literature suggests that information is important to help parents cope, develop confidence, and manage the uncertainty of their child's illness. While limited, research provides evidence that timing and education of parents using different forms of information delivery such as didactic teaching, booklets, and the Internet, may lead to improved parental understanding and patient outcomes. The Internet has been recognized as an important source of information from parents, yet in many situations does not meet their needs and is unreliable. Additional research is required to better understand how the use of technology can be used for effective educational delivery for parents of children with IF, providing trustworthy and accessible sources to meet their informational needs.

Structure of the Thesis

This thesis is a hybrid of stand-alone chapters (Chapter 1 and 3) and a manuscript (Chapter 2). Chapter 1 provides an introduction to background information, statement of problem

and thesis overview. Chapter 2 (Manuscript) presents the research project and has been submitted for publication. Finally, Chapter 3, the concluding chapter, provides a discussion of overall research results and implications for nursing policy, education, practice, and research. References for all chapters appear at the end of the thesis.

The manuscript provided in Chapter 2 has been submitted and is currently under review for publication in the Journal of Pediatric Nursing. It was prepared according to the guidelines provided by the Journal, and thus, had different referencing and in-text citation styles. To ensure consistency of this thesis, the manuscript was converted into APA 7th edition style. Permissions for the published manuscript are included in Appendix D.

Manuscript One - Exploring Informational Needs of Parents of Children with Intestinal Failure: A Thematic Analysis

This manuscript describes the main findings from interviews conducted with families caring for children with IF, and more specifically, exploring their informational and educational needs during their children's initial hospital admission as well as their transition home. Due to the rarity and complexities experienced in this patient population, the management of children with IF is challenging and intensive; however, to date, there are no evidence-based resources to guide healthcare professionals with supporting informational and educational needs of these families. The goal of this research was to gain a better understanding of the topics of information needed by families, as well as assess if online technology might be effectively leveraged to address these needs. Findings revealed that families indicated reliable information relevant to their child's unique needs were lacking. Although an electronic resource was desired for seeking information, participants preferred a blended approach of in-person discussion and technology for receiving knowledge and learning skills. As their child matured, practical and relatable

information was also valued over medical knowledge. These findings suggest that creation of an education tool with a user-friendly, flexible design, and emphasis on practical information is required. Addressing parental emotional well-being with day-to-day management was also highlighted as an additional gap in the care and management in this patient population. Enhancing social supports such as increased family connections, access to psychological resources, and sharing current research was considered valuable. More research is needed to explore and address this gap.

Dissemination

Dissemination of research is important for the application and utilization of knowledge gained to improve health outcomes and strengthen health care systems. Dissemination to other researchers, policymakers, and healthcare professionals will lead to an increased awareness of the research topic while maximizing the impact of the results by reducing the research to practice gap. It will also facilitate evidence-based uptake in decision-making processes and clinical practice, thus improving the health outcomes of the target population. To disseminate the research findings to a wider audience, I have presented the research in several local, national, and international meetings and conferences, as well as submitted the manuscript for publication. The potential impacts of these dissemination efforts are outlined as follows:

1. Published manuscript - Ragan, L. A., Duffett-Leger, L., Laing, C. M., & Boctor, D. L. (submitted) Exploring information needs of parents of children with intestinal failure: A thematic analysis. *Journal of Pediatric Nursing*. A publication in a scholarly journal will facilitate widespread uptake and dissemination of research findings to other researchers and clinicians not only in the field of IF but also who are involved with families impacted by medically complexity and rare diseases in the pediatric population. Families of

children with CMCs or rare diseases face similar informational gaps and challenges, and these research results could give healthcare professionals insight and guidance on ways to address them. This could also facilitate collaboration to create innovative educational tools that may be shared between similar patient populations.

2. Local presentation to the Alberta CHIRP team: This research was initiated through collaboration with the local CHIRP team who was interested in developing an online educational tool to better help support families in their ongoing care and management. Research findings are directly transferable to this group as participants were recruited from this program. Research findings disseminated to this team may impact and potentially guide decisions made on content and development of an online educational tool for their patients and families. It has the potential to inform and create sustainable practice changes supported by evidence-based research, leading to improved health outcomes.
3. Poster presentation at the International Pediatric Intestinal Failure and Rehabilitation Symposium (June 2020): The conference aim was to provide the latest advances in all aspects of pediatric medical and surgical IF care to healthcare professionals including pediatric gastroenterologists, surgeons, hepatologists, scientists, and allied health professionals, who have dedicated themselves to the care of children with IF. The theme of the conference was “Breaking the Boundaries of Pediatric Intestinal Rehabilitation and Transplantation.” Initially the abstract submitted was selected for an oral presentation, however due to the current pandemic, the format of the symposium was changed to a Virtual Town Hall session. The abstract was then changed to be presented as a poster presentation and was awarded “Poster of Distinction” based on the high scientific value.

Presenting at this conference facilitated widespread uptake of the research findings to expert clinicians working with this patient population. As there are currently no published comprehensive educational resources for families with infants and children with IF, the research findings give insight into the importance of addressing this gap to improve care provided to this patient population. Awareness of this topic may also create increased collaboration between centers to share online informational and educational resources developed for patients and families, avoiding any potential duplication of work.

4. Presentation at the Annual Meeting of Pediatric Intestinal Rehabilitation Programs in Western Canada (Edmonton, Vancouver, and Winnipeg): This group is an established community of networks across Canada that currently have pediatric multidisciplinary intestinal rehabilitation programs. Development of a tool that will be useful across the spectrum of IF is a large undertaking, thus dissemination of research findings to this group may increase partnership and engagement to develop a comprehensive educational tool for all families across Canada. Coordinating knowledge and education with other centers could also increase the standardization of resources, education, and clinical practice, thus improving the care provided between provinces. Collaboration on an online resource could also increase innovation, avoid duplication of work, and decrease costs associated with technology creation and use.

Conclusion

Education and information are important nursing strategies to improve patient care (Oprescu, et al., 2013). Currently, no evidence-based practices are available to guide the effective delivery of education and information to families and patients impacted by IF. In pediatric complex and chronic illness, families frequently seek information to cope, gain

confidence, and increase knowledge before visiting a care provider (D'Alessandro & Dosa, 2001; De Rouck & Leys, 2012; Pain, 1999). If their informational needs are unmet, families look to other sources of information such as the Internet that are easily accessible but often unreliable. Incorporating a combination of educational delivery methods in this population has shown to improve patient outcomes (Culkin et al; 2009; Drews et al., 2017); however, further research is required to identify innovative and advanced ways of using technology to provide ongoing education to better meet parent/ caregiver informational needs. Research has demonstrated that there is an opportunity for healthcare providers to design reliable Internet-based interventions to meet the informational needs of parents (Nicholl et al., 2017; Powell et al., 2011). Development of high-quality and trustworthy websites may give parents better access to more accurate and individualized information, positively impacting their capacity to manage the care of their child.

**Chapter 2: Exploring Informational Needs of Parents of Children with Intestinal Failure:
A Thematic Analysis**

Ragan, L. A., Duffett-Leger, L., Laing, C. M., & Boctor, D. L. (2020) Exploring informational needs of parents of children with intestinal failure: A thematic analysis. Prepared for submission. Target journal: *Journal of Pediatric Nursing*.

Abstract

Purpose: Information seeking has been observed to be important for the coping and empowerment of parents of children with rare diseases. This study was conducted to better understand the education needs of families of children with pediatric intestinal failure (IF) and how technology might be effectively leveraged to address these needs.

Design and methods: A qualitative methodology using thematic analysis was utilized. Purposeful sampling was adopted to recruit 10 parents/caregivers of children with IF. Participants participated in a 1:1 semi-structured interview. Interviews were recorded, transcribed and themes identified through open and focused coding.

Results: Four themes emerged: (1) reliable electronic or printed information resources relevant to their child's unique needs are lacking; (2) educational program with in-person and hands-on learning is preferred for transition to home; (3) practical and relatable information was valued over medical knowledge as children's needs evolved; and (4) creation of electronic resources would be useful for information seeking and sharing.

Conclusion: To cope with the responsibilities of caring for a child with IF, participants sought information beyond what they received. Participants preferred a blended approach of care team discussions and electronic tools for receiving knowledge and skills. Parents' connections with other caregivers was important for practical day-to-day management information, as well as supporting their well-being.

Practice Implications: Creation of educational tools with a user-friendly, flexible design, and emphasis on practical information is required. Enhancing social supports such as increased family connections, access to psychological resources, and sharing current research is also considered valuable.

Keywords: intestinal failure, parent information, information needs, electronic resources, qualitative research, thematic analysis

Exploring Informational Needs of Parents of Children with Intestinal Failure: A Thematic Analysis

Advancements in medical knowledge, technology, and treatment have given rise to a new subset of pediatric patients with chronic and complex conditions who require significant medical support (Oprescu et al., 2013; Peter et al., 2011). Patients with pediatric intestinal failure (IF) represent one of these emerging populations. Intestinal failure is defined as reduced functional gut mass resulting in a dependence on parenteral nutrition to meet fluid and nutritional needs for adequate growth and development (Dore et al., 2017; Duggan & Jaksic, 2017; Murray & Mahoney, 2012). Etiologies of IF include surgical causes of short bowel syndrome, gastrointestinal dysmotility, and other rare cases. Only 50 years ago, infants and children with diagnoses leading to IF did not survive (Murray & Mahoney, 2012). Improved treatment options with the advent and further development of parenteral nutrition (PN), advanced surgical procedures, and development of multidisciplinary programs have dramatically increased the survival of children affected by IF (Bines, 2009; Cohran et al., 2017; Dehmer et al., 2011).

The management of children with IF is complex and challenging for both families and healthcare professionals. This population of children have complex, multi-system diseases requiring the long-term use of medical devices including enterostomy tubes, indwelling central venous catheters, and ostomy appliances (Cohran et al., 2017; Murray & Mahoney, 2012; Nelson et al., 2015). The goals of medical management are to optimize growth, stimulate intestinal adaptation, enhance nutritional intake, minimize hepatotoxicity and sepsis, and over time reduce dependency on parenteral nutrition and ultimately, when possible, to achieve enteral autonomy (Culkin et al., 2009; Dore et al., 2017; Duggan & Jaksic, 2017). However, intestinal adaptation takes time and resources. The progression of each child with IF is unique based on their

anatomy, length, and quality of the intestinal bowel (Dore et al., 2017, Squires et al., 2012). Similar to children with rare genetic diseases, manifestations can present differently with every child (Oprescu, et al., 2013; Van den Bree, 2013) and in some cases IF may be irreversible. In many cases, pediatric IF is a lifelong disease with many stages of transition throughout the illness.

The volume of work and complexity of managing a child with IF at home can be overwhelming and requires advanced skills. The complex home management of children with IF may include stoma (ileostomy, jejunostomy, or colostomy) or fistula care, aseptic central venous access, infusion of PN, monitoring nutritional intake, and daily stoma/stool/urine outputs (Culkin et al., 2009; Murray & Mahoney, 2012). Families must also learn about an extensive list of potential complications including: IF associated liver disease, catheter-associated bloodstream infections, metabolic bone disease, dehydration, metabolic disturbances, small intestinal bacterial overgrowth, D-lactic acidosis, cholelithiasis, and nephrolithiasis (Cohran et al., 2017; Duggan & Jaksic, 2017; Fullerton et al., 2017). Treatment complications often result in high rates of hospital readmissions related to their chronic conditions (Anderson et al., 2013), specialized care needs (Culkin et al., 2009; Visschers, et al., 2011), and medical technology use (Drews et al., 2017).

Parents of children with chronic complex conditions may become overburdened with the demands of their child's care and increased parental stress may lead to decreased medical compliance and poor patient outcomes (Edelstein et al., 2017). As a result, families often experience a variety of stressors such as social isolation, financial difficulty, increased anxiety, and marital problems (Dehmer et al., 2011; Edelstein et al., 2016; Zamvar et.al, 2014).

Central to family and patient empowerment, education has been shown to decrease parental anxiety and increase patient outcomes (D'Alessandro & Dosa, 2001; Woodgate et al., 2015). However patient education resources for complex or rare diseases are insufficient as there is little evidence-based literature regarding management options (Hummelinck & Pollock, 2006; Pelentsov et al., 2015; Spring, 2014; Van den Bree, 2013). In the field of pediatric IF, there is limited evidence for many of the treatments and clinical factors related to enteral autonomy due to heterogeneity of the disease, varying cases of severity, and low prevalence rates (Duggan & Jaksic, 2017). Furthermore, the information needs of parents with children with chronic illnesses may change over time as they become experts in their child's day-to-day management (Hummelinck & Pollock, 2006). With unmet information needs, families increasingly seek out other sources of information, such as the Internet, to fill gaps in knowledge. However, parents often become frustrated by the lack of reliable and trustworthy information resources (Benedicta et al., 2019; Dol et al., 2017).

Evidence suggests that multidisciplinary intestinal rehabilitation programs improve the management of pediatric IF (Bines, 2009; Culkin et al; 2009; Merritt et al., 2017, Squires et al; 2012). However, it is not known which educational methods delivered by the team would be most effective in meeting the informational needs of parents. Thus, an opportunity exists for researchers and healthcare providers to design reliable Internet-based resources to address this gap (Nicholl et al., 2017; Powell et al., 2011). Given the unique and evolving needs of IF children, a better understanding of informational needs of caregivers would help healthcare professionals provide families with optimal educational support. To our knowledge, no research to date has qualitatively explored the informational needs of parents with IF. A qualitative examination may offer important insights about the evolving informational needs of parents

during the stages of their child's illness, and how technologies such as the Internet could be leveraged to help bridge gaps in their education needs.

Aims

This study was designed to address the information and education needs of parents caring for their children with IF to help inform the future development of online tools to better enable healthcare providers to support families in the ongoing care and management. Specifically, the focus of this research aimed to answer the following questions:

3. What are the informational needs of parents/ caregivers of children with IF during: a) initial diagnosis and hospitalization; b) preparation to go home; and c) throughout their ongoing care and management thereafter?
4. How can the use of technology be effective in supporting and meeting the informational needs of families of children with IF?

Methodology

Design

A qualitative methodology was utilized to examine the research questions. Inductive thematic analysis as per Braun and Clarke (2006) was used to identify, describe, organize, analyze, and report rich, complex, and detailed accounts of data. This method has been compared to other qualitative methods such as grounded theory or interpretative phenomenological analysis yet provides more flexibility with data analysis as it is not linked to a particular theoretical framework (Braun & Clarke 2006). Thematic analysis using a semi-structured individual interview design was chosen as the most appropriate method to uncover themes related to the meanings and experiences of parents caring for children with IF and how these influence their information and education needs.

Setting and Participants

The study was conducted in a stand-alone, academic, tertiary care pediatric hospital in Western Canada between November 2018 and February 2019. The hospital provides emergency, inpatient, surgical, medical, oncology, and both pediatric and neonatal intensive care for over 90,000 patients and 315,000 ambulatory visits each year. Participants attending the Intestinal Rehabilitation Program (CHIRP) clinic at the Alberta Children's Hospital, (Calgary, Canada) were approached. Ethical approval was granted from the institutional review board (CHREB 18-0636).

Purposeful sampling was used to identify and select participants for the study. Identified parents or caregivers were approached by a non-research team member and given a poster introducing the study. If they voiced interest, potential participants were then contacted by the first author for consent. Parents were eligible for participation if they: (1) cared for a child with a primary gastrointestinal diagnosis of IF who is followed primarily by the CHIRP team; (2) has a child who was admitted to the hospital or has been in clinic within the last year related to IF management; and (3) could speak and understand English. Exclusion criteria included any parents/caregivers of children who have IF secondary to a non-gastrointestinal diagnosis such as cancer. In the event that both parents chose to participate, they were considered separate participants. A sample size of 5-10 participants was expected to be adequate for data saturation.

Eleven out of fourteen parents/caregivers who were contacted agreed to participate in the study. Written consent was obtained prior to their participation. One participant dropped out during the consent process, leaving a total of 10 participants for the study. Participants were given the option to attend a focus group session or a 1:1 interview. All participants choose to participate in a 1:1 interview due to distance or scheduling conflicts.

Data Collection

Semi-structured interviews were used to collect study data. Interviews were completed over the phone with the participants and were audio-recorded, ranging in length from 45 minutes to 80 minutes. Demographic characteristics of participants and children of participants were collected using a researcher-designed survey. Questions for the interview guide were informed by study aims, current literature, and developed in discussion with the local intestinal rehabilitation clinic team to ensure face validity. The interview guide consisted of open-ended questions to elicit genuine participant responses. Questions were divided into two sections: experiences with IF while admitted in the hospital and experiences with IF after discharge home. Interview questions were refined with sequential participant interviews as emerging concepts and themes unfolded.

Data Analysis

Data analysis occurred simultaneously with data collection and followed the six-phase guide to performing thematic analysis developed by Braun and Clarke (2006). In phase one, transcripts were read repeatedly to ensure familiarization with the entire data set. Initial thoughts and ideas were recorded through memo-writing or field notes after each participant session; the act of reflexivity is encouraged to document gained insights, build codes, and record personal accounts of the researcher's own values in the process of discovery (Nowell, Norris, White, & Moules, 2017). In phase two, line-by-line coding was completed by hand to generate initial codes based on specific interest, characteristics, and frequency. Relevant codes were grouped together and compiled into meaningful statements. In phase three, in order to develop preliminary themes, code extracts were inductively explored with clinical staff and other Canadian pediatric IF experts. Phase four included reviewing and refining potential themes for fit

and emerging patterns. Evolving themes were generated, reworked, evaluated and discarded based on their appropriateness in relation to the research aims (Braun & Clarke, 2006). In phase five, themes were named and defined with a detailed analysis and corresponding code extracts (see Table 1). Lastly, phase six evaluated the validity of the themes. Identified themes and descriptions were confirmed and discussed by a qualitative research expert, and further verified by an experienced pediatric gastroenterologist with expertise in the area of IF.

Formal and informal methods of reflexivity such as memo writing and member checking with local experts and clinicians was utilized to enhance the credibility and dependability of the study. An audit trail that included reflexive memos and notes was utilized to document decisions, rationales, and personal insights with interviews, transcriptions, coding sessions and group discussions. This process allowed for peer debriefing and helped examine evolving themes. Transferability and confirmability were addressed through presenting and sharing themes to other pediatric intestinal rehabilitation programs in western Canada.

Results

There were 10 participants in this study; nine females, one male, with an average age of 35 years (range 27-50). The children of the participants were five male and five female, with an average age of four and one half years (range seven months-10 years). The mean number of medical devices for a child was two and the mean number of current treatments including parenteral nutrition, enteral nutrition, modified diet, anti-coagulant therapy, and oral medication for a child was three. The length of time each child had been on PN or actively followed by the CHIRP clinic ranged from < 6 months (n=1), 13-24 (n=2), 3-5 years (n=3), and > 5 years (n=4).

Four main themes emerged from the data analysis: (1) reliable electronic or printed information resources relevant to their child's unique needs are lacking; (2) educational program

with in-person and hands-on learning is preferred for transition to home; (3) practical and relatable information was valued over medical knowledge as children's needs evolved; and (4) creation of electronic resources are useful for information seeking and sharing. Subthemes were identified for all main themes (see Table 1). While there was variability with respect to each parent's experience, all themes and subthemes emerged from participants' experiences acquiring and seeking out information during the initial hospitalization and their current perceptions of managing their child at home.

Table 1

Themes and subthemes that describe experiences of parents/ caregivers of children with IF and their informational needs

Theme/Subthemes	Description	Example quotes
<i>Reliable electronic or printed information resources relevant to their child's needs are lacking</i>		
Information is given verbally and difficult to retain	Main form of acquiring information is through verbal discussions with the medical team. No additional resources were available for further information, understanding, and retention.	It would be nice if there was something to refer to. My brain will catch on to something they said and I'll miss the next things, whatever they said right after – P6
Internet is not reliable or relatable for information seeking	Despite sharing the umbrella diagnosis of IF, all children were considered unique cases. Internet searches did not generate relatable or accurate information.	Everybody's different, I don't think there is any information out there that is really accurate – P1
A consistent medical team is the preferred first contact for trusted information	Information is trusted from sources that aware or relatable to child's unique situation and needs.	My number one go-to is the care team before somebody else – P5
<i>Educational program with in-person and hands-on learning was viewed as most valuable for transition to home</i>		
Tailoring teaching needs and flexibility	A flexible approach was important to help build trust and confidence for home transition.	I liked that the teaching was convenient, even with work, you guys were really flexible with that – P9

Theme/Subthemes	Description	Example quotes
Hands-on practice cannot be replaced virtually <i>Practical and relatable information was valued over medical knowledge as children's needs evolved</i>	Real life hands-on practice was most valuable to build skills and confidence.	The more you do it, the more comfortable you get it with – P3
Content: Living with IF	Information seeking progresses to normalizing, providing enhanced childhood experiences, and better quality of life while growing with IF.	There's lots of stuff that you're just asking for tips and advice on that the nurses or whoever might not really know, like kids on potty training that are on total PN every night – P6
Support: Parent/ child connections <i>Creation of electronic resource would be useful for information seeking and sharing</i>	Sharing similar experiences is a valuable support not only for information seeking, but also for mental health.	That was helpful... when they would put us in connection with other parents that have a kid similar ages, similar issues – P4
Visuals and videos	Creation of visual resources were suggested as important for understanding information, troubleshooting, and confidence building for skills.	If there was an easy thing for me to physically see, it's reassuring to see that I'm doing it right – P8
Sharing resources with support system	Ability to share reliable information with others was important.	My family and friends ask (questions) ...I think they mentioned that but I don't remember – P2

Theme/Subthemes	Description	Example quotes
All in one place for information seeking and tracking	Opportunity to review any topics in their own time as well as share information about their child's condition with the team was viewed as desirable.	I would still probably look at it on my own time versus asking – P8

Theme 1: Reliable Electronic or Printed Information Resources Relevant to their Child's Unique Needs are Lacking

In all cases, participants identified a lack of informational resources at the time of their child's initial diagnosis. Information was provided to them mostly through verbal discussions without written resources to reference afterwards. Timing of information and cognitive load may have impacted their ability to understand and process the information, since many parents were faced with a medical situation with a critically ill child and an unexpected chronic diagnosis. Some participants described that they were too shocked and overwhelmed to fully grasp any information given. One participant shared: "When in the NICU, I didn't understand a thing, I was too depressed, I was too sad to understand" (P1).

In addition, these discussions were often difficult to understand as they contained high level information, complex medical terminology, and numerous acronyms. For most participants, this was their first exposure to a medical crisis and leading to feelings of being overwhelmed. Confusing information and difficult terminology often detracted their attention from the rest of the discussion, causing them to miss parts of the conversation and made it difficult for them to retain the information received. As one participant explained, "You know sometimes you get too many informations [sic] in one session, your brain shuts off actually. You're stuck in one point, you can't hear the rest of the stuff" (P10). The same was noted to be true with participants who stated they had a medical background. Despite their professional experience in the medical field, participants shared that caring for their own child was much different and overwhelming.

Many participants recognized that the lack of information was due to the complexity and rarity of some IF etiologies. All participants unanimously highlighted that their child's presentation was unique, recognizing that a diagnosis of IF can manifest differently with every

child. Participants acknowledged there were a lot of resources available for general information, such as the medical skills needed to transition home; however, the information they desired about the unique needs and diagnosis of their child was lacking due to the future uncertainties of their child's IF course and management. Participants attributed the lack of information to limited research in the field, contributing to uncertainty on prognosis, illness progression, and treatments. One participant explained, "We understand that they can't tell us a hundred percent because one, 'my child's' case is unique and two, it's a small population" (P7). When asked about resources, another participant shared, "There was no pamphlets or links. I mean, what 'my child' has, I don't think there is a pamphlet" (P9).

The lack of information about IF due to overwhelming uncertainty was an emotional struggle for participants. Trying to cope with the "unknown" was one of the main drivers for them to continually seek out information. Searching for information was part of the journey leading to understanding and accepting how their child came to have IF. It was also used to regain a sense of control over the outcome of their child's illness. One participant shared, "There is nothing concrete, nobody's going to answer how this is going to be in two years from now, but you try to find it" (P10). However, many participants explained there were too many unknowns regarding the diagnosis. Participants noted that often limited information could be given by the medical team on effectiveness of individual treatments options and outcomes. This caused participants to feel disempowered and contributed to increased stress in their inability to help their child manage their illness. One participant explained,

When you're (parent) figuring stuff out, we just want to prevent more problems. You want to prevent more pain for your child. So when you know nothing and the doctors

know nothing and you just trying to figure it out as you go, it's really difficult on the parent because that doesn't help you prevent any harm or pain to your child. (P4)

Another participant shared,

It's so complex with the guise that every kid's different and there's different problems that arise or that don't arise for the kids, and it's just there's so much to it, that it's so hard getting a clear picture of what that means for your child. (P6)

Unknown and uncertain information often left parents feeling distressed over their child's future. Participants shared the constant stress in making the best decisions for their child's evolving needs. This was heightened by overwhelming worries about the unknown and unpredictable long-term effects of treatment options. In reference to medications, one participant stated,

We got a crapload of steroids, antibiotics and this and that, pumped into 'my child's' body. What will the effects of these products? I mean not right now, not the 3 or 4 years, but in the 15 years from now? (P10)

Additionally, it was described as common for children to change treatment paths multiple times depending on the response of their child, or information gathered in surgeries. This perceived "trial and error" approach was described as difficult to navigate information as changes could be sudden and outcomes unexpected. One participant shared,

Everything was kind of broken up. It's not like you got all the information and knew everything about the condition all at once. It was the initial diagnosis and then you find out the basics of what it is, but then maybe a few months later my child will go for another surgery and you find out something else and oh we'll (be) branching off down this way. You know, just seemed like always changing. (P6)

To cope with their lack of understanding and minimal informational resources, all participants used the Internet to gather more knowledge about pediatric IF. Due to ease and accessibility of the Internet, parents frequently relied on online information for information pertaining to diagnosis, prognosis, treatment options, and troubleshooting care needs. However, as their child's presentation was often perceived as unique, participants were quickly frustrated by the lack of accurate, relatable, and reliable information. Participants explained that the Internet produced more generalized and nonspecific information that was not relevant to their own child. As an example, one participant described, "We have Googled intestinal ulcers. Well, it gives you this information that really has nothing to do with short gut intestinal ulcer" (P7). Another participant shared, "It was easy for me to find information, but it's not exact information...Everybody's different, I don't think there is any information out there that is really accurate" (P1).

Some participants shared that they found the Internet to be overwhelming as they were presented with too many negative possibilities, sometimes contradictory to information given by the medical team, often leading to increased feelings of stress and anxiety. One participant shared an experience of searching the Internet, stating "Very rarely are you gonna have some positive stuff" (P8). Another participant indicated, "I didn't want my mind to start racing into all these other issues that probably weren't actually an issue... I knew doing my own research wouldn't be helpful because I have nowhere to start" (P4).

None of the participants felt that information on the Internet effectively met their needs, thus they relied heavily on the medical team for informational and service support. All participants noted they were in frequent contact with their primary medical team consisting of a small number of nurses and doctors. As a result, they developed strong relationships with the

team and trusted only them as a source of reliable and trustworthy information. One participant explained, “When I Google something, it’s kind of like ... some people talking. It’s like a conversation that I’m opening. It’s not the real source... It’s more safer to go straight to the team than somebody else” (P5).

Many participants also acknowledged that this was an issue when they did not have access to their consistent medical team, leading to increased stress. A few participants explained they preferred not to call other sources of support for help, such as the physician on-call, as they were unfamiliar with their child’s history, unique needs, and treatment plan. “They’re not always familiar with what’s going on right now. So sometimes, I know that’s the source I can access, but sometimes I’m like, well do I bother?” (P3). Another parent explained,

It’s exhausting to explain that to a doctor that isn’t on the same page because they’re the on-call doctor. It’s exhausting to explain and then to trust their suggestion because they haven’t been in the loop for the last week or month. (P4)

With limited nursing and medical resources, this made it incredibly difficult not only for families but also for the healthcare providers as informational expectations were unrealistic and unmet.

Overwhelmingly, parents identified good communication and honesty from the medical team as vital in times of uncertainty. Despite being ambiguous, knowledge and information received from their medical team gave participants opportunities to feel better prepared for the unknowns, as well as unexpected changes and challenges. One participant stated, “I think it needs to be a more... realistic conversation about, here is the best-case scenario, but here is also the worst, and you need to be prepared that it could go either way” (P8). Participants also appreciated knowing information about other cases, giving them hope that the field was

progressing and there may be other possibilities in the future. One parent suggested knowing the medical team's "guesses" (P4) was reassuring.

In summary, participants described resources specific to their child's medical diagnosis and unique needs were lacking. While information received by a consistent medical team was perceived by parents as trustworthy, its impact was limited by its verbal delivery and the lack of written reference material. This led to participants missing information or trying to fill knowledge gaps with more accessible but less reliable sources from the Internet.

Theme 2: Educational Program with In-Person and Hands-On Learning Most Valuable for Transition to Home

This theme describes participants' experiences with the pediatric IF educational program and transition home. Overwhelmingly, participants identified that the local nurse-led educational program was exceptional in meeting their learning needs. It consistently featured lots of hands-on learning, tailored teaching needs, and a flexible approach, critical in building trust and confidence in developing the medical skills required for parents to care for their child at home. Participants unanimously identified that personal hands-on practice was the most valuable approach for learning medical skills. Aside from a written manual, no other resources or methods of learning were identified, however it was emphasized that additional electronic resources could not replace hands-on learning provided by the program.

Prior to discharge home, participants were required to complete two 'rooming in' days, in which they had to assume full responsibilities for their child's care. To facilitate more opportunity to practice skills, some participants suggested starting teaching earlier and extending 'rooming in' days. One participant described, "When it's your child, it's so different. It's really- It's overwhelming...the more you do it the more comfortable you become with it" (P3).

Flexibility in the program, such as scheduling teaching sessions and number of sessions, was also identified by participants as important. Participants were assured that transition to home would occur only when they felt comfortable, confident, and competent in the medical skills required. One participant remembered being told, “We (nurses) will take as long as you need. This (three weeks) is the minimum time we can teach somebody, but we’ll take as long as you need that you feel comfortable before you go home” (P4). Another participant echoed, “It makes it better to understand that the...nurses won’t let you go ‘til you learn the whole thing” (P5).

A lack of psychological support for parents was identified as another gap with home transition. Many participants indicated they were overwhelmed and isolated. One participant commented, “There’s an entirely new lifestyle that is not common in any way...there needs to be some sort of more support for the parents’ mental state as well when they have to take this on” (P4). The transition right after discharge was identified as the most challenging period for participants.

Many participants reflected although they were prepared medically for the transition home, they were not prepared mentally. Participants found the change to the home environment a challenging adjustment and were overwhelmed by the increased responsibility. One participant described,

Hospital life was one thing and doing it at home was a complete other thing. As much as we were literally doing the exact same thing...it fell on me, on my shoulders to be the one responsible for her medical care...So it’s one thing to sit around a little round table in a small room and practice drawing up meds, but that’s not the routine that you get in when you’re at home. (P8)

Participants voiced needing reassurance from unit nursing staff to help build confidence. However, unit nursing staff lacked specific knowledge to support home procedures. As IF program nurses had limited availability, having more hospital staff trained to support home equipment and procedures was identified as a way to improve home readiness. It was also suggested there be more emphasis on developing a routine and adapting needs to the actual home environment.

Theme 3: Practical and Relatable Information was Valued Over Medical Knowledge as Children's Needs Evolved

Two subcategories of practical information needs emerged from the interviews with participants: (1) practical information for managing the child and improving experience in life; and (2) inter-connecting with other families as a resource of information and support.

Participants discussed how their informational needs changed over time as their child's illness and management evolved. Many participants explained that specific information about their child's medical condition and necessary management skills was the most important during the acute stages of their diagnosis. As the status of their child became more "stable" or "unchanging" participants unanimously desired more practical day-to-day management knowledge. As their child's medical status changed to chronic, participants became more concerned about enhancing their child's resilience and quality of life. Practical informational needs related to a lack of understanding of two main topics: troubleshooting medical devices and enhancing childhood experiences and milestones.

Participants noted that adapting and growing with medical devices was a challenge for their child, many of whom began their journey with IF as an infant and encountered challenges throughout the stages of their development, such as managing mobility with total PN and

participating in physical activities. Although all participants stated that they would rather receive information from their medical team, they often found this support lacking with respect to childhood developmental needs. One parent stated, “There’s lots of stuff that you’re just asking for tips and advice on that the nurses... might not really know, like kids on potty training that are on total PN every night” (P6). One parent also shared challenges with managing mobility, “There were little things like that we had to innovate and come up with ourselves because we didn’t have an IV pole at home, so okay, well, now what do we do?” (P8).

Participants noted they frequently struggled to find information related to practical day-to-day management of their child’s IF. While children with IF often do not exhibit physical disabilities, they require daily complex medical interventions. One participant shared a challenge with finding a school suitable and accepting of their child’s medical needs.

They (the medical team) don’t really know (schools to attend)...I was the one who pushed my child to go...I just searched like where would the kid with ostomy and a CVC could go... Google give me a lot of lists of schools, so I called every school and they said no, ‘my child’ can’t be here. (P5).

Given the lack of resources from their medical team, participants had to be proactive in finding information on their own. Frequently parents utilized social media networks for informational and social support. Knowledge gained from the experiences of other parents/caregivers of children with complex medical needs was a helpful and important source of support. Overall, participants found that other parents were eager to share their knowledge and guidance, were readily available, and provided useful and relatable experiences for troubleshooting unique solutions for their own children. As one participant shared, “That’s the thing, it’s not always an emergency. So, you don’t always want to call GI on call or go to the

hospital because it's like, you just need help with walking through something with someone" (P3). One participant shared, "It's real people who answer your questions. It's not just a computer that you need to research and sometimes you will get the wrong answers" (P1).

Participants found parent/caregiver connections were empowering because they gave them increased ability to help their own children. Learning about different strategies and approaches from other parents enabled participants to collaborate more with the medical team, providing alternative care options and leading to positive impacts on their child. One participant shared, "Even having those ideas of different things that have worked for different people and different ideas to try I think this is important and making you feel that you have more control too over you know helping your child" (P6).

Participants acknowledged, however, that the information provided by parents and social media sources was not always relatable and reliable. This was especially true when connections were not made in-person, or if children of participants did not share similar diagnoses. One participant spoke about the general online Facebook group as, "It's not a medical resource, it's not necessarily reliable" (P3). Other participants shared that they only communicated with and trusted the advice of other parents of children who belonged to the same clinical program.

Many participants identified that sharing similar experiences was a valuable source of mental health support and helped them manage the distress of uncertainty. One participant shared,

When I grew a friendship with somebody who was involved in 'the program', it made a world of a difference because...as much as our kids are different, I could talk about what

I'm going through, and it's a language that is understood. (P8)

Another participant highlighted,

It's not all the same, I understand, but it is good to know that there are parents, there are people out there that have the same situation as my 'child' ... Sometimes they would cheer me up. (P1)

Some participants emphasized that family connections were as valuable in helping mentally support and empower their children throughout their illness journey. Participants recognized that children who connected and shared their own relatable experiences provided mentorship to other children, had an opportunity to build their own sense of identity, and learned how to manage their own medical needs. One participant shared,

We know these kids are surviving and they're thriving and they're gonna go into the community right? How do we make sure that they're inclusive, that they understand their own cares and needs, and what kind of supports are there, or fun ways that we should teach them on how to start self-managing their (own) care. Having kids that are similar kind of come together, because then these kids can identify with each other and they can maybe teach each other something. (P9)

Creating connections between children was also noted as important to support siblings of children with IF, who often felt displaced by their sibling with special needs. One participant shared,

(Meeting others) That was beyond fantastic for the kids and for both our kids... So it was like unbelievably psychologically helpful... for 'my child' to meet other kids like him, but then for 'my child's sibling' to meet other kids like 'my child' and siblings of kids like 'my child'. (P7)

Unfortunately, participants found that making family/caregiver connections was often difficult. They suggested such connections could be facilitated by the medical team during

admissions or local clinic education events. One participant shared, “It wasn’t easy for me to find any other families until I met these people in the CHIRP (education) event” (P1). Also, instead of a general hospital wide social media parent group, many participants suggested to have local pediatric IF social media group for more helpful and trustworthy information sharing.

Theme 4: Creation of Electronic Resource Would be Useful for Information Seeking and Sharing

As all participants admittedly used the Internet for information seeking, many welcomed the possibility of an electronic resource curated by the medical team as a timely, accessible, trustworthy, and reliable information resource. Many participants suggested the inclusion of visual resources such as instructional videos to support their understanding, troubleshooting, and skills development. One participant shared that visual information would be helpful for understanding medical knowledge encountered during discussions, stating, “If we have this picture, if we have this diagram, if we have all these visual resources, I think it would be easier for parents to understand” (P1). Another participant shared that visual aids would promote their self-efficacy in undertaking medical skills, “When it’s your child, you lose all confidence, so if you had links to refer to or even videos or whatever just to be able to review...it may be (really) helpful” (P3).

As previously stated, verbal information provided by the medical team was overwhelming to process within the initial hospital admission. Participants reflected on the value of electronic summaries related to the discussions provided by the medical team as a reference for later review of information. One participant shared that it would be helpful to have access to the summary of the clinical team’s weekly rounds, “We (could) just go on our (potential) portal and we can see what’s their thoughts, what are next steps might be” (P1).

Participants also indicated an electronic resource could contain important troubleshooting information, often provided to parents by the medical team in paper copies when they initially received skills training, but inconvenient to access quickly in times of needs. As participants became experts in their child's care, they identified they had the ability to triage non-urgent concerns without the assistance of the medical team. An accessible and reliable resource would provide these parents with the ability to navigate a solution quickly and autonomously. One participant shared,

It's something that isn't like, I need to do something about this, right the second. If it's something that you had time to look up and be like, okay, well, I know that I can go directly to this website, or whatever, and look at this video or look at this information, I think it would be nice. (P6)

While many participants favoured printed materials, they preferred easily accessible digital information. Accessible electronic resources would give them ability to readily share reliable information with their support systems, enabling them to better provide important details or clarify inaccurate information to their family and friends. One participant shared an experience clarifying information to a parent,

My mom was asking questions about, well, how come you can't do a fecal transplant? Or there was a couple other questions she had...we knew they were irrelevant but my mom needed the chance to ask those...we'd explain to her why those things couldn't happen because those are things that are (only) applicable to a general population intestinal problem...GI kids are not the same. (P7)

The ability to access electronic visuals, such as instructional videos provided by the medical team, was identified as a valuable support for medical procedures once their child

transitioned home. In addition to their increased caregiver responsibilities, participants also assumed the role of educator to their support systems as they frequently required assistance with specialized home procedures. For some, this experience led to additional stress as few resources were available to share and participants were uncomfortable delivering educational alone. One participant shared, “When I came home and I needed help...I needed my mom to help with ‘my child’s’ total PN, help with ‘my child’s’ hookup or help with anything” (P4). It was suggested that videos provided by the medical team could ensure practical skills review at a high standard and reduce potential for errors.

Participants suggested that an electronic tracking resource template could decrease the time needed to correspond with the medical team about their child’s status. Many participants were in contact frequently with the medical team regarding their child’s outputs, food intake, hydration status, and growth measurements; however, each described a different method of tracking and sharing information. Participants suggested more guided resources or templates on a shared online platform could be helpful in streamlining and standardizing the information provided to the medical team. Participants voiced that this shared online resource could also be helpful in accessing patient history, as well as events and treatment plans, thereby enabling consistency between providers and caregivers. One participant shared,

I type out day by day, like the date, the output, how many times she vomited, and in that information what antibiotics she’s on at the time and weights, I want to show all that information and it’s time consuming and sometimes it’s hard to find that time... dealing with everything else... We have to look at the facts, we’ve already been through so much and need that record to kind of look (back). (P3)

Participants indicated a desire to learn more about current research related to pediatric IF, as this information often provided a sense of hope; however, accessibility to this information was identified as a barrier. It was suggested that specific topics could be curated by the medical team in an online or digital resource, allowing participants to review in their own time and at their own pace. One participant shared, “You know anything around us, if there is something, yes, I would love to hear it or hear about it. Any bit helps” (P10).

There was no consensus regarding the type of electronic platform that would be most useful, as participants were split between a website and a mobile phone application. Accessibility and ease of use were noted as the two important factors required for any electronic resource provided. One participant shared, “I wouldn’t mind getting into the web, then I can access with my phone or ipad or something, that would be awesome” (P10). At the same time, however, there was some resistance to the idea of an electronic resource. All participants emphasized that an electronic resource could not replace their ability to contact and connect with the medical team. Rather, the ideal resource was envisioned to complement their learning, gather reliable information, and enhance communication with the team.

Discussion

In this qualitative study, informational needs of parents/caregivers of children with IF were explored. To our knowledge, this study is the first to provide insights about the information seeking experiences of these parents. This study revealed that parents of children with IF have high informational and educational needs that vary from the time of diagnosis in the hospital to home, where parents are largely responsible for managing their child’s chronic condition. The needs of parents/caregivers also vary from child to child due to the heterogeneity of IF and rarity of certain etiologic causes. Often, they perceived a lack of reference information from healthcare

professionals related to the diagnosis, prognosis, and outcome of their child, and required additional resources to navigate their day-to-day care and management. Digital media sources were most used to address their information needs, however, families reported that current online resources such as social media forums and Internet searches were often unreliable and untrustworthy. Furthermore, while the nurse-led home PN educational program was identified as sufficient for skill development, a blended learning approach including online resources was preferred for informational delivery. Finally, psychological needs of families emerged as important as they transitioned from hospital to home. The findings from this study suggest that informational, educational, and psychological needs of families impacted by IF are diverse and require resources and methods that are innovative, technology-based, and patient specific to address their needs.

Overall, as their child's medical status evolved to a chronic state, participants placed more emphasis on informational needs related to practical day-to-day management over medical knowledge. Information and medical knowledge about the diagnosis, related complications, and skills required for home management were most important during the initial hospitalization. These needs quickly changed as families developed familiarity and awareness of the medical team, medical language, and healthcare system. Practical information about managing their children's unique needs and enhancing quality of life was found to be more valued than medical information. This finding was supported by a systematic review that found parents of children with long-term conditions had evolving learning needs depending on their child's age, disease trajectory, and their own confidence in the management of their child's condition (Nightingale et al., 2015). Prior to this study, limited evidence-based practices were available to guide the effective delivery of education and information to families and patients impacted by IF. The

results of this study may help healthcare professionals focus on the needs identified and facilitate more effective ways to address gaps in information.

Types of educational approaches and the timing of information were important factors in parent's ability to understand and integrate knowledge about their child's diagnosis and care. Participants in this study found it challenging to understand and process information at the time of diagnosis due to the verbal delivery of the information at a time of heightened stress. This finding is supported in the literature that found that parents who were given large amounts of medical information led to poor retention and knowledge integration (Hummelinck & Pollock, 2006; Van den Bree et al., 2013). Timing of information may have impacted their ability to understand and process information given the stressful situation. While overwhelming, if information is not made available to parents, they can experience increased stress and anxiety trying to interpret, understand, and cope with the challenges of their child's condition (Van den Bree et al., 2013). Providing an accessible summary to parents with notes on information discussed by the medical team merits further focus. Ming and colleagues (2018) found that a mobile complex care plan synthesizing important patient information for CMCs, facilitated parental engagement and was an important reference tool in improving their understanding of their child's overall medical situation. Enabling parents to review important information when they have the cognitive load to attend to the information provided may help parents integrate their knowledge and better understand future action plans.

In this study, participants unanimously reported that a blended approach of verbal, written, and electronic resources was the preferred method of educational delivery. Although participants identified an electronic resource would be helpful for visual learning and providing reassurance, they felt strongly that it could not replace in person hands-on learning provided by

the healthcare team. Similarly, Jaks and colleagues (2019) found that online resources are seen as complementary by parents and not a substitute to traditional methods of receiving health information. Our findings support previous research that found that providing a variety of methods of educational delivery, including video-format education along with handouts and in-person learning, improved parent understanding and navigation of stressful environments for patients and families in a special care nursery (Hunter et al., 2019). Other researchers have reported that interactive teaching approaches, such as gaming platforms using visual and auditory signals, could be used to help increase parents' knowledge and management of their child's chronic conditions (Annaim et al., 2015). In the current study, all participants emphasized that electronic visual tools would increase their confidence, understanding, and reassurance, positively impacting the care and management of their child at home. A blended approach to education delivery would be beneficial in addressing a variety of learning styles and literacy levels, allowing individuals to access and review educational content at their own pace.

While participants in the current study regularly used the Internet for information seeking, they were often frustrated by the quality, reliability, and relevancy of information. This finding was not unexpected as the literature has commonly shown that online health information differs significantly in reliability and accuracy (Benedicta et al., 2019; Jaks et al., 2019). Consequently, parents/ caregivers heavily relied on the medical team as their main source of trusted information, which caused unrealistic expectations and increased stress when the medical team was unavailable to address practical troubleshooting and informational needs. Informational needs unrelated to IF and within the realm of general pediatric practice, such as potty training and schooling, could be better addressed by integrating community providers. Collaborated care with other available community providers such as pediatricians and home care

services, may provide families with a more timely and holistic approach to care in support of their child's day-to-day management and developmental concerns. Additionally, providing families with trustworthy and accessible digital resources such as links to credible websites has been found to increase parents' digital health literacy, enhance their ability to gather information autonomously, and increase effective communication between them and the medical team (Benedicta et al., 2019).

Given increasing information technology use in our society, there is an opportunity for educational programs to utilize technology-based systems for general information delivery to patients and their families. Implementation of an information communication technology (ICT) approach where the learner engages in a face-to-face video conversation and receives a real time expert response from pre-recorded clips, has been shown to be effective in increasing patient knowledge on general topics and interventions (Knapp et al., 2013). Given current fiscal and time constraints within the healthcare system, providing one-on-one informational support is neither sustainable nor practical. Leveraging technology may be an effective and cost-effective way for medical teams caring for this population to supplement and reinforce basic information that is common among children with IF, decreasing parents' reliance on the medical team for minor troubleshooting concerns.

Implementation of a shared digital resource was also suggested by participants as a way to streamline information and communication of their child's condition to and from the medical team in a more efficient and timely manner. Electronic telehealth platforms have been shown to improve communication between patients, families, and healthcare providers through the use of video-conferencing, remote monitoring, and high resolution images and video files (Utidjian & Abramson, 2016). As a result of the novel coronavirus disease 2019 (COVID-19) pandemic,

there has been a shift towards providing remote healthcare services delivery using telehealth technology. Wosik and colleagues (2020) found that adoption of telehealth practices have provided successful delivery of hospital services and clinical interactions in a variety of U.S healthcare organizations. Creating an electronic resource for parents to share information and notes (verbal discussions, meetings, and current research), receive skills training (instructional videos), and track their child's status (daily measurements) could provide more accurate, timely, and patient-specific information between families and care providers. A digital platform may also enable more flexible follow up, especially for families who are required to travel long distances for clinic appointments since IF rehabilitation teams are typically located in tertiary centres.

While digital platforms for parent education exist, there is limited evidence on the quality and suitability of use in complex medical health (Davis et al, 2107). Davis and colleagues (2017) also reported that digital resources developed without collaboration with healthcare professionals and relevant users can affect the content delivery, functionality, and usability. To address these challenges, development of an electronic informational and educational tool must include the parents of children with IF as partners in the design. Accessibility and ease of use were noted as the two important factors required for any electronic resource provided. Participants also voiced that a digital platform with online resources should not be designed as a replacement but instead as a complement to learning, ability to gather reliable information, and enhance timely communication with the medical team. It is important to note that any digital platform tailored to each child's medical condition is not feasible. Future collaboration with participants in the development of a user-designed online system could identify innovative ways of providing the tailored information they require to meet their identified needs. Additional research is needed to

determine if the creation of a digital platform for information would be effective in improving knowledge, parental self-efficacy, and health outcomes in this population.

In the current study, parents reported emotional distress over the lack of reliable and trustworthy resources about the diagnosis and outcomes of their child's condition. Support related to managing the uncertainty of the disease was highlighted as the greatest area for improvement. Families of children with IF live with a large degree of uncertainty, largely related to the rarity of the disease and heterogeneity among diagnostic characteristics. Families affected by rare disease have shown to be more prevalent with feelings of isolation, chronic sorrow, confusion, and grief that complicate the management of the condition (Glenn, 2015). If healthcare professionals are aware of these outcomes, they may be able to effective ways to foster resiliency and provide more psychological support to parents. Good communication and reframing the delivery of information to families can give participants opportunities to be better prepared for the unknowns, as well as unexpected changes and challenges. As well, the addition of psychological counselling for caregivers could be valuable in assisting with parental adaptation and adjustment. There is emerging evidence suggesting that educational programs designed using narrative therapy, allowing individuals and families the opportunity to tell their stories, has been demonstrated to increase their sense of well-being (Jackson et al., 2016). Laing and colleagues (2017) demonstrated that digital storytelling was valuable for helping children and youth experiencing cancer cope with psychosocial trauma, acquire education, or simply used as a needed distraction from therapy (Laing et al, 2017). Further evidence is needed to determine if the parents of children with IF might also benefit from sharing their experiences, particularly through digital storytelling, as a coping strategy for unavoidable lack of information about their

child's diagnosis. Future research to address outcomes and feasibility of providing these types of interventions for caregiver mental health within the routine care setting is required.

Connecting with other parents of children with medical complexities was identified by participants in our study as an important way to gather informal information about practical day-to-day medical knowledge and optimizing their child's quality of life. These connections were also reported to assist parents in coping with their own mental and emotional health through empathetic understanding and sharing of realistic experiences. Similarly, researchers found that cultivated parent networks were instrumental in providing parents' insights to enhance quality of life and reduce the stress associated with the uncertainty of their child's diagnosis (Rafferty, Beck & McGuire, 2020). However, due to the complexity and rarity of IF, many participants perceived that general online connections were not as meaningful and trustworthy as face-to-face encounters or connections facilitated through the medical team. Glenn (2015) found that exposure to negative information on these online communities could provoke chronic sorrow or cause extraneous information overload. Families in the study expressed the need for more facilitation of meaningful family connections within the local community of caregivers impacted by IF. Although connections facilitated by social work or program led parent educational days were useful in establishing these connections, these settings were noted as infrequent due to lack of resources. While preferred as a more reliable source of information, timely face-to-face access may not be practical given economic, personal, and more recently COVID-19 restraints. Creative strategies to facilitated and maintain parental meaningful connections while being cognizant of potential negative consequences of online communities merits further consideration.

Also noteworthy, findings from this study suggest that development of connections with similar families may also be an important source of informational and emotional support for

children with IF. Research has demonstrated that children who more accurately understand their chronic illness have an improved emotional state, reduced anxiety, and increased overall quality of life (Emedo, Godfrey, & Hill, 2010). Similarly, children who can achieve some degree of self-sufficiency are more empowered and develop more advocacy for their own care needs (Rafferty & Beck, 2019). Participants in this study identified that organized mentorship between children in similar situations could empower and assist them in developing a stronger sense of identity. As children age, healthcare professionals need to consider providing age-specific educational programs to enhance their knowledge and learning about their illness. Further research is required to better understand how children are affected by IF and develop unique resources to empower them in their care. Early engagement with other disciplines such as child life, social work, and child psychology should also be considered in facilitating social connections between families and children with IF to better support their psychological needs.

Limitations

There were several limitations to this study. Although themes were validated by experts in other programs caring for children with IF, there may be limited transferability of results as responses reflect the processes and education of a single center. Due to time constraints, themes were not verified through feedback to participants. Interviewing parents and caregivers in different programs could enhance credibility and validity of the themes identified. As well, selected participants varied greatly in years of experience in the program (seven months to 10 years). Thus, there may have been improvements to standards of care and updates to the educational program within that time range, leading to different retrospective observations from participants and lapses in recall. Additionally, participants in this study who have been in IF rehabilitation program longer may reflect families/caregivers of children who are more complex,

have irreversible IF, and require higher medical needs such as indefinite PN infusions. Thus, their experiences related to uncertainty and lack of information of these participants may not be similar to families of children who achieve intestinal adaptation and no longer require PN infusions after a few years. Furthermore, given that only one male participated in this study, there was an over representation of the female perspective. More responses by male caregivers could have reflected different experiences and informational needs and warrants further study.

Conclusion

The information needs for families/caregivers caring for children with IF are high, diverse, and change over time. The findings of this study illustrate the need for other trustworthy, reliable and accessible sources of information not only for parents/caregivers of children with IF, but also for healthcare professionals who provide their care. A blended approach to care team discussions with user-centred digital tools may benefit families by increasing their accessibility to reliable information, as well as time efficient, high quality care and monitoring. Finally, more psychological support for parents including facilitation of parent caregiver connections and their children with IF is needed to improve their overall mental well-being.

CRedit authorship contribution statement

Lily Ragan: Conceptualization, Investigation, Formal analysis, Writing – Original draft preparation. Linda Duffett-Leger: Supervision, Validation, Resources, Writing – Review and Editing. Dana Bactor: Conceptualization, Validation, Writing- Review & Editing. Catherine Laing: Writing- Review and Editing

Chapter 3: Conclusion

Advancements in medical treatment and technology have increased the survival rates of pediatric patients with previously terminal diagnoses (Opreescu et al., 2013). As such, the nature of patient complexity has changed, and a new population of patients have emerged who are chronically complex yet remain critically ill. This complexity poses many challenges for families who are increasingly expected to take greater responsibility of ongoing and high resource medical management of their children in the community. In recent years, more research has emerged focusing on the needs of CMCs (Peter et al., 2011), however, there is limited studies specifically in the area of pediatric intestinal failure (IF). This patient population is commonly technology dependent, requires high medical resource utilization and is at risk for multiple comorbidities (Duggan & Jaksic, 2017, Squires et al., 2016). Due to the complexities of this population, the management of children with IF is challenging and intensive for both families and healthcare professionals. My work as a registered nurse specializing in field of pediatrics influenced the development of this research to explore the informational needs of parents caring for children with IF.

Over the past 11 years, I have worked as a pediatric nurse with the Alberta Children's Hospital Rehabilitation Program (CHIRP) team providing education to families and children with medical complexities (CMC) as they prepared for their transition home. During this process, I was struck by the challenges regarding lack of resources and information available to myself, families, and other healthcare staff caring for children with IF. Educational materials provided to families were outdated and inconsistent from practice standards in comparable programs. Access to informational resources including anatomy, medical/ surgical interventions, common complications, and nutrition was limited for both staff and families. Further, no

resources were accessible through digital technology. Finally, practices were inconsistent between families and staff, causing tension and frustration among parents regarding the care management on the unit.

The above challenges were addressed, in part, by implementing a few practice changes for the care team and staff on the unit. I assisted in developing an online electronic summary form for clinic visits to provide better access to patient history, action plans, and enhanced communication between healthcare providers. Through collaboration with nurse clinicians and educators from different local and national programs, I was also able to update a few patient and family educational resources. In addition, I assisted the CHIRP program in planning their first family education day where families who attended received current evidence-based education and were encouraged to develop social connections with other families. During this one-day event, a survey was provided to parents/caregivers for their feedback regarding the potential development of an educational online tool for families of children with IF. The response was overwhelmingly positive and emphasized the importance of providing current and accessible education for all patients with IF and their families.

Prior to this study, the informational needs of families with children with IF had not been well researched and limited knowledge existed about which types of educational methods would be most effective in meeting their needs. Thus, the primary focus of this research was to explore the informational needs of parents and caregivers in order to provide better understanding of what and when information is needed in their child's journey with IF. Secondly, since the Internet is becoming increasingly popular for information seeking amongst families (Nicholl et al., 2017), another objective was to offer important insights about how the use of technology could be leveraged to help bridge gaps in their informational needs. When this study was first

conceptualized, it was hypothesized that families would benefit from an electronic educational platform largely containing basic medical knowledge required by parents in the care of their children with IF. Four main themes emerged in the study including: (1) reliable electronic or printed information resources relevant to their child's unique needs are lacking; (2) educational program with in-person and hands-on learning is preferred for transition to home; (3) practical and relatable information was valued over medical knowledge as the child matured; and (4) creation of electronic resources would be useful for information seeking and sharing. Subthemes were identified for all main themes (see Table 1). The findings from this study suggest that informational and educational needs of families impacted by IF are multifactorial and require resources and methods that are patient specific and leverage technology to address their needs for accessibility and social connectedness. In this final chapter, I will describe the study results, discuss limitations, and implications for nursing practice and research.

Lack of Relevant Information and Resources

Several challenges were identified by parents/caregivers that contributed to a perceived lack of information and resources, such as traditional approaches for information delivery, timing, and rarity of disease. Due to the complexity of the disease and unique management of the illness, participants found there was limited accessible and trustworthy resources available, making it difficult for healthcare professionals to meet their informational needs.

Verbal Medical Information Delivery

Participants reported commonly receiving important medical information through verbal discussions with the medical team which contributed to decreased understanding, retention, and increased stress. Discussions were often difficult to understand as they often contained high level information, complex medical terminology, and numerous acronyms. Confusing information

often distracted parents'/caregivers' attention from the rest of the discussion, causing them to miss parts of the conversation and making it difficult for them to retain the information received, further compounded by the fact that this was a highly anxious time for them. This finding was supported in the literature that reported poor retention and knowledge integration among parents who received large amounts of verbal medical information (Hummelinck & Pollock, 2006; Van den Bree et al., 2013).

Timing of Information Critical to Knowledge Integration

The timing of information delivery may have also impacted participants' ability to understand and process information as information was received at a time of heightened stress. Understandably, participants reported feeling a range of emotions including depression and devastation when receiving information early in the diagnosis as this was often their first exposure to a medical crisis. However, a similar response was noted among participants who had a medical background; thus, while they had experience in the medical field, participants shared that caring for their own child was much different and overwhelming. This is a common theme reported in families with other populations of children who require intensive medical care such as in neonatal intensive care (Hunter et al., 2019) and cancer (Aburn & Gott, 2014).

While the information is often overwhelming, if is not made available to parents they can experience increased stress and anxiety trying to interpret, understand, and cope with the challenges of their child's condition (Van den Bree et al., 2013). Pelentsov and colleagues (2015) found that information empowered parents and increased their involvement in the care specific to their child's condition. Enabling parents to review important information when they have the cognitive load to attend to the information provided may help parents integrate their knowledge and better cope with future action plans.

Need for Information Tailored to Unique Medical Issues

Families of children with IF live with a large degree of uncertainty, largely related to the rarity of the disease and heterogeneity among diagnostic characteristics. Many participants recognized that the lack of available information was largely due to the complexity and rarity of IF. All participants unanimously highlighted that their child's presentation was unique, recognizing that a diagnosis of IF can manifest differently with every child. Participants acknowledged there was certain general information available, such as the medical skills needed to transition home; however, the information they desired about the unique needs and diagnosis of their child was frequently lacking and at times unavoidable given the uncertainties of IF. This led to feelings of emotional distress and disempowerment related to their inability to help manage their child's illness. Similarly, Glenn (2015) found that families affected by rare diseases commonly shared feelings of isolation, chronic sorrow, confusion, and grief that complicated the management of the condition.

Unknown and uncertain information also left parents feeling distressed over their child's future. Participants shared their experience of constant stress in making the best decisions for their child's evolving needs. This was largely due to constantly changing treatment paths which depended on the response of their child, or information gathered in surgeries. This "trial and error" approach made it difficult for parents to navigate information as changes could be sudden, outcomes unexpected, and unpredictable long-term effects of treatment options.

Addressing the Psychological Needs of Parents/Caregivers

Support related to managing the uncertainty of the disease was highlighted as the greatest area for needed improvement by participants. Providing effective interventions that target parental coping and resilience could address their psychological needs. For instance, good

communication and reframing information delivery can give parents opportunities to be better prepared for the unknown, as well as unexpected changes and challenges. As well, there is emerging evidence that educational programs designed using narrative therapy, which allows individuals and families the opportunity to tell their stories, can increase parents' sense of well-being (Jackson et al., 2016). Laing and colleagues (2017) demonstrated that digital storytelling was valuable for helping children and youth experiencing cancer cope with psychosocial trauma, acquire education, or serve as a needed distraction from therapy (Laing et al, 2017). Further evidence is needed to determine if the parents of children with IF might also benefit from sharing their experiences, particularly through digital storytelling, as a coping strategy for the unpredictability of their child's diagnosis.

In addition, a lack of psychological support for parents was identified as another gap with home transition. Participants found the change to the home environment a challenging adjustment and were overwhelmed by the increased responsibility. Many participants reflected while they were prepared medically for the transition home, they were not prepared mentally and often felt overwhelmed and isolated. The addition of effective interventions such as psychological counselling could improve caregiver resiliency and enhance parental coping with adaptations and adjustments to care management for transition home. Future research to address outcomes and feasibility of providing these types of interventions for caregiver mental health within the routine care setting is required.

Educational Delivery for Transition Home

In this study, participants unanimously reported that a blended approach of verbal, written, and electronic resources was the preferred method of educational delivery. In person hands-on learning provided by the healthcare team was the more preferred way of learning.

Participants identified that the addition of easily accessible digital resources would be a valuable way to provide them reassurance and reinforce their skills. These results support findings that online resources are seen as complementary by parents and not a substitute to traditional methods of receiving health information (Jaks et al., 2019). Similar to other studies, we found that providing a variety of methods of educational delivery, such as video-format education along with handouts and in-person learning, improved parents' understanding and ability to navigate stressful environments (Hunter et al., 2019). Other researchers have reported that interactive teaching approaches, such as gaming platforms using visual and auditory signals, could be used to help increase parents' knowledge and management of their child's chronic conditions (Annaim et al., 2015). In the current study, all participants emphasized that electronic visual tools would increase their confidence, understanding, and reassurance, positively impacting the care and management of their child at home. A blended approach to educational delivery would be beneficial in addressing a variety of learning styles and literacy levels, allowing individuals to access and review educational content at their own pace.

Flexibility in the program, such as scheduling teaching sessions and number of sessions, was also identified by participants as important. Mackay and colleagues (2020) found that a flexible approach to care was important for building trust between healthcare professionals and parents with medically fragile infants. Participants in our study were assured that transition to home would occur only when they felt comfortable, confident, and competent in the medical skills required; however, participants were only given two "rooming in" days prior to discharge home to take on the full responsibilities of managing their child's care. To facilitate more opportunity for parents to practice skills and gain self-efficacy, increased flexibility should be considered, such as starting teaching skills earlier and extending "rooming in" days.

Participants voiced the need for reassurance from unit nursing staff to help build their confidence; however, unit nursing staff lacked specific knowledge to support home procedures. As IF program nurses had limited availability, having more hospital staff trained to support home equipment and procedures was identified as a way to improve home readiness. This gap could be addressed with the development of an online education tool accessible to both families and healthcare providers to enhance information, collaboration, and consistent practices. Developing digital solutions to address the informational needs of parents will be discussed in a later section.

Emphasis on Practical Information for Evolving Needs

Overall, participants stressed the importance of their informational needs related to practical day-to-day management rather than medical knowledge. Parents expressed that information and medical knowledge about the diagnosis, related complications, and skills required for home management were most important during their child's initial hospitalization. These needs quickly changed as their child's illness and management evolved and they developed familiarity and awareness of the medical team, medical language, and healthcare system. Practical information about managing their child's unique needs and enhancing quality of life was found to be more valued than medical information as the status of their children became "stable" or "unchanging". Similarly, a systematic review reported that parents of children with long-term conditions had evolving learning needs depending on their child's age, disease trajectory, and their own confidence in the management of their child's condition (Nightingale et al., 2015). Two subcategories of practical information needs emerged from the interviews with participants: (1) practical information for troubleshooting in managing the child and improving experience in life; and (2) inter-connecting with other families as a resource of information and support.

Practical Information Needs

Participants noted that adapting and growing with medical devices was a challenge for their children, many of whom began their journey with IF as an infant and encountered challenges throughout the stages of their development, such as managing mobility with total PN and participating in physical activities. Participants noted that the medical team lacked information beyond the necessary medical care of medical devices as information needed was more experiential rather than medical. Unlike other CMCs, children with IF often do not exhibit physical disabilities, thus, integrating their complex medical interventions in daily life requires more creativity and innovation from families.

Participants also found that the medical team had limited ability to support their child's developmental needs, such as potty training, schooling, and enhancing child identity and self-efficacy. As their child developed and matured, participants became more concerned about enhancing their child's resilience and quality of life. Participants reported increased responsibility to independently seek out additional information or create their own solutions to manage the practical needs of their child. Healthcare providers caring for this population should consider integrating other community resources to help build parents' capacity to address day-to-day concerns. Increased collaboration and a shared model of care with other available community providers, such as pediatricians and home care services, may provide families more timely guidance and support to meet their day-to-day management needs and child developmental concerns.

Importance of Establishing Connections with Other Parents

Connecting with other parents of children with medical complexities was identified by participants in our study as an important way to gather informal information about practical day-

to-day medical knowledge and optimize their child's quality of life. Participants often turned to social media networks to address their practical informational needs. Glenn (2015) found that establishing connections to an online community was critical in addressing the support and informational needs of mothers caring for children with rare disease. Participants found that other parents were eager to share their knowledge and guidance, were readily available, and provided useful and relatable experiences for troubleshooting unique solutions for their own children. Learning about different strategies and approaches from other parents empowered participants to collaborate more with the medical team, providing alternative options and leading to positive impacts on their child's care.

These connections were also reported to assist parents in coping with their own mental and emotional health through empathetic understanding and sharing of realistic experiences. Similarly, researchers found that cultivated parent networks were instrumental in providing parents' insights about how to enhance quality of life, thereby reducing stress associated with the uncertainty of their child's diagnosis (Rafferty, Beck & McGuire, 2020). However, due to the complexity and rarity of IF, many participants perceived that general online connections were not as meaningful and trustworthy as face-to-face encounters or connections facilitated through the medical team. Parental connections with online communities have also reportedly provoked chronic sorrow prompted by a focus on negative information causing extraneous information overload (Glenn, 2015). While preferred as a more reliable source of information, timely face-to-face access may not be practical given economic, personal, and more recently COVID-19 restraints. There is a need for healthcare providers to facilitate more meaningful family connections within the community of caregivers impacted by IF. Creative strategies to facilitated

and maintain parental meaningful connections while being cognizant of potential negative consequences of online communities merits further consideration.

Benefits of Establishing Connections Between Children with IF

Noteworthy, findings from this study suggest that development of connections with similar families may also be an important source of informational and emotional support for children experiencing IF. Research has demonstrated that children who more accurately understand their chronic illness had an improved emotional state, reduced anxiety, and increased overall quality of life (Emedo, Godfrey, & Hill, 2010). Similarly, children who can achieve some degree of self-sufficiency are more empowered and develop more advocacy for their own care needs (Rafferty & Beck, 2019). Participants in this study identified that organized mentorship between children in similar situations could empower them to develop a stronger sense of identity. As children age, healthcare professionals need to consider providing age-specific educational programs to enhance their knowledge and learning about their illness. Further research is required to better understand how children are affected by IF and develop unique resources to empower them in their care. Early engagement of families with other disciplines like social work or child psychology should also be considered in facilitating social connections between parents and children with IF to better support their psychological needs.

Creation of an Electronic Informational Tool

In the current study, participants used the Internet for information seeking yet were frustrated by the quality, reliability, and relevancy of information. Participants explained that Internet searches produced more generalized, nonspecific information, and numerous negative possibilities, heightening their frustration and anxiety level. Further, material gathered online was often contradictory to information received by the medical team, compounding feelings of

stress and anxiety. Similar research has demonstrated that online health information differs significantly in reliability and accuracy (Benedicta et al., 2019; Jaks et al., 2019). Consequently, in our study the parents/caregivers heavily relied on the medical team as their main source of trusted information, which caused unrealistic expectations and increased stress when the medical team was unavailable to address practical troubleshooting and informational needs. Providing accessible and trustworthy digital resources has been found to increase parents' sense of trust and effective communication between them and the medical team (Benedicta et al., 2019). All participants in the study agreed that an online electronic resource curated by the medical team would be valuable as accessible, trustworthy, and reliable information resource.

Increasing Access to Information

Participants identified that a reliable and accessible electronic resource would be valuable for troubleshooting non-urgent medical interventions and concerns. Given increasing technology use in our society, there is opportunity for educational programs to utilize innovative and technology-based systems for general information delivery to patients and families. Ming and colleagues (2018) found that a mobile complex care plan synthesizing important patient information for CMCs, facilitated parental engagement and provided an important reference tool improving their understanding of their child's overall medical situation. The implementation of a virtual technological approach where the learner engages in a face-to-face video conversation and receives a real time expert response from pre-recorded clips, has also been shown to be effective in increasing patient knowledge on general topics and interventions (Knapp et al., 2013). Given current fiscal and time constraints associated with healthcare delivery, solely providing one-on-one informational support is not practical or sustainable. Alternatively, leveraging technology may be an effective way for medical teams to supplement or reinforce

general information more accurately. A digital solution may decrease parents' reliance on the medical team for minor troubleshooting concerns, allowing them more time to address urgent and critical needs.

Accessible electronic information was also noted as important by the participants for their child's transition home. The ability to access electronic visuals, such as instructional videos, could enable participants to gain much needed help with home procedures from trusted support systems. Once home, many participants assumed the role of educator, requiring them to teach medical skills; thus, videos provided by the medical team could support parents' skills development and reduce potential errors. Participants also had a desire to learn about current research related to pediatric IF once their child's health status was more stable at home. This type of information often provided a sense of hope, however, limited accessibility to this information was identified as a barrier. It was suggested that specific topics could be curated by the medical team in the electronic resource, allowing participants to review in their own time and at their own pace.

Digital Tools to Enhance Communication with Medical Team

Participants suggested that an electronic tracking resource template could decrease the time needed to correspond with the medical team about their child's status. Many participants were in frequent contact with the medical team regarding their children's outputs, food intake, hydration status, and growth measurements; however, each described a different method of tracking and sharing information. Implementation of an electronic resource was suggested by participants as a way to streamline information and communication of their child's condition to and from the medical team in a more efficient and timely manner. Electronic telehealth platforms have been shown to improve communication between patients, families, and healthcare providers

through the use of video-conferencing, remote monitoring, and high resolution images and video files (Utidiyan & Abramson, 2016). As a result of the novel coronavirus disease 2019 (COVID-19) pandemic, there has been a major shift towards providing remote healthcare services delivery using telehealth technology. Wosik and colleagues (2020) found that adoption of telehealth practices have provided successful delivery of hospital services in a variety of U.S healthcare organizations. Creating an electronic resource for parents to share information and notes (verbal discussions, meetings, and current research), receive skills training (instructional videos), and track their child's status (daily measurements) could provide more accurate, timely, and patient-specific information between families and care providers. A digital platform may also enable more flexible follow up, especially for families who are required to travel quite a distance for clinic appointments since IF rehabilitation teams are typically located in tertiary centres.

Usability of a Digital Platform Important

There was no consensus regarding the type of electronic platform that would be most useful, as participants were split between a website and a mobile phone application. Davis and colleagues (2017) found that while there are many digital platforms available that address a variety of healthcare needs, there is limited evidence about the quality and suitability for complex medical health applications. Technologies developed in collaboration with healthcare professionals and relevant users are needed to ensure content delivery, functionality, and usability of these systems (Davis et al, 2017). Given some resistance by participants in our study to the idea of resources shifting to a virtual platform, development of an electronic informational and educational tool *with* parents of children with IF as partners in the design is necessary to assure better relevance and uptake of the digital solution. Accessibility of relevant content and ease of use were noted by parents as the two important factors required for any electronic

resource provided. This virtual resource should not be designed as a replacement, but rather a complement to their learning, offering them the ability to gather reliable information and enhance timely communication with the medical team. Additional research is needed to develop a virtual tool and determine its efficacy in improving parents' knowledge and child health and developmental outcomes.

Limitations

There were several limitations related to the qualitative design of this study. Although themes were validated by experts in other programs across Canada caring for children with IF, there may be limited transferability of results as responses reflect the processes and education of a single center. Due to time constraints, themes were not verified through feedback to participants. Interviewing parents and caregivers in different programs could enhance credibility and validity of the themes identified. As well, selected participants varied greatly in years of experience in the program (seven months to 10 years). Thus, there may have been improvements to standards of care and updates to the educational program within that time range, leading to different retrospective observations from participants and lapses in recall. Additionally, participants in this study who have been with the CHIRP team longer may reflect families/caregivers of children who are more complex, have irreversible IF, and require higher medical needs such as indefinite PN infusions. Thus, their experiences related to uncertainty and lack of information of these participants may not be similar to families of children who achieve intestinal adaptation and no longer require PN infusions after a few years. Furthermore, given that only one male participated in this study, there was an over representation of the female perspective. More responses by male caregivers could have reflected different experiences and informational needs and warrants further study.

Implications for Nursing Practice

Our study findings have several implications for nursing practice. Currently, the pediatric IF population is growing with increased survivorship; however, findings of this study indicate that informational and educational needs of parents of children with IF were found to extend beyond what is presently offered by their primary healthcare team. Given current healthcare reform which aims to optimize care provided in the community, there is a need for advanced practice nurses to lead transitional care models, bridging acute, ambulatory, and home care settings of complex and chronic populations (CNA, 2019). Thus, there is an opportunity for advanced practice nurses in this complex population to develop innovative family-centered programs and resources, providing increased access to information and education to support patient–healthcare team communication for safe and effective care in the home.

The findings from this study have the potential to guide decisions on the development of an online educational tool for patients and families affected by IF and inform the creation of sustainable practice changes supported by evidence-based research. Advance practice nurses are responsible for using appropriate delivery methods to disseminate knowledge and creating educational programs that promote learning (CNA, 2019) highlighting a critical role for APNs in the development of these resources. Although the hands-on educational program provided by CHIRP nurses was identified as effective, additional resources to complement understanding and build self-efficacy would be beneficial when first learning skills as well as for management at home. Given the current situation with the world pandemic, a shift towards providing more remote or telehealth technology has never been more essential. Planning and implementing a diversified approach that uses a blend of digital and traditional methods of information delivery has the ability to capture a variety of learning styles and literacy levels to increase engagement

and comprehension. Trustworthy online information and educational sessions may also be valuable to support out of province patients who do not have similar local resources and access to the medical team. Future research and collaboration with participants in the development of a user-designed online system could identify innovative ways of providing tailored information to meet the unique needs of families identified in this study.

Applying emerging evidence and new technologies to change, enhance, or support healthcare providers in addition to the client and family is a core competency of advanced practice nursing (CNA, 2019), underscoring an opportunity for APNs to lead the development of a digital solutions to better address the health care needs of families. An accessible and updated digital resource would enhance knowledge of healthcare staff both in acute and community care, creating consistency between both areas. While updating resources to meet the large variety of needs of this population may be a large undertaking, it would encourage collaborative partnerships with other national and international clinicians. Coordinating knowledge and education with other centers could also increase the standardization of resources, education, and clinical practice, thus improving the care provided between centers in North America. This collaboration would increase innovation, avoid duplication of work, and decrease costs associated with technology creation and use. Creating standard informational resources may also decrease inconsistencies in practice between healthcare staff and families.

Another key finding of this project was the negative impact of uncertainty on caregiver emotional and mental health. Using a holistic and integrated approach, advanced practice nurses have the ability to provide comprehensive family-centered care in collaboration with other members of the healthcare team (CNA, 2019). As uncertain information is unavoidable due to the complexity and rarity of IF, additional clinical resources and research of enhanced

psychological supports among caregivers is needed. Advanced practice nurses working with families of children with IF could collaborate with other disciplines such as psychology or social work on effective interventions to improve caregiver resiliency. Assessing parents and introducing measures could enhance coping during the initial hospital admission, in preparation for the transition of their child's care, and extending to chronic care management.

Conclusion

The informational needs of families and caregivers caring for children with IF are complex, diverse, and change over time. The findings of this study highlight the need for additional sources of trustworthy, reliable and accessible information not only for parents/caregivers of children with IF, but also for healthcare professionals who provide their care. Parents' heavy reliance on the medical team for information is unrealistic and often leads to unmet informational needs. An opportunity exists for APNs to lead the development of electronic resources that enable better access for patients and families to reliable information while providing more time efficient, high quality care and monitoring. A blended approach to care team discussions with user-centred digital tools may benefit families by increasing their accessibility to reliable information, as well as time efficient, high quality care and monitoring. Finally, more psychological support for parents including facilitation of parent caregiver connections and their children with IF is needed to improve their overall mental well-being.

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APPENDIX A: RECRUITMENT POSTER

Exploring the Informational Needs of Parents of Children with Intestinal Failure

PARENTS: We would like to understand your informational and educational needs when caring for children with Intestinal Failure.

Study Background:

Intestinal Failure (IF) in children is a rare, complex, and chronic condition. Management of this condition needs much medical attention and can be challenging. In this study, we hope to help better understand the informational needs of parents and caregivers with children with pediatric IF. Family education has been shown to improve patient outcomes and lower parental anxiety. Results of this study could help healthcare professionals provide better educational support and possibly through the use of online technology or tools.




Do you have a child:
Who is followed by the CHIRP clinic for nutrition and/or growth issues?

THEN WE WOULD LIKE TO TALK TO YOU!

Interested?

Give your name and contact information (phone or email) to the CHIRP RN and someone from the research team will contact you.



The University of Calgary Conjoint Health Research Ethics Board has approved this research study. (REB 18-0636)

APPENDIX B: CONSENT FORM

STANDARD CONSENT FORM

TITLE: Exploring Information Needs of Parents of Children with Intestinal Failure: A Thematic Analysis

SPONSOR: University of Calgary

INVESTIGATORS: Dr. Linda Duffett-Leger and Lily Sia Lu. Dr. Duffett- Leger can be reached at University of Calgary, PF2224, 2500 University Drive NW, Calgary Alberta, Canada, T2H 1N4. Ph: [REDACTED].

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form for your records.

BACKGROUND

Intestinal Failure (IF) in children is a rare, complex, and chronic condition. Management of this condition needs much medical attention. Children with IF can have long hospital stays, experience many re-admissions, and need medical devices for nutrition and growth support. This complex management can be challenging for both families and healthcare professionals.

Family education has been shown to improve patient outcomes and lower parental anxiety. As IF is rare and can be unique to every child, there are no consistent guidelines available to help direct care and management. Even with resources provided by the care team, parents still have questions and are using other resources from the Internet to answer their questions and manage their children's care. These resources can be unreliable and do not always give the right information. In this study, we hope to help better understand the informational needs of parents and caregivers with children with pediatric IF. This will help healthcare professionals provide effective educational support. More specifically, we hope this information will help develop online tools to help with parent education in this area.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to explore the informational needs of families with children with pediatric IF from initial diagnosis and through ongoing care and management.

Together with Alberta Children’s Hospital partners, knowledge from this study will be used to develop an online resource to support and meet the informational needs of families with children with IF.

WHAT WOULD I HAVE TO DO?

If you agree to take part in this study, you will have the option to participate in either a focus group or in a one-on-one interview. Questions asked will be about your experience with information and education given to you during your child’s illness journey. Interviews are expected to be approximately one hour long. The information provided will be kept confidential and only be used to create a general picture on the informational needs of families of children with IF.

You may also be asked if you would be willing to be contacted at a later date to validate any responses given in the interview. This would involve providing your name, phone number and/or email. All personal information provided will be kept strictly confidential.

WHAT ARE THE RISKS?

There are no known direct risks associated with participating in this study.

WILL I BENEFIT IF I TAKE PART?

If you agree to participate in this study, there may or may not be a direct benefit to you. The information we get from this study may help us to provide better educational resources in the future for families caring for children with pediatric IF.

DO I HAVE TO PARTICIPATE?

Your participation is voluntary. You may refuse to participate, or choose not to answer any questions. You may also withdraw from the study at any time with no negative impacts. However, since this is a group exercise, we will not be able to withdraw your contributions up until the time that you physically withdraw from the study.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

You will not be required to pay anything to participate in the study. If needed, you will be reimbursed for parking cost for the interview at the Alberta Children’s Hospital.

WILL MY RECORDS BE KEPT PRIVATE?

Your participation in the study will be treated as confidential. Your identity will be kept anonymous and will not be referred to by name in any report of the study. Information collected will be stored in password-protected files. Only individuals involved in the study will have access to this information.

SIGNATURES

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a participant. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without consequence. If you have further questions concerning matters related to this research, please contact:

Dr. Linda Duffett-Leger [REDACTED]

Or

Lily Sia Lu [REDACTED]

If you have any questions concerning your rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary at 403-220-7990.

Participant's Name	Signature and Date
Investigator/Delegate's Name	Signature and Date
Witness' Name	Signature and Date

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.

APPENDIX C: DEMOGRAPHIC QUESTIONNAIRE

Participant Identifier	
Parent Information	
1. Age	
2. Gender	<input type="checkbox"/> Male <input type="checkbox"/> Female
3. Marital Status	<input type="checkbox"/> Single (never married) <input type="checkbox"/> Married <input type="checkbox"/> Other: _____
Child Information	
1. Current Age	
2. How long has your child been on parenteral nutrition or actively followed by the CHIRP clinic?	<input type="checkbox"/> less than 6 months <input type="checkbox"/> 6-12 months <input type="checkbox"/> 13-24 months <input type="checkbox"/> 25-35 months <input type="checkbox"/> 3-5 years <input type="checkbox"/> more than 5 years
3. Gender	<input type="checkbox"/> Male <input type="checkbox"/> Female
4. Medical Devices	<input type="checkbox"/> Central Line <input type="checkbox"/> Ostomy appliance <input type="checkbox"/> Enteral tube <input type="checkbox"/> Other: _____
5. Current applicable treatment(s)	<input type="checkbox"/> Parenteral Nutrition <input type="checkbox"/> Enteral Nutrition support <input type="checkbox"/> Modified Diet <input type="checkbox"/> Oral Medications (number?) <input type="checkbox"/> Clinic visits (divided by frequency?) <input type="checkbox"/> Anti-coagulant treatment <input type="checkbox"/> Other: _____

APPENDIX D: INTERVIEW GUIDE

Experiences with Intestinal Failure while still in the hospital

1. Think back to the time you received your child's diagnosis. What type of information did you receive from the healthcare team that was helpful in understanding your child's diagnosis?
2. What other resources did you use to help you understand your child's condition and management and how did you access them?
3. What part of your child's diagnosis or care was the most difficult to understand and why?
4. Tell me about your experience in preparing to go home:
 - a. What was most helpful for learning the skills needed to care for your child at home?
 - b. When did you feel prepared to go home with your child?
5. If you were to make improvements on the information you were provided during your stay in the hospital and your preparation to go home what would they be?

Experiences with Intestinal Failure after the first discharge home from the hospital

1. What resources do you currently use to get health information about your child's condition and care management?
2. How do you access those resources?
3. What makes those resources helpful to help you manage your child's care?
4. What improvements could be made to those resources to be more helpful for you?
5. Are there any topics about your child's disease, minimizing complications, or daily care you would like to learn more about?

6. What would be helpful in learning to feed your child?
7. How do you manage your child's medical information? What would helpful?
8. What type of format (web page, mobile app, brochure, one-on-one teaching etc.) would you prefer to answer your concerns and questions about your child's management and care?

APPENDIX E: PERMISSIONS FOR PUBLISHED MANUSCRIPT

November 10, 2020

Dear Dr. Duffett-Leger,


I am writing to request permission to include our co-authored manuscript listed below in as part of my Master thesis. My thesis will be deposited with the University of Calgary's institutional repository (<https://prism.ucalgary.ca/>) and the Library Archives Canada (Library and Archives Canada <http://collectionsCanada.gc.ca/obj/s4/f2/frm-nl59-2-e.pdf>).

The manuscript requested to be included in the thesis is:

- Ragan, L. A., Duffett-Leger, L., Laing, C. M., & Boctor, D. L. (2020) Exploring informational needs of parents of children with intestinal failure: A thematic analysis.

Prepared for submission. Target journal: *Journal of Pediatric Nursing*.

Your signature will indicate that you agree to this manuscript being reproduced in its entirety as part of Lily Ragan's thesis entitled "Exploring Informational Needs of Parents of Children with Intestinal Failure: A Thematic Analysis".


A black rectangular box redacts the signature of Dr. Duffett-Leger. Below the box, a horizontal line is visible, and the bottom of the signature's strokes can be seen.

Co-author's signature
Dr. Duffett-Leger

Thank you,

Lily Ragan

November 10, 2020

Dear Dr. Boctor,

I am writing to request permission to include our co-authored manuscript listed below in as part of my Master thesis. My thesis will be deposited with the University of Calgary's institutional repository (<https://prism.ucalgary.ca/>) and the Library Archives Canada (Library and Archives Canada <http://collectionscanada.gc.ca/obj/s4/f2/frm-nl59-2-e.pdf>).

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Prepared for submission. Target journal: *Journal of Pediatric Nursing*.

Your signature will indicate that you agree to this manuscript being reproduced in its entirety as part of Lily Ragan's thesis entitled "Exploring Informational Needs of Parents of Children with Intestinal Failure: A Thematic Analysis".



Co-author's signature
Dr. Boctor

Thank you,

Lily Ragan

November 10, 2020

Dear Dr. Laing,

I am writing to request permission to include our co-authored manuscript listed below in as part of my Master thesis. My thesis will be deposited with the University of Calgary's institutional repository (<https://prism.ucalgary.ca/>) and the Library Archives Canada (Library and Archives Canada <http://collectionscanada.gc.ca/obj/s4/f2/frm-nl59-2-e.pdf>).

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- Ragan, L. A., Duffett-Leger, L., Laing, C. M., & Boctor, D. L. (2020) Exploring informational needs of parents of children with intestinal failure: A thematic analysis. Prepared for submission. Target journal: *Journal of Pediatric Nursing*.

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Co-author's signature
Dr. Laing

Thank you,
Lily Ragan