The Development and Evaluation of a Knowledge Translation Tool for Caregivers of Children with Heart Failure

by

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Abstract

Background: Having a child diagnosed with pediatric heart failure (PHF) is an anxiety-provoking experience for caregivers due to its high morbidity and mortality. PHF can follow a more chronic trajectory (e.g., cardiomyopathy, neuromuscular disease, myocarditis, etc.) where children who have exhausted or have no surgical options experience lifelong burdensome symptoms. With advancements in clinical management, children are now surviving and being discharged home. Thus, the focus has shifted from mere survival to day-to-day disease management and quality of life. For a child to be safely discharged home, caregivers need to acquire, understand and apply complex information about their child's heart failure. Daily decision-making about their care largely rests on caregivers in the home and can affect the child's outcome. Empowering caregivers in this context with relevant and understandable health research through targeted knowledge translation strategies will have better knowledge uptake, improve day-to-day management (decision-making) and experience less stress. These elements also reduce stress on the healthcare system. Currently, little is known about caregivers' information needs, experiences and preferred platforms.

Purpose: Guided by the Knowledge to Action Framework, this research utilized a multi-phase process to develop and evaluate a caregiver-targeted knowledge translation tool about PHF to enhance knowledge uptake about their child's health condition. The four aims were: 1) Identify and evaluate online caregiver-targeted PHF educational KT tools to understand gaps in current online education; 2) Examine what currently published knowledge and gaps exist about caregiver's information needs and lived experience; 3) Understand what lived experience and learning needs through qualitative interviews; and 4) Develop, refine and disseminate a digital

KT tool for caregivers about their child's PHF informed by research stages 1 and 2, medical guidelines and substantive expert opinion.

Methods: Four research approaches: 1) Environmental Scan, 2) Qualitative Evidence Synthesis (QES), 3) Qualitative Description (QD) and 4) Usability and Knowledge Acquisition Testing.

Results:

1) Phase 1. ES: Findings revealed no apps and few online tools for caregivers (n=17), with resources scoring in the superior literacy range. This study identified gaps and features that informed the creation of the final knowledge translation tool that targeted caregiver audiences (e.g., plain English, improved graphics, relevant reading level).
2) Phase 2a. QES: One article met the inclusion criteria, highlighting the limited qualitative knowledge used to inform previous educational strategies in the clinical setting. These findings emphasize that caregiver education is primarily based on a combination of healthcare practitioner perception, limited input from caregiver groups, and a lack of research evidence.
3) Phase 2b: QD Interviews: This study's findings highlight caregivers' learning needs and experiences caring for a child with heart failure. The coding of 11 caregiver interviews shaped two main categories (a traumatic diagnosis of heart failure influences learning and a new reality for life going forward).
4) Phase 3: Development, Evaluation, and Refinement of a Knowledge Translation Tool. From the subsequent two phases of research about caregiver experiences and learning needs, medical guidelines and substantive expert opinion, we created and evaluated a knowledge translation tool for caregivers of a child with PHF. This resulted in a highly

rated educational tool for caregiver audiences, demonstrating a predominant knowledge improvement and requiring minimal refinements.

Conclusions: The findings from this research identified and addressed several significant knowledge gaps about existing chronic PHF educational tools and previously published literature. Caregivers' lived experiences and learning needs were also explored. These phases informed the development of a patient-targeted online educational tool about PHF, along with the most recent evidence-based care recommendations and substantive expert opinion. With collaboration from a graphic designer, this research informed the development of an online infographic into more understandable formats for caregiver audiences to learn about their child's disease, reduce stress and provide research-informed care.

Preface

The papers in this dissertation are original works by Chentel Cunningham. The University of Alberta, Research Ethics Board granted ethics approval ("Partnering with Families to Co-Create an Arts-based Knowledge Translation Tool about Pediatric HF," Pro00106559, March 3, 2021). Dr. Scott provided the overall concept formation of this dissertation after being approached with a clinical problem. Papers one and three have been published; paper two is prepared for publication and paper four is under review.

Paper one has been published as Cunningham C, Sung H, Benoit J, Conway J, Scott SD. Multimedia knowledge translation tools for parents about childhood heart failure: ES. *J Med Internet Res: Pediatr Parent*. 2022;5(2):e39049. doi:10.2196/39049. A correction was submitted and published due to a minor typo in my PRISMA flow diagram as Cunningham C, Sung H, Benoit J, Conway J, Scott, SD. Multimedia Knowledge Translation Tools for Parents about Childhood Heart Failure: ES. *J Med Internet Res: Pediatr Parent.* 2022;5(2):e39049. doi:10.2196/39049. I was responsible for the search, qualitative interviews, data extraction and analysis, manuscript composition, writing, submission, and response to the peer reviewers' feedback. Ms. Sung assisted as a second reviewer for inclusion and analysis of the internet search results and manuscript edits. Dr. Conway was the substantive expert and contributed to the various stages of manuscript construction. Dr. Scott was the supervisory author and contributed to conceptualizing the study, composition, and manuscript edits.

Paper two is prepared for submission as Cunningham C, Schroeder K, Conway J, Scott, SD. A QES exploring caregiver's information needs and experiences about caring for a child with heart failure to *Prog Pediatr Cardiol*. I was responsible for the study design, search, analysis, and manuscript composition. Ms. Schroeder was the second reviewer. Ms. Plesuk provided the search expertise and manuscript feedback. Dr. Conway was responsible for providing substantive advice on the search concepts and manuscript composition and edits. Dr. Haykowsky provided substantive advice, methodology input and manuscript feedback. Dr. Scott, the senior author, provided formative feedback on the manuscript at various stages, librarian support, advice throughout the study and submission process and manuscript publication advice.

Paper three is published as Cunningham C, Conway J, Zahoui Z, Scott SD. Exploring Caregiver Experiences and Learning Needs Caring for a Child with Heart Failure: A Qualitative Study. *CJC: Pediatr Congenit Heart Dis.* 2024;3(4):152-160. doi:10.1016/j.cjcpc.2024.05.003. I was responsible for conducting the semi-structured interviews, data collection, cleaning and analysis, and manuscript preparation. Mr. Zahoui was responsible for data cleaning and analysis. Dr. Conway contributed to the manuscript composition with feedback. Dr. Scott, the senior author, provided ethical guidance on how to store data and provided advice and feedback on every stage of analysis and manuscript preparation.

Paper four is under review as Cunningham C, Conway J, Schroeder K, Khoury M, Urschel S, Haykowsky M, Scott SD in *J Med Internet Res: Cardio* (Submission ID: MS 59748). I was responsible for the tool development, data collection and cleaning, analysis, manuscript composition, writing and editing, and will submit responses from peer reviewers. Dr. Scott provided guidance and expertise on tool development, recommendations for a professional graphical designer and tool design, and manuscript edits. Drs. Conway, Urschel, Khoury, and Mrs. Schroeder provided content expertise on tool content and manuscript edits. Dr. Haykowsky contributed to guidance on manuscript edits. Dr. Scott provided the infrastructure to develop and refine the knowledge translation tool through her Canadian Institutes of Health Research and the Stollery Science Lab's Distinguished Researcher funding. Dr. Scott was the supervisory author of this project and was extensively involved in developing and evaluating the knowledge translation tool.

Dedication

I dedicate this dissertation to my best friend and husband, Wesley Cunningham. You provided unwavering support to continue and finish throughout this six-year journey, even when the path wasn't always straightforward. Words could never express my gratitude and appreciation for your love, support, and sacrifices, which allowed me to pursue my passion and dreams of pursuing and finishing my graduate education.

To my children, Addison and Vaughn Cunningham. For most of your lives, you have watched me study without reservation. You have been supportive, proud, patient and understanding during this long process. Even though you had a limited understanding of my awards and successes along the way, you still cheered me on. My work ethic and love for advanced education will inspire your future pathway in life. I love both of you very much.

To my parents, Brian and Leanne Cikaluk. All your encouragement and belief in me inspired me to achieve success. You have given me the confidence to tackle complex tasks, shown me to always choose integrity and morals, be thankful for advanced education, and taught me that life involves continuous learning. Mom and Dad, I watched you raise a young family with few resources, and your hard work and dedication to our family undoubtedly shaped who I am today. Thank you for all your unconditional love and guidance.

To my sister, Kristin. Thank you for always making me laugh and encouraging me to reach the finish line. Your positive attitude, willingness to compromise, and support helped me reach this important milestone.

To my late brother, Craig Cikaluk. Even though you are not today to see or read this accomplishment, I know you were and would be incredibly proud. My doctoral degree will symbolize to your son the importance of having an advanced education, hard work, and finishing. I promise to support Lane during his educational journey in your memory.

Acknowledgements

To my doctoral supervisor, Dr. Shannon Scott. My gratitude for accepting me as a student, providing continuous support and encouragement while learning, and showing me strategic ways of navigating my doctoral journey was the underpinning of my success. I am so grateful that I could have you as my supervisor. Your support allowed me to develop an excellent foundational research skillset, and your mentorship allowed me to grow as a person, leader, and mother with a prestigious career. You also had confidence in me, which has shaped me to become a successful clinician-researcher. Your previous work inspired my research to help families who encounter heart failure. Thank you so much.

Thank you to my mentors and committee members, Dr. Jennifer Conway and Dr. Mark Haykowsky. Your knowledge, feedback, and steadfast support were instrumental in completing this work. Jennifer, you allowed me to embark on this journey, even though it meant some sacrifices to our Heart Failure program. I am forever grateful to be surrounded by such intelligent, outstanding mentors and committee members.

Thank you to the present and former ECHO staff: Hannah Brooks, Anne Le, Samantha Louie-Poon, and Kathy Reid. Your assistance undoubtedly contributed to my success. I would also like to extend a thank you to the staff at the Faculty of Nursing, especially Anita, Tracy, and Janet.

Thank you to all my new friends and nursing colleagues I have met along this journey. Starting this road alone was intimidating, but connecting with a few remarkable people also embarking on their PhD provided the support I needed to succeed. Your friendship, stories, support, motivation, and laughs helped me cross the finish line. Many thanks to Alison Campbell, Lisa Knisley, Keith King and Higinio Fernández-Sánchez. Thank you to Katie

Schroeder for your support along this journey and co-worker. Your help was also critical to this journey.

I would also like to thank all the organizations that supported me financially as a doctoral student. Without the educational funding, this degree would not have been possible. Thank you to the Women and Children's Health Research Institute, the Canadian Nurses' Foundation, the Alberta Registered Nurse Educational Foundation and the Faculties of Nursing and Graduate Studies and Nursing at the University of Alberta. Finally, Dr. Shannon Scott's research funding and the Canadian Institutes of Health Research. Your funding helped me become the successful and competitive student I have become today.

Most importantly, thank you to my patient population and families. Sharing your stories has been life-changing and the inspiration for this research. I now better understand the difficult and uncertain trajectory families face as caregivers when then they are told their child has heart failure. You are the underpinnings of this dissertation work and have changed how I think and execute my advanced nursing practice.

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Glossary of Terms

Pediatric Heart Failure (PHF). HF in children (aged 0-18 years) can be defined broadly as the failure of the heart to supply oxygen and nutrients to either systemic or pulmonary circulation at an appropriate rate of their metabolic needs, resulting in adverse effects on the heart, vasculature and skeletal muscle.[1] Children with a more chronic trajectory of heart failure are a heterogeneous group of children with congenital and acquired heart failure that have a heart muscle disease that is not amendable to surgical intervention.

Environmental Scan (ES). Environmental scanning is a method used to collect and organize information on the contexts and appraise available tools or resources' impact on a target audience's decision-making.[2]

Qualitative Evidence Synthesis (QES). QES is an evidence-based practice because researchers collate qualitative research on similar contexts across a large area of literature to synthesize the best evidence.[3]

Qualitative Description (QD). QD is a method used in qualitative research for studies that are descriptive in nature and is particularly common in qualitative studies in health care and nursing-related phenomena. These studies look to describe the who, what, and where of the events or

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[1] Kantor PF et al. Presentation, diagnosis, and medical management of heart failure in children: Canadian Cardiovascular Society guidelines. *Can J Cardiol*. 2013 Dec;29(12):1535-52. doi:10.1016/j.cjca.2013.08.008

[2] Diouf NT et al . Training health professionals in shared decision making: update of an international environmental scan. *Patient Educ Couns*. 2016 Nov;99(11):1753-1758. doi:10.1016/j.pec.2016.06.008

[3] Ludvigsen MS et al . Using Sandelowski and Barroso's Meta-Synthesis Method in Advancing Qualitative Evidence. *Qual Health Res*. 2016 Feb;26(3):320-9. doi: 10.1177/1049732315576493

experiences by gaining insight from informants that cannot be answered by numerical data collection.[4]

Patient Engagement (PE). PE is the integration of patients becoming actively engaged as patient partners in the research project and governance by contributing to the priority setting, developing the research questions, and performing certain parts of the research itself.[5]

Knowledge Translation (KT). KT is defined as a dynamic and iterative process that includes synthesis, dissemination, exchange, and ethically sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system.[6]

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[4] Kim H et al. Characteristics of Qualitative Descriptive Studies: A Systematic Review. *Res Nurs Health.* 2017 Feb;40(1):23-42. doi:10.1002/nur.21768

[5] Canadian Institutes of Health Research. *Strategy for Patient-oriented Research - Patient Engagement Framework*. 2014. Retrieved from http://www.cihr-irsc.gc.ca/e/48413.html

[6] Canadian Institutes of Health Research. *Guide to Knowledge Translation Planning at CIHR: Integrated and End-of-Grant Approaches*. 2015. Accessed March 23, 2024. https://cihr-irsc.gc.ca/e/45321.html

CHAPTER 1. Introduction: Situating the Research

This chapter introduces the main elements of this dissertation research, including background information on PHF and its clinical management, caregivers' role, and a general discussion of knowledge translation research and patient engagement. This overview will present details of the research in phases with the philosophical and theoretical foundations. Each paper that shaped the dissertation is briefly introduced and its connection.

Background

PHF Overview

Imagine hearing that your child has heart failure. After surviving a life-threatening infection, a cancer diagnosis with chemotherapy treatments, numerous cardiac surgeries, or having a previously healthy child, parents are undoubtedly thrown into a sea of anxiety and uncertainty about their child's survival. Heart failure in children is becoming more prevalent due to increased recognition in the last few decades from pediatric cardiology healthcare providers. Approximately 11,000 – 14,000 pediatric hospitalizations are due to PHF annually in the United States, with 87% of all initial cases being diagnosed after a severe decompensation requiring invasive, life-saving medical interventions.[1] Currently, no Canadian data has been reported.

PHF is a combination of symptoms that can result from numerous health conditions.[1-3] Heart failure symptoms have numerous etiologies that are a consequence of either cardiac and non-cardiac conditions, and can result from over circulation or reduced oxygen and nutrients circulating to the other organs in the body, triggering a cascade of circulatory, neurohormonal, and molecular responses.[4] These responses are an attempt to compensate (e.g., tachycardia, fluid retention, peripheral constriction to major organs) for the reduced blood flow. Long-term, these compensatory mechanisms are harmful and produce symptoms of heart failure. Children with heart failure experience different combinations of symptoms compared to adults exhibiting growth failure, fatigue, activity limitations, poor feeding, gastrointestinal upset, dyspnea and edema. These symptoms impair a child's ability to grow and develop and can be life-limiting.[2-4]

A subset of patients with heart failure experience a more chronic trajectory due to pump failure or heart muscle disease from numerous etiologies (e.g., cardiomyopathy, neuromuscular disease, myocarditis, or children with single ventricle physiology).[2] They are burdensome and can pose lifelong burdensome exacerbations, affecting a child's quality of life and placing uncertainty about their survival. The underlying etiologies are not amenable to surgical (anatomical) repair to relieve symptoms, like children with anatomical overcirculation.[2] Chronic heart failure symptoms unfold a different healthcare journey with unique needs due to care considerations related to surgical repair of their heart defect. Rather, medications and medical therapies are the mainstay of treatment, with the goal of care focusing on reducing or avoiding exacerbations. Some children experience refractory heart failure where advanced therapies such as home intravenous inotropes, mechanical assist device implantation or cardiac transplant are the only options for survival.[3] Children with congenital heart disease who have undergone previous anatomical repair are also at risk and can experience heart muscle disease or pump failure, making this a heterogeneous, complex population. Due to the increased recognition by healthcare professionals and advancements in management strategies continually evolving (e.g., clinical guidelines), improved survival is now occurring in children with HF.[1] To explicitly state as a boundary, this dissertation will focus on the population of children and families who experience chronic heart failure.

Evolution of Published Care Guidelines in PHF

Two key published North American guidelines exist as references for management in children with heart failure in this dissertation. In 2013, Kantor et al. and the Canadian Cardiovascular Society published the first paper on care guidelines for the presentation, diagnosis and medical management of children with heart failure.[2] This set of guidelines was an evidence-based consensus of a Canadian panel of multidisciplinary substantive experts in children's heart failure to provide a reasonable and practical evidence-based approach to guide care.[2] The quality of evidence was evaluated using the Grading of Recommendations Assessment, Development and Evaluation (GRADE) method. The focus is on the acute management of heart failure exacerbations, which can affect children who are initially diagnosed or have repeated chronic exacerbations. The target audience for these guidelines is office-based or emergency room healthcare professionals who require management guidance in more acute scenarios.

One year later, Kirk et al. and the International Society of Heart and Lung Transplantation updated the second guideline.[3] This guideline was an updated version of the previous 2004 recommendations.[5] Key stakeholders involved in the document include multidisciplinary experts from multiple organizations in North America and Europe (90 contributors from 13 countries across 4 contents). Like Kantor's Canadian guidelines,[2] Kirk's guidelines comprehensively reviewed and came to a consensus about the most recent published evidence for heart failure management in children using the Canadian Task Force on the Periodic Health Examination, but from a more chronic end-stage lens. These guidelines are a component of this group's completed monograph series, intended for healthcare and academic audiences regularly encountering chronic PHF in their daily practice.

Caregivers’ Essential Role in the Management of Chronic PHF

Since care has evolved and improved, patients with a chronic trajectory now involve discharge and outpatient management rather than merely focusing on survival. Evidence-based PHF guidelines recommend weight monitoring, fluid restrictions, tailored nutritional plans, polypharmacy, CPR training, frequent testing, and hospital visits.[2,3,7] As family-centred care remains the hallmark of pediatrics,[6] parents or designated caregivers are responsible for ongoing daily management following discharge. Successful outpatient management involves caregiver suitable education to acquire new medical knowledge about PHF symptom recognition and management.[6] The attainment of this immense volume of knowledge by parents can be extremely daunting, presenting an opportunity for caregiver knowledge gaps about their child’s health condition and management, leading to anxiety and stress.

Caregiver Knowledge Gaps

Many factors can be attributed to caregiver knowledge deficits in the PHF context. While it is well established that caregivers avidly search for health information online,[10-13] it is also well respected that health information exclusively prepared by healthcare professionals may be too complicated or not provide needed detail, leaving caregivers with uncertainties and knowledge gaps about their child’s health condition.[6,9] Furthermore, there has been a significant lag in knowledge translation strategies to provide this knowledge in understandable formats for caregivers. These gaps can result in numerous unnecessary access to the healthcare system, less participation in healthcare decisions, and heightened familial anxiety.[14] Similar to PHF in terms of the demand for intensive monitoring, the pediatric hypoplastic left heart syndrome literature has highlighted that caregivers can become hypervigilant as a result of stress and uncertainty.[15] Additionally, when caregivers face stressful events, like hearing their child has heart failure or their health is worsening, this stressful event can disrupt crucial memory processes, giving rise to gaps in knowledge.[16] However, to help lessen parental knowledge gaps, knowledge translation (KT) tools have been developed in other child health conditions (e.g., asthma, croup, bronchiolitis, pain).[17-21] These tools effectively translate complex medical knowledge into more effective educational resources and have been shown to reduce caregiver knowledge gaps.[22]

Throughout my advanced clinical practice, I have experienced many caregivers demonstrating knowledge gaps pertaining to their child's heart failure. Furthermore, no evidence-based recommendations exist for health care practitioners or families regarding the quality or types of educational tools about PHF that can be used to educate these families. I will understand these knowledge gaps with my dissertation and co-create a resource about PHF with patient-engaged research techniques. Having a tool developed with these patient-engaged methodologies will create an evidenced-based tool that is accurate, credible, and relevant.

Online Knowledge Translation Strategies

With the creation of the internet, online digital KT tools (e.g., online tools, applications) have evolved to be a key component of delivering complex health information and come in various formats (e.g., digital infographics, videos, or e-storybooks).[10-13] This format can be easily updated by health professionals and accessed by most caregivers.[14] Several childhood illnesses have successfully employed this information delivery in acute and chronic pediatric conditions.[14,22] The purpose of a KT tool is to lessen caregivers' knowledge gaps via technology-driven formats that will help reduce their stress, empower their decision-making capabilities, and potentially improve their child's health condition.[14] To date, there is little understanding of what tools or resources exist for caregivers who have a child with heart failure.

Patient Engagement and Public Participation Spectrum

Patient engagement encompasses the concepts of patient-centeredness, education provision, and empowerment.[23] Engaging patients (or end users of healthcare) can (re)shape their care and treatment to fit their needs and preferences, ultimately improving outcomes and satisfaction.[24] PE is used in the context of education and policies and in enhancing health services and governance.[25] Examples of methods used to engage patients are focus groups, surveys and participatory research (most active form).[26] Patient engagement can include patients and their caregivers in pediatrics to make healthcare care delivery more relevant to their needs.[27] However, different methods exist for pediatric engagement due to growth and development considerations and proxy caregivers. Patient engagement is critical to developing an educational intervention that is relevant and applicable. Furthermore, it can result in research strategies that are more streamlined and impactful to caregivers' everyday lives.

There is no one accepted definition or recipe for effective participation in research.[27] First proposed in the early 2000s, patient participation in research can be on a spectrum, as outlined by the International Association for Public Participation (IAP2) group.[28] Their goal is to advance public participation globally, which can increase community influence.[28] They have developed a spectrum suggesting different levels of public participation in projects with increasing intensity of participation from left to right (i.e., Inform, Consult, Involve, Collaborate, and Empower). Bobbi (2023) supports this spectrum by suggesting that varying proposals, models, arrangements, methods, and devices have been produced using different levels to achieve patient engagement.

Careful consideration of the population under study in this dissertation (i.e., caregivers of children with chronic heart failure) was needed as they face a heavy schedule with multiple daily tasks, appointments and monitoring of their child, especially shortly after diagnosis when they face the most stress and learning. For this dissertation, I chose to balance the needs of my parent group with the needs of the dissertation while still producing a product with a mid-level of caregiver participation and feedback to make it relevant. For those reasons, I chose the public participation level at the spectrum's mid-level "Involve" stage. Involve is defined as 'to work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood." One method through which patient engagement is enacted is through involvement level qualitative interviews.[29] The first two studies were also related to grey and published searches of the literature to articulate current knowledge gaps. The most meaningful and impactful participation in this dissertation happened during the qualitative interviews and tool design, which involved caregivers of children with chronic heart failure with qualitative interviews to shape the design and surveys to provide feedback.

Reflexivity: Evolution of the Dissertation

My worldview for this dissertation work is shaped by my pediatric advanced nursing practice and a holistic view of helping families through their difficult journey. Following graduation from my undergraduate degree, I practiced in the Pediatric Intensive Care Unit as a Registered Nurse, caring for some of the sickest children with cardiac conditions in Western Canada. This experience allowed me to gain exposure and interact with many families in their most vulnerable and desperate times. I observed how stress affects their ability to retain and apply complex information. After 11 years of practice, I decided I was ready to make a more widespread impact by contributing to nursing science to gain more independence and work with families in a more independent and autonomous role, so I enrolled in the Master of Nursing program. From 2008-2012, I focused on garnering more knowledge to build my now successful pediatric advanced nursing practice in cardiology. My final placement was in pediatric cardiology, built on my intensive cardiac care clinical practice as a registered nurse. This role brought new challenges of practicing in an advanced role as a nurse practitioner within pediatric cardiology. I accepted an advanced practice role in the pediatric cardiology department, caring for children during the postop period on the ward.

During this time, I developed an advanced nursing skill set in this highly intense environment, being able to care for the sickest children on the ward while building meaningful relationships with caregivers. Through my excellent performance, leadership, and strong connection to my patients and families, I was offered the opportunity to develop the first PHF service in 2013 by the cardiology divisional director. The director believed I would succeed with my previous intensive care experience and observed my ability to build long-lasting relationships with families in these vulnerable situations. Since developing the first children's heart failure program and later developing the home milrinone program, I have been able to experience the complexities and challenges of how knowledge is translated to families when they have a child with heart failure. I have witnessed first-hand how their knowledge gaps can complicate and hinder their child's medical journey or how knowledge can empower and help them through stressful times. Knowledge gaps hinder caregivers' health, not only their children's, as they are prone to anxiety and stress-related issues. This led me to embark on my PhD, wanting to study and explore essential questions pertaining to knowledge translation strategies with caregivers. Also, I want to pass my noteworthy nursing knowledge and the high standard of care I have garnered onto the next generation of nurses entering our discipline. I hope to improve family and patient outcomes and the healthcare system through the final KT tool that results from my dissertation work. I am very passionate and committed to ensuring families are well supported during their unique heart failure journeys.

Throughout my career and doctoral coursework, it has become evident that I possess a pragmatic approach to both my approach to patient care and my new research skill set. I have always been passionate about finding answers to clinical questions and providing valuable solutions using many approaches. This theoretical realization became clear during my theory courses: pragmatism was a natural philosophical approach that deeply resonated with me. Pragmatism is well-known for its distinct and practical approach to finding the truth through mixed methods approaches.[27] I have made significant contributions to the discipline of nursing through this work by melding my philosophical underpinnings and clinical practice, using a philosophical pragmatic approach. Due to the nature of the nursing role, which allows for close contact with patients and families, nurses are in the perfect position to work together (or engage) with families to develop resources to meet their information needs.[25-27] Nursing embodies a holistic approach, providing the optimal relationship to understand a diagnosis's impact on a child and their family. Nurses are in the unique position to have a firsthand view of how families' lives are forever changed after their child receives a diagnosis, especially in scenarios that involve chronic illness.

Ontology: The Nature of Reality

Ontology is the study of being and is concerned about what constitutes reality or what can be known about reality.[25] The ontological perspectives of pragmatism are that reality exists within various life contexts, is dynamic and is perceived differently depending on what viewpoint or lens.[26] The ontological approach to my dissertation is shaped from a pragmatic perspective, as I know that multiple realities exist for myself and the caregivers I encountered. From this, acknowledgement and value can be placed on the fact that all information needs differ for all families and healthcare providers. To further situate the ontology in the field of PHF and my clinical practice, there is no one truth, as experiences with PHF are unique and nuanced; therefore, this ontological lens also holds multiple realities.

Epistemology: The Nature of Knowledge

Epistemological assumptions relate to the study of knowledge, which looks at how knowledge can be created, developed, and communicated and how academics can be confident about what they know.[30,31] The epistemological view of pragmatism looks to combine how to build knowledge through meaningful actions. In essence, pragmatism looks to find truth in situations through practical, real-world applications.[32] Pragmatism also looks to uncover the truth through real-world lived experiences, which also lends to this practical philosophical stance.[32] This epistemological view aligns with my dissertation work as I seek to uncover new, relevant research about patients and their families from my real-world experiences caring for patients with PHF in my clinical care. The resultant tool will be one that I can meaningfully apply to the practice domain of PHF for myself and other practitioners who may have similar questions. Also, the goal is to better educate and empower caregivers with understandable information to improve their decision-making skills and improve the outcomes and health of their child.

I have adopted the theoretical belief of pragmatism to position and conduct this research. Pragmatism stems from the ability to flexibly apply different methodological approaches in the right circumstances to solve real-world, valuable questions. Applying the best methodological approach to answer research questions underpins the pragmatic perspective.[31,32] This theory is methodologically congruent and can guide my dissertation work as I develop and refine a KT tool for families with a child with PHF through a rigorous multiple-phase, multi-method approach. This KT tool will be useful in my clinical practice as it will educate and empower families and improve outcomes in this population. I have been guided by several methodological approaches, such as QD, throughout my dissertation work. Applying several methodological approaches is necessary for conducting justified and rigorous research while also serving as the perfect opportunity to grow a well-rounded research acumen.

Knowledge to Action Framework (KTA)

First published in 2006,[33,] Graham outlined the framework's rationale with a visual roadmap for navigating and employing the pragmatic implementation of an intervention. The KTA Framework consists of two distinct cycles, knowledge creation and action, pictured in the figure below. The framework's purpose is to provide knowledge through a structured approach for eliciting behaviour change in a group, as it is based on 31 planned action models.[34] It aligned with the goal of the dissertation: to enhance caregivers' knowledge by providing the most recent care guidelines tailored to support better decision-making in this population (e.g., behaviour). The knowledge creation phase consists of knowledge inquiry, a rigorous synthesis process completed to create a product or tool for a specific context.[33] This cycle is where my first three phases will uncover what knowledge gaps exist in PHF concerning caregiver knowledge needs and experiences, shaping the foundation for my tool. The action stage will guide my work to the 'monitoring knowledge use' stage. I am placing a boundary for my dissertation work at this phase of the cycle to ensure feasibility and carve out future opportunities for future research work.

As a practicing clinician who anecdotally suspected a significant knowledge gap and lags in knowledge provision for caregivers, the KTA provided the initial steps of knowledge creation, which lead to implementation, which is best suited the aims of this dissertation. Other process models (e. g., User-centered design, Active Implementation, and Quality Implementation Framework) only focus on implementation rather than including the creation phase, which was a key component. Through knowledge creation, the foundational studies (knowledge inquiry and synthesis) identified previously created educational tools and literature and what knowledge gaps existed. Furthermore, rating each tool's health literacy also uncovered whether the current tools provided adequate health literacy for caregivers in this context. Those results were the foundation to shape my semi-structured interview questions and uncover a platform based on caregiver perception. Qualitative interviews were conducted with caregivers to understand lived experience and learning needs while also exploring preferred platforms (e.g., storybooks, pamphlets, and online websites). The final incorporates design with a graphic designer and refinement with caregiver feedback, through usability and knowledge acquisition testing. Since the knowledge creation funnel employs an iterative process that incorporates each action cycle step (e.g., indicated by the dotted circle outside of the knowledge creation funnel), this dissertation adapted knowledge to the local context and accessing barriers to knowledge use (qualitative interviews), and the final step of selecting, tailoring by (usability and knowledge acquisition testing). Future steps not focused on in this dissertation would be implementing the educational intervention in clinical practice, as well as diffusion and dissemination to other caregivers and practitioners in the field of PHF.

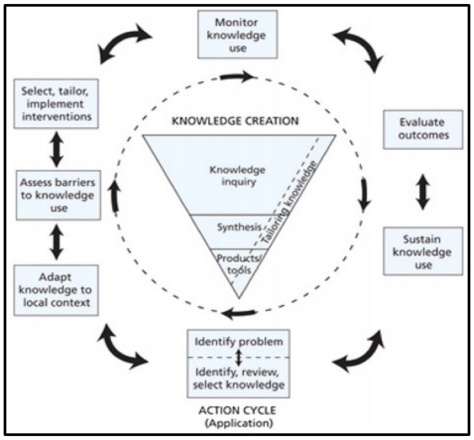

Figure 1.1. Graham ID et al. (2006) *J Cont Educ Health Prof*

Dissertation Overview

A multi-phase, multi-method approach (Figure 1.1) was used to produce a patient-engaged, evidence-based educational tool for caregivers about PHF. Four distinct but related papers were the result of this dissertation work. These papers have been formatted to the specifications of the journals to which they have been published or submitted. There were no adaptions or disruptions to this dissertation work; it was designed with appropriate and ethical approaches to be conducted through the COVID-19 pandemic. The figure below depicts how each phase was conducted in relation to the other phase.

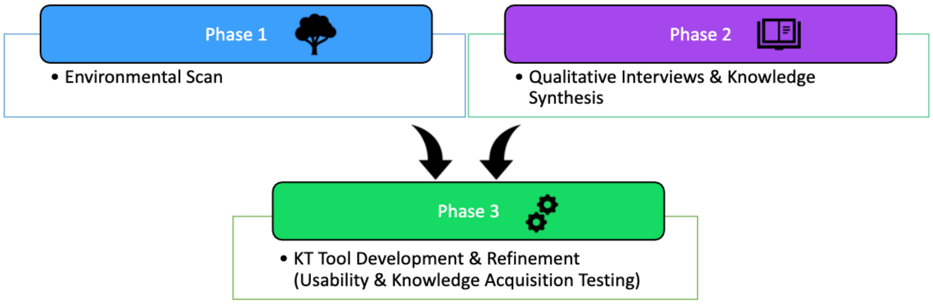

Figure 1.2. PhD Dissertation: Adapted Knowledge Creation Funnel

Chapter 2 details the first paper of my dissertation work, which involved conducting an ES of existing educational resources and tools for PHF. Chapter 3 describes a qualitative literature synthesis of caregivers' information needs and experiences caring for a child with HF. Chapter 4 details qualitative interviews examining the same concepts of information needs and experiences of caregivers. Chapters 2, 3 and 4 are essential as the foundation to inform the development of the KT tool, along with expert opinion and current evidence-based guidelines.[2,3] In Chapter 5, the 4th paper described the KT tool development and refinement process in detail. My tool was created with the collaborative efforts of a graphic design team, knowledge about caregiver experience and substantive expert opinion. Throughout this process, I was guided closely by my primary supervisor, Dr. Shannon Scott, an expert in knowledge translation tools for caregivers and substantive knowledge from my practice and pediatric cardiology healthcare colleagues. To ensure the widespread dissemination of this dissertation work, integrated KT methods (iKT) were woven throughout this dissertation work. iKT strategies related to or engaged caregivers of children with heart failure to help base the KT tool development. I also disseminated each stage of the dissertation work at multiple annual conferences and shared my dissertation progress within my clinical environment with my colleagues and researchers. End-of-grant KT methods will include using the tool in my clinical setting, sharing it with applicable organizations (e.g., Children's Cardiomyopathy Foundation, American Heart Association, Stollery Children's Hospital) and posting it to relevant websites (e.g., www.trekk.ca).

Paper 1. Multimedia Knowledge Translation Tools for Parents About Childhood Heart Failure: Environmental Scan

This study aimed to identify and evaluate current educational tools available for families about PHF online and in popular application (app) stores in April 2020. The search was conducted by environmentally scanning the internet using a popular search engine (e.g., Advanced Google search) and two app stores (Apple and Google Play). Seventeen relevant online tools were identified. Using the Suitability Assessment of Materials (SAM) evaluation,[35,36] 15 of the 17 tools scored in the adequate range (40-69%). Most tools (13/17) had a higher than recommended reading level (ninth-grade Flesh Kincaid Score). Four qualitative interviews with six key stakeholders covered three key themes that were factors in tool development: 1) timely and introductory information, 2) credibility and trustworthy information, and 3) challenges and the evolution in knowledge.

This paper identifies KT tools aimed at caregiver audiences developed within North America. This study determined that no apps related to PHF exist for caregivers. The SAM evaluation was used to evaluate the tools currently being developed. [35,36] Fifteen of the 17 tools scored in the adequate range (40-69%), with no tools scoring in the superior range (70-100%). Scores were superior (70-100%) in layout and typography (i.e., font type and size) but scored either the adequate (40-69%) or not adequate range (<39%) for the graphics and readability (<69%) (e.g., suitable reading level) items. Furthermore, this search also simulated findings of what caregiver audiences would encounter when they searched for information about PHF online, highlighting the need for search engine optimization when placing tools online. Issues related to content (complex language and graphics) highlighted our tool's focus areas. Our tool highlighted that audiences of caregivers would benefit from an online tool associated with PHF.

Paper one has been published as Cunningham C, Sung H, Benoit J, Conway J, Scott SD. Multimedia Knowledge Translation Tools for Parents about Childhood Heart Failure: ES. *J Med Internet Res: Pediatr Parent,* 2022;5(2):e39049. doi:10.2196/34166

Paper 2: Caregiver Information Needs and Experiences in Children's Heart Failure: A Qualitative Synthesis

Paper two aimed to examine and synthesize published qualitative literature about caregivers' information needs and experiences caring for a child with heart failure, initially conducted in June 2021. It was guided by Sandelwoski and Barroso's qualitative synthesis handbook[37] by two independent reviewers, supervised by Dr. Scott, with search guidance from two librarians. Due to the limited literature in this area, the search strategy was formulated by PICOS formulated the search strategy, as the literature suggests that this method is more comprehensive than using SPIDER.[38] With the original search (2021), findings did not identify any relevant qualitative papers (empty review), signifying a significant knowledge gap. An identical search was re-run for currency in November 2023 to include only one paper authored by Zhang et al. 2023.[38] Data extraction and critical appraisal were conducted; however, no metasummary or metasynthesis could be conducted due to only having one relevant study.

This paper aimed to explore and highlight the knowledge gap related to published qualitative knowledge about caregivers' information needs and experiences. This study was used as a foundation for the following research phase, qualitative interviews, guiding what aspects needed to be included in our qualitative interview guide. The data extracted in the relevant paper included three themes, with many sub-themes, that related to caregiver experience (e.g., weakened family socialization, the experience of five psychological stages, and family management dilemmas). Within the family management dilemma, a sub-theme related to low social awareness marginally acknowledged the significant caregiver knowledge gap.

This paper is ready for submission to the Journal of *Prog Pediatr Cardiol* as Cunningham C, Schroeder K, Plesuk T, Conway J, Haykowsky M, Scott SD. Caregiver information needs and experiences in children's heart failure: a qualitative synthesis.

Paper 3: Caregivers' Information Needs and Experience Caring for a Child with Chronic Heart Failure: A Qualitative Study

Paper three aimed to fill the significant knowledge gap recognized in paper two by employing a semi-structured interview format. QD guided our semi-structured interview approach, followed by qualitative content analysis, to remain as close to the data as possible, keeping the essence of participant interviews. Through the lens of caregivers, this study aimed to understand their information needs and experiences caring for a child with heart failure to guide tool development. A second purpose was to explore what formats caregivers prefer to learn complex information related to their child's heart failure. With the QES' initial search being an empty review and the second search only identifying one paper, the guiding interview questions were kept broad to thoroughly explore both fundamental topics and obtain rich details and context during each interview.

The purpose of this paper was to qualitatively explore caregivers' information needs and experiences caring for a child with heart failure. Two main categories emerged related to learning and caregiver lived experience. This paper aimed to fill the knowledge gap about caregivers' information needs and experiences identified in paper two and explore the medium/platform, which were critical aspects of co-creating a tool based on caregivers lived experience.

This is published as Cunningham C, Conway J, Zahoui Z, Scott SD. Exploring Caregiver Learning and Experiences Carding for a Child with Heart Failure: A Qualitative Study. *CJC: Pediatr Congenit Heart Dis.* 2024;3:152-160. doi:10.1016/j.cjcpc.2024.05.003.

Paper 4: Development, Evaluation and Refinement of an Online Educational Infographic for Caregivers about Pediatric Heart Failure

Development and evaluation of an evidenced-based digital KT tool about PHF was the final stage of this dissertation, which addressed the knowledge gaps of current tools outlined in the previous three studies (phases 1 and 2). Compiling all the findings from the first three papers, current evidence-based guidelines, and substantive and committee input while also considering the feasibility of completing my doctoral dissertation, it was decided that an online interactive tool was an appropriate KT platform to design for this work. My committee and I developed all the content (text and visual) and worked with a graphic designer. An interactive online digital tool was designed with the expertise of a professional graphic designer (Renee Woods, Anti-

Gravity Design) as the finished product. The tool design started in August 2023 and underwent four revisions based on feedback from the primary supervisor (SDS) and two substantive experts (JC, KS). The tool was then evaluated using SAM to ensure it met superior criteria (70-100%), filling the gap highlighted in paper 1 (ES) before it was piloted with 10% of the calculated sample size. The next step was to assess and refine the KT tool, measuring 1) the caregivers' perception of the tool's usability (Likert scale survey and open-ended questions) and 2) the experience of a change in knowledge after viewing the digital KT tool (pre- and post-knowledge questions). Statistical inferences (Wilcoxon signed rank) for the knowledge change (pre- and post-) and usability were statistically significant, indicating that caregivers found the tool to be useable and that it elicited a positive change in their knowledge. Minor refinements were made to content related to sodium intake where caregivers scored lower, and design aspects were made to make headers more prominent and remove the rotating bullet timer in the daily care considerations.

This paper is under review at *J Med Internet Res: Cardio* as Cunningham C, Conway J, Schroeder K, Khoury M, Urschel S, Haykowsky M, Scott SD. Development, Evaluation and Refinement of an Online Educational Infographic for Caregivers about pediatric heart failure. April 7, 2024. (Submission ID #59748).

Ethics Approval: University of Alberta Research Ethics Office (ID Pro00106559).

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CHAPTER 2. Paper 1: Multimedia Knowledge Translation Tools for Parents about Childhood Heart Failure: Environmental Scan

This paper is published as:

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Abstract

Background: Childhood heart failure is a factor in many hospital admissions each year. It can impose a steep learning curve for parents who need to learn the key information to care for their child at home. In this study, we conducted an ES to identify and assess web-based knowledge translation tools about childhood heart failure for parent audiences developed within North America.

Objective: This study aims to inventory tools publicly available to parents about childhood heart failure from popular web-based venues, assess how each tool communicates health information, and explore how they were developed.

Methods: Our search strategy included two commonly used multimedia-based platforms: two app stores (Google Play and Apple App Store) and one search engine (Advanced Google Search). Common search terms were used, and results were uploaded to Microsoft Excel for screening between 2 reviewers. The inclusion criteria for the tools were as follows: content focused on educating parents about their child's heart failure, developed in the English language, and originating within Canada and the United States. A total of 2 reviewers screened the app store and internet search results for relevant tools. Each tool was assessed using the Suitability Assessment of Materials (SAM), a validated tool that objectively assesses the suitability of how health information is communicated to a particular audience. Key informants who were involved in tool development were identified and invited for a qualitative interview using a semi-structured format to provide data about the development process. Key themes were identified in the semi-structured interview process.

Results: Frequencies and SAM percent ratings of eligible tools were reported. No apps exist for parents relating to PHF. Overall, 17 relevant internet tools were identified, and their suitability was assessed for the parent audience. Most tools scored well in layout and type but lower in readability and graphics. Qualitative interviews with key informants revealed three key themes: timely and introductory knowledge, credible and trustworthy knowledge, and challenges and evolution in knowledge.

Conclusions: This is the first ES looking for parent tools relating to childhood heart failure in Canada and the United States. Findings from this study reveal that there are no apps on this topic and there is a small number of tools for parents on the internet (n=17). Using the SAM, no tools scored in the superior range, and further work in knowledge translation strategies needs to be done in this area to improve more effective education to parents and caregivers who have a child with heart failure. These findings will inform the development of a new resource on children's heart failure that targets parents and caregiver audiences.

Keywords: environmental scan, pediatric heart failure, parent audience, knowledge translation, web-based educational tools

Introduction

Background

Parents who have a child with heart failure need understandable and reliable knowledge. Approximately 11,000 to 14,000 annual pediatric hospitalizations in the United States are due to children's heart failure, with 87% of all initial cases diagnosed after an exacerbation in heart failure symptoms requiring invasive, life-saving medical intervention.[1] Heart failure in children can invoke uncertainty, heighten stress levels, and impose a steep learning curve on parents.

Since the release of North American evidence-based guidelines,[2,3] more children with heart failure have been surviving, and parents have been caring for them in the outpatient setting. Parents are uniquely positioned to be termed proxy health information seekers, as they require advanced and ongoing information to provide day-to-day management for their ill child.[4,5] Aside from their health care team, the internet is a source that parents rely heavily upon for health information to make daily decisions about their child's care.[5] Parents who have children with chronic health conditions have identified they require adequate and appropriate information to care for their child.[6] However, despite the call for this necessary information among parents, the literature still suggests that they feel generally unsupported in their quest for health information.[7] Undoubtedly, this need exists for parents of children with heart failure given the scarce amount of literature on this topic.

Multimedia-based educational tools (e.g., e-books, apps, videos, and whiteboard animations) posted on the internet are strategies that can fill this knowledge gap by providing easy-to-access educational content to parents and caregivers who need it.[8] These tools have the ability to creatively accentuate evidence-based health information, resulting in better uptake by parent audiences.[9] They positively influence learning styles by providing complex information that is palatable, relevant, and understandable.[10] Knowledge translation tools have been created for parent audiences in other contexts and have been shown to provide understandable, accessible, and evidence-based knowledge that helps improve care.[11] Multimedia-based knowledge translation tools have yet to be widely explored in the context of childhood heart failure. To date, there is currently no understanding of what web-based knowledge translation tools exist for parent audiences about PHF and how they are rated in terms of how they communicate medical information to parent audiences.

Objectives

Our research seeks to better understand what tools are currently available for parents who have a child with heart failure and to assess each tool's ability to enhance their knowledge. Therefore, our study aimed to understand what publicly available educational tools are available to parents of children with heart failure on the web and app stores.

Methods

Overview

The ES methodology is used to scan the environment in an organized manner for gray information pertaining to a specific topic or context.[12] Our ES was conducted in 4 stages searching Canadian and US-based educational tools for children's heart failure that targeted parental audiences in June 2020.

A multimedia tool was included if it (1) was developed in either Canada or the United States, (2) focused solely on children's heart failure content, (3) was developed in English language, and (4) targeted a parent or caregiver audience. Tools were only included if they were from Canada and the United States to preserve the feasibility of the study. Duplicate tools were excluded. Given the anticipated limitation in tools, a date range was not applied to the internet search to maximize our findings.

Data collection occurred in four separate phases: (1) app search, (2) internet search, (3) Suitability Assessment of Materials (SAM) evaluation, and (4) key informant interviews. Key informant interviewers serve to augment the findings of the search as they will provide richer detail about each resource's development process. Appendix 1 outlines the screening process of the app and internet search.

Ethics Approval

As our study included a qualitative interview component with key informants, ethical approval was obtained from the University of Alberta Research Ethics Office (Pro00106559).

Phase 1: Application Search

Two app stores (Apple App Store and Google Play) were searched using the broad layman search term heart failure by the primary researcher (CC). Using the same term, a second researcher (JB) used a web scraping search strategy to ensure comprehensiveness. Web scraping is the systematic process of using a web bot (or software agent) to produce more comprehensive search results.[13] Searches were limited to Canada or the United States in the advanced search function, totaling two searches. Modeled after previous ES methods,[14] only the first 50 apps from the Canadian and US search in each app store were archived for review. The primary reviewer (CC) compiled all the internet and app results into Microsoft Excel spreadsheets for screening. Screening for eligibility was completed by the primary reviewer, and all data were verified independently by a second reviewer (HS) to ensure accuracy.

Phase 2: Internet Search

The primary reviewer (CC) performed the search using three broad laymen's search terms all the words function of Google Advanced Search: (1) child heart failure, (2) PHF, and (3) child heart failure guidelines. The primary reviewer ran each term separately for each country (e.g., Canada or the United States), resulting in 6 separate searches. Other strategies to increase search results included disabling cookies and turning off personalization to help reduce search bias. Again, no date restriction was placed to maximize our search results. To keep the search feasible, the search was limited to English language tools and within Canada and the United States. Another reason to limit the search to any North American tools was to tailor our findings to apply to an educational tool we are developing about children's heart failure that will be used in this area.

Similar to other ES methods,[12] the first 100 webpage results from each search string were archived using screenshots and uploaded into a Microsoft Excel spreadsheet for screening by two reviewers (CC and HS). Adapted from data extraction and screening methods in systematic review processes to avoid data extraction errors,[15] CC completed the initial screen and data extraction, and HS verified all data line by line. All discrepancies in data extraction and relevancy were flagged and discussed between the 2 reviewers, with no disagreements needing to be brought forth to the senior author (SDS). To increase the quality and accuracy in data collection, CC (an experienced PHF clinician) educated the second reviewer about children's heart failure.[15] All included Internet educational tools were downloaded and examined in detail.

To prevent missing any relevant educational tools in the search process, the primary reviewer also consulted with a subject expert (JC) in the field of PHF (e.g., pediatric cardiologist) to review the list of screened websites, identifying any further relevant tools that may exist but were missed. An additional tool was identified by our subject expert (April 2020). This tool was posted to the web after the date of our initial search, and it was added to our relevant list of tools for health literacy appraisal.

Descriptive statistics and frequencies in Microsoft Excel were used to analyze the characteristics of both app and internet resources. A list of any relevant web-based tools in either the app or internet search was reported for the apps and web-based tools.

Phase 3: SAM

All relevant internet and app resources that met the inclusion criteria were downloaded in full and scored independently by two reviewers (CC and HS) using the SAM scoresheet. The SAM assessment is a validated tool, developed by experts in health education for adults, that assesses the readability, usability, and suitability of health information [16]. SAM evaluation can pinpoint specific strengths or deficiencies in educational materials or compare different education materials for specific patient populations and suggest areas of improvement or refinement.[16] This method of scoring has not been applied in the PHF context but in other pediatric contexts.[17,18] The original SAM scoring tool was developed by Doak et al.[16] and was subsequently adapted with permission by Smith.[19] The version developed by Doak et al.[16] includes 6 domains with 22 subfactors. The updated version by Smith[19] includes the 6 domains but with only 21 subfactors, omitting the scope evaluation within the content section. The modified version by Smith[19] was used, as the scope of this assessment was already tailored to include only tools about children's heart failure that specifically educated the parental audience.

A rating score was obtained from each assessment (not suitable=0, adequate=1, and superior=2). Scores were then transformed into percentages (percent ratings: 0%-39%=not suitable material, 40%-69%=adequate material, and 70%-100%=superior material). A rating of not suitable would indicate that a web-based resource requires some refinement to make it more suitable for the intended audience, whereas a superior rating would indicate that no further refinements are needed and a high level of health literacy.[16] Resources were not excluded from inclusion based on their SAM score, but rather the assessment was completed to provide a sense of the overall scope and quality of educational content that is available to parents who care for a child with heart failure. To ensure minimal bias in the review process,[20] CC and HS both independently SAM rated each relevant educational tool, and then scores were disclosed and discussed. Any highly discrepant scores (>10 points difference) were discussed in detail among reviewers to understand the large variability in scores (e.g., errors in scoring). Given the subjective nature of this scoring tool, an average overall rating between both reviewers for each domain was generated, giving an average SAM score for each resource.

Phase 4: Key Informant Interviews

Key informant interviews were conducted to complement the SAM ratings and add depth about the characteristics, distribution, and development process of each tool. Interviews with key interviewees were conducted by CC who contacted organizations from the information provided on the webpage. To maximize the number of informant responses, 3 attempts were made to contact each key informant (n=17) either by phone or by email provided on the tool's webpage. This approach was modelled after the method developed by Dillman[21] for achieving responsiveness in the context of surveys. All interviews were conducted and recorded using the Zoom video conference platform.[22] All interviews were listened to several times and live-coded to allow for detailed context and meaning in the results.[23] All participants provided written consent before the interview.

Data collection and analysis occurred iteratively, allowing for a more precise and purposeful process. The number of interviews achieved was not decided based on data saturation but on the positive responses accepting the invitation to participate in a qualitative interview by key informants who played an integral role in tool development.

Thematic analysis was used to synthesize and identify common themes among key informants described in the semi-structured interviews. Thematic analysis was modelled after the study by Braun and Clarke.[24] Their approach outlines four key stages: familiarization with the data, initial coding, searching for categories among the initial open codes, and constructing final major themes that best represent the data. A data-driven inductive approach was used to link the developed codes and themes to the data themselves.[25] The interviewer became immersed in the data through repeated listening of the recorded video interviews with live coding into summary tables. Codes remained genuine as they stayed as close to the participants' own words. Codes became more general and focused as they were grouped into categories and then major themes. All codes and videos were then re-examined to ensure consistency and accuracy of the interpretation.

Results

Overview

A detailed flowchart outlining the screening process is presented in Appendix 1. The screening and SAM ratings occurred over a 9-month period (July 2020 to March 2021).

Phase 1: App Search

The app search was conducted in July 2020. In total, 112 apps were retrieved, 89 from the layman search strategy, and 24 additional from the scraper method. Unfortunately, no apps met the inclusion criteria, highlighting a knowledge gap in this platform for parents and caregivers about children's heart failure.

Phase 2: Internet Search

The internet search was completed in August 2020. A combined total of 575 websites were retrieved across 6 search terms. Screening of the 455 websites occurred between two screeners (CC and HS). Details of the included web-based PHF tools are shown in Appendix 2. A total of 16 relevant tools met the inclusion criteria, 13 from the United States and 3 from Canada. An additional relevant tool from the United States was identified following consultation with a subject expert (JC) in the field of children's heart failure. This tool was not missed in the original search; it was developed and posted on the internet after August 2020. The most relevant internet tools were in the form of webpages (n=13) and handouts (n=3). The content for the relevant tools focused on a varying range of information (e.g., general information, symptoms, treatment strategies, and testing).

Phase 3: SAM Evaluation Rating Scores

The average overall SAM factor rating between the 2 reviewers ranged from a low suitability score of 38% (16/42) to a high score of 62% (26/42; Appendix 3). The total possible SAM suitability scores were out of 42 (100%). No tool scored 100% (26/26). Overall, 15 tools' ratings were in the adequate range (40%-69%), and 2 tools' ratings were in the not suitable range (0%-39%). No tools scored within the superior range (70%-100%).

Each tool was scored individually according to each of the 6 SAM factors in each domain (e.g., content, literacy demand, graphics, layout and typography, learning stimulation and motivation, and cultural appropriateness). Raw scores for each factor of the 17 tools were combined on each SAM factor, and a percentage score was calculated, demonstrating the overall current state of web-based tools included in this ES (Appendix 4). Overall, most of the tools had a higher reading level than recommended, averaging over a ninth grade reading level (13/17, 76%). Layout and type scores were all within the superior range—typography (17/17, 100%), layout (10.5/17, 62%), and subheadings (7/17, 41%). In contrast, all graphic scores were in the not suitable range—cover graphics (12.5/17, 74%), type of illustrations (10.5/17, 62%), relevance of graphics (10.5/17, 62%), graphic explanation (17/17, 100%), and graphic caption (16/17, 94%).

Phase 4: Key Informant Interviews

Key informant interviews were conducted between April and June 2021. Of the 17 relevant webpage educational tools, only 16 (94%) had contact information available. In addition, 1 tool only included a customer support tab as opposed to a contact tab (e.g., Contact Us or phone number). When the customer support tab was clicked on, the researcher was directed to a generic table of contents related to the website with no further contact information provided. After three attempts, 41% (7/17) of the organizations did not respond. In addition, 29% (5/17) of the organizations declined an interview with the rationale that their tool was developed by an outside vendor (n=4) or that the individual who made the tool was no longer employed at the organizations (n=1). Of the key informants who agreed to an interview, an average of 2 attempts were made before a response was received. Of the 17 key organizations, 4 (24%) agreed to participate in a qualitative interview. Moreover, three interviews had 1 participant, and the fourth interview had 3 participants. From all four interviews, interviewees were either medical professionals (n=4) or employed in leadership roles within the organization (n=2; e.g., manager or director).

In total, 3 major themes arose from the semi-structured qualitative interviews, which focused on the content, knowledge distribution and development process, and perceived impact. These three major themes are as follows: timely and introductory knowledge, credible and trustworthy knowledge, and challenges or evolution. Interviews were assigned a reference marker (e.g., I2) for quotes present in support of the themes identified in our results.

Timely Introductory Knowledge

Participants in this study agreed that the knowledge included in their tools was very timely and focused more on the introductory phase, meaning that this tool was typically used shortly after the child was diagnosed with heart failure. However, participants did express that this tool could be provided to parents at times when they needed a review of the information. A participant explicitly stated, “the tool is mostly intended to be given at diagnosis but can be distributed for a refresher if needed” [I4].

Another participant highlighted that they also revise or add content to their tool based on trends from social media posts or parent inquiries to their foundation, highlighting that their tool was timely by addressing current parent questions, “Content in the tool is based on social media posts” [I1].

To also ensure that parents were not overloaded with too much information at the time of diagnosis, other key informants strategically placed knowledge in small chunks to avoid overwhelming parents. This was highlighted with the quote: “From our parent meetings, parents prefer knowledge in bite-size pieces” [I4]. This was a strategy that allowed parents to build on their knowledge rather than try to learn it all at once, demonstrating that key informants were aware of the huge learning curve that happens with parents who are in this situation.

Credible and Trustworthy Knowledge

All the participants in the interviews described the information presented in their tools as evidence-based. A participant shared that “guidelines are biggest go-to for information” (I2), meaning that they drew most of their information from published peer-reviewed material, along with some anecdotal knowledge from years of clinical experience. A second participant also confirmed that their tool was also “based off medical guidelines” (I2 and I4).

Participants indicated that their information was mostly distributed in the hospital setting despite being posted on the web. They indicated that their information could be handed out in the form of printouts or families can be shown how to access digital or multimedia tools that were posted on their hospital webpage or reputable organization by hospital staff on the parent’s mobile device. One participant stated, “I share the website with the parent using their phone. They search on their phone, and I confirm it is the correct website. This is so they can find the information in the future” (I4).

Challenges and Evolution in Knowledge

Despite the good intentions of healthcare professionals to share complex knowledge with parents in easier-to-understand formats, this piece is complex and presents challenges. Some of the challenges were issues related to the web-based sharing of information. A challenge that inherently comes with web-based knowledge sharing is optimizing search engines. A participant shared that their organization is working with the Google search engine as they acknowledged that their tool is not easily found on the first few pages of results, affecting the reach to their intended parent audience. They highlighted that they are “working with Google to improve their search optimization so parents can find their tools” (I4).

Another challenge faced by developers of the tools in our interviews is that the tools often do not include credible references, making it difficult for parents to discern whether the information is evidence-based. A participant acknowledged this, saying that “we do not include the references in our tools we distribute to families” (I3).

An additional challenge outlined in the interviews was related to having the tools available in only the English language when there are families where English is not their first language. This posed a challenge to the health care providers in the interviews because they felt that perhaps their tool was not as effective at translating that critical knowledge. At times, a participant stated that they would have to spend more time with the parents to ensure they understood the material because they could not read or write in the English language. A participant expressed, “Our Center has a large population of individuals fluent in Spanish. There are times we have read the pamphlets to families because they could not read English themselves” (I4).

The last challenge participants outlined was making the time for refinements or updates to their tools. A participant described, “Heart failure is a complex disease, so we are always looking to refine our tools.” (I2). All participants acknowledged that they do not have regular set time intervals for editing and updating their tools. They all typically completed this task when they “thought about it” or when clinical practice changes occurred (I1, I2, I3, and I4). Some of the participants work with others who could alert them when updates were needed (e.g., nursing staff or family comments) or simply relied on memory to update the documents.

Discussion

Principal Findings

This is the first ES to conduct a search for internet sources for parent audiences relating to children’s heart failure within North America. First, our ES identified that no apps exist on this topic, highlighting a significant knowledge gap for parents who are trying to seek information from this digital platform. Furthermore, our research highlighted that 17 web-based tools about children's heart failure exist tools and were assessed to be adequate using SAM percent ratings.

We have highlighted that a modest number of relevant educational tools exist from our internet search (n=17), with varying degrees of content and health literacy for parent audiences. Notably, 88% (15/17) of the tools found appeared to be developed by clinicians for parents, instead of having parents actively involved in the development process. There were 2 tools that involved parent recommendations and feedback from an advisory group but were not created using parent experience evidence. Given the complexity of health journeys for families who have a child with heart failure, there is a critical need and gap to develop a tool based on parents' lived experience to help deliver tools that are relevant and applicable to parents needs.

Of the relevant internet-based parent tools, no tool scored in the superior range, highlighting that work in the area of health communication and literacy could be improved upon. Most tools scored lower in the summary and review subsection, literacy subsection, and overall graphics section. Improving on these key aspects will provide parents, especially parents with lower literacy skills, information that is easier to understand with improved repetition of key information. However, the field of pediatric cardiology poses its own unique challenge in that this field contains many words with >2 to 3 syllables (e.g., echocardiogram or cardiomyopathy). This aspect undoubtedly played a factor that increased the reading level and reduced the score in many of the tools. One of the key informants in the qualitative interviews highlighted their process for dealing with complex medical language to ensure that language was consistent, well defined in simpler terms, and providing information in bite-size pieces for parents and caregivers to enhance their uptake.

In the category of graphics, SAM scores identified that major refinements are needed in this area. An explanation for this lower score was that all relevant tools were website based and it was difficult to score these tools in relation to a graphic cover as suggested in the tools' instructions. The recommended illustrations that Doak et al.[16] outlined in their tool stated that simple line drawings can promote realism without distracting the details. As noted, this tool was developed in 1996 and intended mostly for print materials, so reviewers acknowledge that technology has advanced to include more digitalized, web-based infographics that can be just as impactful as line drawings. Infographics in today's educational materials involve simpler computer infographics with more vivid, crisp colors that attracts the reader's attention. Perhaps, updating of the assessment tool to include those aspects would have scored a few of the tools in the superior range, as reviewers found some of the graphics to be well done.

It is imperative that we improve knowledge translation strategies to improve the health literacy of parents and caregivers who care for children with heart failure in the home environment. Knowledge translation strategies that include parents as cocreators bring their unique perspective or lived experience that will improve uptake and understanding, as families in similar contexts will likely share similar knowledge needs.[26] When parents have a lack of understanding toward treatments or health conditions, worse outcomes occur in children's health.[27] One way to mitigate these poor outcomes is to have robust health information available on the internet, and in alternative formats, that is based on research knowledge and parental lived experience. This is done through the avenues of improving parental and caregiver knowledge bases to make better decisions, reducing parental stress levels and invoking improved conversations with their child's health provider through questions.[28,29] In addition, when clinicians are armed with credible and effective sources of information that can be easily shared with their parent audience, better relationships will result as parents will have more confidence in their healthcare provider.

As all tools did not include evidence-based references to indicate that they were developed from peer-reviewed research, the average parent would have difficulty discerning if the material from any of the tools was credible or even evidence-based. Recently published literature has demonstrated that many parents who searched the internet had difficulty discerning if the literature they found was credible; furthermore, they were not confident in bringing it to a trusted healthcare professional.[29] Even more troubling is that parents will make health decisions based on the information they find on the internet,[28] which may or may not be based on the most credible sources. Despite clinicians' good intentions of simplifying information for parents by not citing the source of their information, diligently citing evidence from where they derived the material may relieve the stress of parents trying to discern whether the tool is evidence-based material.

Limitations

As this search was conducted in July 2020, it is possible that more tools are now available to parents and caregivers or that the current tools scored in our search have now been updated to reflect different or enhanced content. As we know, the internet and app stores rapidly add more content or update existing materials daily. Our search was only a snapshot in time, and it would be difficult to replicate the same results.

A limitation of our search was the use of only a single search engine (Google) to provide results, which may have exposed our results to an element of search bias. Published literature on search engines, such as Google, has suggested that theories relating to filter bubbles or personalized algorithms can change results based on who searches for health information.[30-32]

Although we took steps to reduce this bias by deleting cookies and turning off personalization, this is not a perfect process. Another solution would be to use engines, in addition to Google, in the web-based search process to provide more robust results.

Although the scoring of health information was performed using a validated SAM instrument, limitations remain. We noticed that updates to the tool may be required in some sections that scored lower (e.g., type of illustration) as the tool gave a higher score for simple adult-appropriate line drawings that are not congruent with today's color infographics that can be generated from graphic artists. Current graphics are now designed as colorful infographics and characters, rather than simple line drawings or sketches, which the authors thought to be distracting. Scoring methods indicate that line drawings provide the least amount of distraction.[16] There would have been an improvement in scores if the tool had been updated to include simple computer infographics that are now commonly designed in current educational materials.

In addition, both reviewers found the culture section in the instrument very difficult to score. This was evidenced by the similarity and lack of variability of scores. Culture within the context of children's heart failure was very difficult to define within the context of PHF solely based on a web-based tool or handout. Perhaps more detailed instructions and a definition of culture could be provided, making it more user-friendly. We found that most graphics included varying races and genders among the photos of parents and children. If tools were included in video format, culture scores would vary more as there would be an increased presence of tone and gender role presentations.

Conclusions

This ES sought to explore what multimedia educational information or existing internet based tools and within app stores for parent audiences about children's heart failure. Our search found 17 parent tools and no apps relating to children's heart failure developed in Canada and the United States. This highlights a gap in knowledge for parents who prefer this type of web-based content for learning about this important topic. Using SAM scoring, most web-based tools scored overall in the adequate range, meaning that they were adequate to teach parents, but there are some key improvements, especially in reading level and graphics, that can be made to maximize their educational effectiveness. The qualitative interviews with key informants who developed the tools highlight three key themes: timely introductory knowledge, credible and trustworthy knowledge, and challenges and points in how organizations plan to evolve this knowledge in the future. Further research is required to evaluate the effectiveness of such parent-targeted tools and their impact on parents' ability to learn and care for these children more confidently in the home setting.

Table 2.1: Screening of Application (Apps) & Web-based Tools

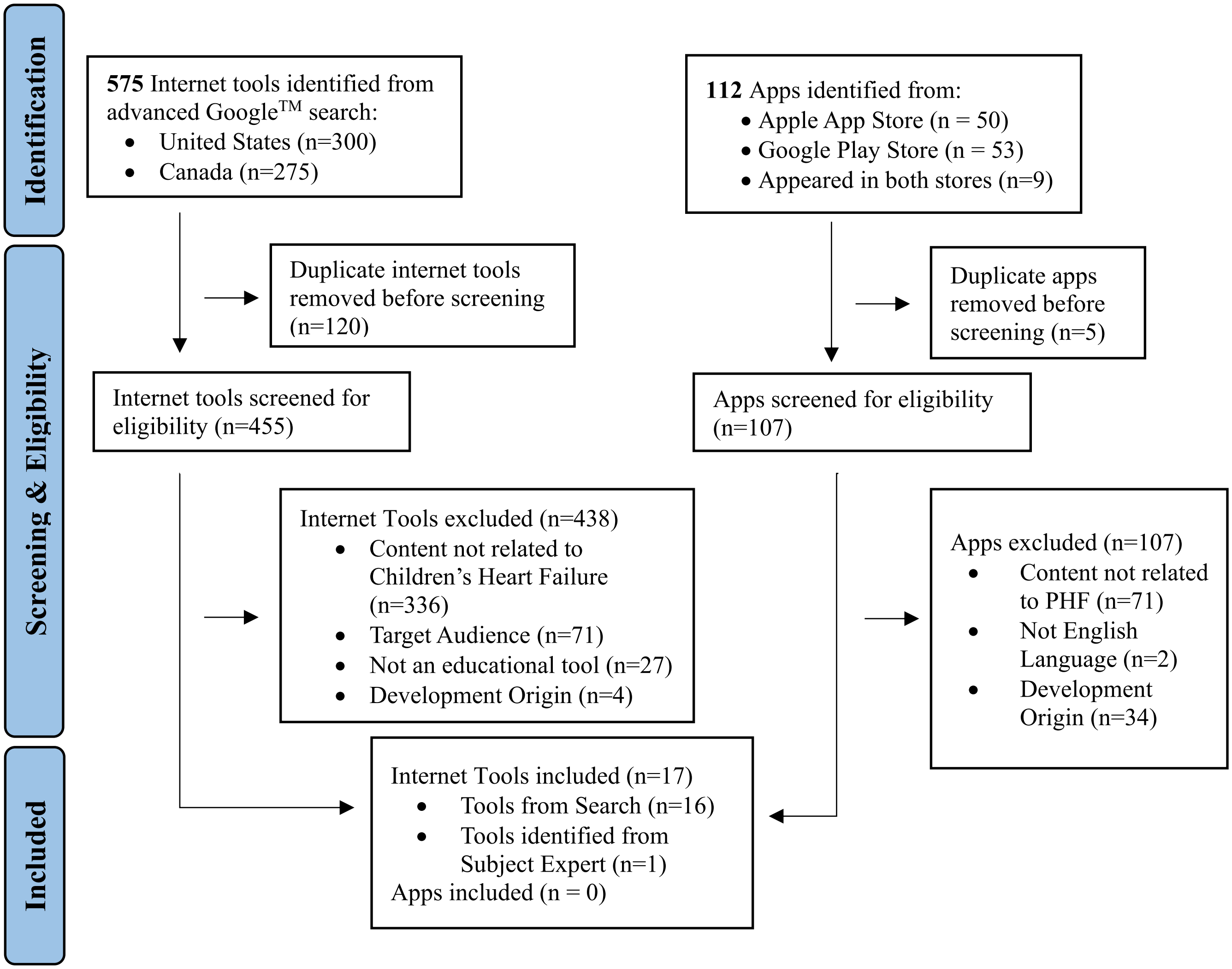

Table 2.2. List of Included Web-based PHF Tools (n=17)

Title	**Author**	**URL**	**Location**	**Year of Last Update**	**Evidence Based**	**Format**
Congestive Heart Failure	About Kids Health	https://www.aboutkidshealth.ca/	Canada	2018	No	Website
Congestive Heart Failure	Western Canadian Children's Heart Network	http://www.westernchildrensheartnetwork.ca/	Canada	2014	No	Handout/ Brochure
Heart Failure in Children: Overview	A.D.A.M Health	https://www.healthing.ca/	Canada	2019	Yes	Website
Heart Failure Fact Sheet	Barth Syndrome Foundation	http://www.barthsyndrome.ca/	United States	2015	No	Handout/ Brochure
Heart Failure in Children	Stanford Children's Hospital	https://www.stanfordchildrens.org/	United States	2021	No	Webpage
Congestive Heart Failure in Infants & Children	Cincinnati Children's Hospital	https://www.cincinnatichildrens.org/	United States	2019	No	Webpage
Heart Failure in Children	Children's Hospital of Philadelphia	https://www.chop.edu/	United States	2021	No	Webpage
Heart Failure in Children – Health Encyclopedia	University of Rochester	https://www.urmc.rochester.edu/	United States	2021	No	Webpage
PHF	Uchicago: Comer Children's	https://www.uchicagomedicine.org/	United States	Not listed	No	Webpage

When Your Children Has Congestive Heart Failure (CHF)	Fairview	https://www.fairview.org/	United States	2020	No	Webpage
Heart Failure in Children	Medline Plus/US National Institute of Medicine	https://medlineplus.gov/	United States	2021	Yes	Webpage
Preventing Heart Failure in Children	Seconds Count	http://www.secondscount.org/	United States	2015	No	Webpage
Congestive Heart Failure	Children's Hospital of Chicago	https://www.luriechildrens.org/	United States	2021	No	Webpage
PHF: A Guide for Parents and Families	Children's Cardiomyopathy Foundation	https://www.childrenscardiomyopathy.org/	United States	2020	No	Handout/Brochure
Heart Failure in Children - Overview	University of Florida Health	https://ufhealth.org/	United States	2018	Yes	Webpage
Understanding Heart Failure in Children	Children's Hospital of New Orleans/LCMC Health	https://www.chnola.org/	United States	2018	No	Webpage
An Introduction to PHF	Action Learning Network	https://myactioneducation.org/	United States	2021	No	Webpage/Handout

Table 2.3. Average Overall SAM Percent Rating for Individual Web-based Tools

Web ID	**Average Rating, n (%)**
Web001	25.5 (61.7)
Web002	20 (47.6)
Web003	21.5 (51.2)
Web004	16 (38.1)
Web005	24.5 (58.3)
Web006	17.5 (41.7)
Web007	16 (38.1)
Web008	19.5 (46.4)
Web009	18.5 (44.0)
Web010	19.5 (46.4)
Web011	19.5 (46.4)
Web012	17.5 (41.7)
Web013	16.5 (39.3)
Web014	23.5 (56.0)
Web015	22 (52.4)
Web016	24.5 (58.3)
Web017	26 (62.0)

Table 2.4. Combined Average SAM Percent Rating Score for All Web-based Tools (n=17) Categorized by Domain

SAM Factor	Score, n (%)		
	Superior	Adequate	Not Suitable
Content			
Purpose	8 (47.1)	4.5 (26.5)	4.5 (26.5)
Content Topics	2 (11.8)	11.5 (67.5)	7 (41.2)
Summary & Review	1.5 (8.8)	1 (5.9)	14 (82.4)
Literacy Demand			
Reading Grade Level	0 (0.0)	4 (23.5.)	13 (76.5)
Writing Style	7 (41.2)	11 (64.7)	0.5 (2.9)
Sentence Construction	12.5 (73.5)	4.5 (26.5)	0.5 (5.9)
Vocabulary	5 (29.4)	6.5 (61.1)	1 (5.9)
Learning Aids	16 (94.1)	0 (0.0)	1 (5.9)
Graphics			
Cover Graphics	0.5 (2.9)	4.5 (26.5)	12.5 (73.5)
Type of Illustrations	0.5 (2.9)	5 (29.4)	10.5 (61.2)
Relevance of Graphics	2.5 (14.7)	5.5 (32.4)	10.5 (61.2)
Graphic Explanation	0 (0.0)	0 (0.0)	17 (100)
Graphic Caption	1 (5.9)	0 (0.0)	16 (94.1)
Layout & Type			
Typography	17 (100.0)	0 (0.0)	0 (0.0)
Layout	10.5 (61.2)	7 (41.2)	1 (5.9)
Subheadings	7 (41.2)	3.5 (20.6)	6.5 (38.2)
Learning Simulation & Motivation			
Interactions Included	1 (5.9)	6.5 (38.2)	9.5 (55.9)
Behaviour Changes Modelled	2 (11.8)	9.5 (55.9)	6 (35.3)
Motivation	11.5 (67.6)	5.5 (32.3)	0 (0.0)
Cultural Appropriateness			
Logic, Language, Experience (LLE)	17 (100.0)	0 (0.0)	0 (0.0)
Cultural Image & Examples	0 (0.0)	17 (100)	0 (0.0)

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CHAPTER 3. Paper 2: Caregiver Information Needs and Experiences Caring for a Child with Heart Failure: A Qualitative Evidence Synthesis

This paper is ready for submission to the Journal of *Prog Pediatr Cardiol* as:

Cunningham C, Schroeder K, Plesuk T, Conway J, Haykowsky M, Scott SD. (2024). Caregiver Information Needs and Experiences in Children’s Heart Failure: A Qualitative Synthesis.

Abstract

Background: Despite substantial knowledge generation and implementation amongst healthcare providers in this field, knowledge translation strategies targeting caregiver audiences have lagged. Our aim was to synthesize qualitative studies relating to caregivers' information needs and experiences caring for a child with chronic heart failure (HF).

Methods: Sandelowski and Barroso's Handbook for Synthesizing Qualitative Research guided our review, cross-referencing the ENTREQ statement for reporting. Seven databases were searched in November 2023. Two independent reviewers screened studies (CC, KS), supervised by a senior author (SDS).

Results: One study met the inclusion criteria outlined in our synthesis. Our findings impeded the ability to conduct any analysis.

Conclusions: One article met the inclusion criteria, highlighting a significant knowledge gap in this area. Further research is needed to augment patient care and improve outcomes. This study emphasizes that previous care strategies and education in the clinical setting are based on a lack of research evidence about caregiver experience. Further research on this critical topic to optimize care and better educate caregivers in the clinical setting.

Keywords: Qualitative, synthesis, nursing, heart failure, pediatric

Introduction

Heart failure (HF) in children is documented to be a complex and burdensome disease.[1-5] Hospitalizations in the United States are estimated to occur in 11,000-14000 children annually.[6] Adult HF is better characterized as limited data on incidence and prevalence exists in childhood HF due to small numbers, varying phenotypes, and lack of an overall standardized definition.[7] It is broadly defined as a clinical and pathophysiological syndrome resulting from ventricular dysfunction, volume or pressure overload, in combination or alone.[3] The cardinal symptoms of children with HF, no matter the etiology, are poor growth, dyspnea, and anasarca.[2,8,9] One subset of children with heart failure experiences heart muscle disease with systolic and diastolic dysfunction, resulting in a more chronic HF phenotype (e.g., cardiomyopathies, myocarditis, toxin-induced heart failure, genetic/metabolic diseases, and nutritional and neuromuscular conditions).[3] The child and family experience a life-long trajectory, with constant burdensome symptom management with a limited number of surgical options to relieve them of their HF symptoms (e.g., ventricular assist devices and cardiac transplantation).[7,10] The care goals are to manage and control symptoms and adverse events through complex medical therapies.[9]

A second HF phenotype includes children with congenital heart disease. HF symptoms result from structural abnormalities[7] and generally present with a more acute presentation from pressure overload or over-circulation.[2] Treatment strategies for this cohort of children are typically surgical approaches (e.g., correction vs. palliation).[10] Children with CHD also experience different clinical trajectories compared to children with chronic HF due to over-circulation, which is typically relieved with surgical correction.[9] However, a small number of children within the CHD population experience chronic HF due to systolic or diastolic dysfunction, which is categorized under the spectrum of chronic HF.[10]

Improved outcomes for children with chronic HF are occurring due to earlier recognition and advancements in evidenced-based treatment strategies that are the result of increased collaboration among healthcare professionals who specialize in children's heart failure.[2,8] These initiatives have led to more children with HF surviving and being discharged into the outpatient setting. Despite these encouraging clinical gains, knowledge translation strategies have not kept pace for the caregiver audiences, bringing about knowledge gaps among caregivers responsible for their child's complex care.[11] Within the congenital heart disease realm, there is a distinct call to improve knowledge translation strategies that target caregivers,[12,13] which has not been documented in the chronic HF population.

When limited relevant educational material is available for caregivers, feelings of stress, anxiety and issues with adherence often result.[14,15] However, when caregivers or caregivers have access to understandable, evidenced-based information, improvements in their confidence and decision-making occur while also reducing healthcare costs.[11] Access to information tailored to caregivers' knowledge, needs and experiences is vital in developing these effective educational tools, promoting improved adherence to complex treatment strategies and fostering resilience among caregivers to withstand a long, complex medical journey better.[16] These benefits are congruent for caregivers who have a child affected by chronic HF. Therefore, the aim was to describe and synthesize all available qualitative knowledge related to caregivers' information needs and experiences caring for a child with chronic HF.

Methods

Sandelowski and Barroso's (2007) Handbook for Synthesizing Qualitative Research guided our synthesis and reporting was in accordance with the ENTREQ statement.[17,18] These guidelines provided a structured yet flexible means to robustly synthesize an increasing area of knowledge in the field of pediatric cardiology care to inform and shape nursing practice in this unique area. No qualitative evidence syntheses with the same focus are registered in the Cochrane Library or PROSPERO database.

Comprehensive Search Strategy

The search was conducted in November. 2023 in seven medical, psychological, and socially based databases (Ovid, combining searches from MEDLINE, Scopus, EMBASE, PsycINFO; and a second combined search in Cumulative Index to Nursing and Allied Health Literature (CINHAL), Educational Resources Information Centre (ERIC), & Education Research Complete). All references were imported into a software reference Manager (EndNote 21). Consultation with two individuals with a library science background occurred before conducting the search (MK, John Scott Librarian at the University of Alberta; TP, and a Registered Nurse with a master's degree in library science employed by our research team). The search was structured around three main concepts based on the PICOS tool, expanded using Medical Subject Headings (MeSH) and organized using appropriate Boolean search terms. Search concepts used were 1) caregivers, 2) pediatric HF, and 3) health information needs, attitudes and experiences.

Study Selection

The primary reviewer (CC) saved search results into the EndNote 21 reference manager and then imported them into Microsoft Excel. A senior researcher guided the entire synthesis process (SDS). The primary and secondary screeners (CC, KS) have several years of clinical nursing experience in chronic children's HF, providing a solid foundation for decision-making during the inclusion/exclusion process.

The primary reviewer (CC) verified the imported study list for accuracy by data validating all columns and confirming available and correct abstracts. To keep screening an independent process, The primary reviewer (CC) uploaded a Microsoft Excel® spreadsheet onto a Google Drive spreadsheet with separate tabs for the second reviewer (KS).

Both reviewers assessed all studies using the developing inclusion and exclusion informed by the structure outlined in the population, intervention, comparison, outcomes and study type (PICOS) tool.[19] As Methley et al. (2014) suggest, the PICOS tool better captures the qualitative study design to ensure a more comprehensive search compared to other tools, such as SPIDER. To ensure clarity and consistency regarding the inclusion and exclusion process, the primary reviewer (CC) compared the first 20 responses provided by both reviewers for accuracy before the rest of the screening took place. The reviewers discussed two studies (CC, KS) with resolution, with no discrepancies needing to be resolved with the senior methodology author (SDS). The inclusion criteria were as follows:

- Population: Participants include parents or caregivers of a child with HF (e.g., parents, relatives or guardians who care for a child aged 0-21 years with HF)
- Intervention: Studies relating to chronic children's HF (e.g., pediatrics, children/adolescents up to age 21 years who have been diagnosed with HF, excluding congenital lesions surgical option amendable for a surgical correction (e.g., ASD or VSD), children who have controlled heart failure on mechanical heart support)
- Comparison: Healthy siblings or not applicable if no other children
- Outcome: Relates to parents/caregivers or parents/caregivers' experiences (e.g., participation, involvement, perception, attitude) and/or their seeking (or accessing) health

information (e.g., oral, online or print information, materials, or resources) about their child’s HF

- Study Type: Primary peer-reviewed, English-only qualitative studies

First, titles and abstracts were screened. The primary reviewer (CC) built the inclusion and exclusion criteria guide into the Microsoft Excel® spreadsheet using the data validation function to avoid any extraneous text answers. Studies that did not automatically import abstracts into the spreadsheet were searched and included by the primary reviewer (CC) or automatically included in the full-text review list. If a study related to pediatric congenital heart disease or other disease states that could result in PHF symptoms, it was automatically included in the final full-text screen for more in-depth consideration.

Quality Assessment & Data Extraction

The Joanna Briggs Institute (JBI) Appraisal Checklist for Qualitative Research is a concise 10-question list that assesses for methodological quality using a structured four-point Likert scale format (e.g., yes, no, unclear, not applicable).[20] The checklist has been used in prior studies, is available online and is a coherent tool with straightforward questions for reviewers.[21] Each researcher completed this stage independently (CC, KS). As Sandelowski and Barroso (2007) outlined, no studies would be excluded from our review due to poor quality due to the nature of qualitative research.[17]

Analysis

Our analysis method followed Sandelowski and Barroso’s (2007) two-stage metasummary and meta-synthesis. This two-stage approach highlights effect sizes and synthesizes previous knowledge into novel interpretations.[17] This method of third-order analysis avoids issues of stripping critical contextual data.[22] This analysis process results in a deeper, more coherent description of a specific qualitative phenomenon, uncovering new findings from primary studies.[17]

Results

The PRISMA flow diagram outlines the study selection process (Figure 1). After de-duplication, 2,425 studies were identified. Thirty-nine made it to the full-text screening stage, and one study met the inclusion criteria.

The included study (Zhang et al., 2023) was conducted in China from April 2021 to 2022 and published in English. The study explored the experience of family management among caregivers who have a child with chronic HF, recruiting caregivers and interviewing them using semi-structured interviews.[23] The qualitative study employed a descriptive phenomenology lens to keep findings as close to the data as possible. The authors stated this was a congruent method for the study design as they sought to understand the family's experience of managing a child with heart failure as the environment and personal relationships impact it rather than interpret it. Data was analyzed using Colaizzi's seven-step analysis. The findings included three themes and 10 sub-themes (Table 2).

Classifying the Findings

Sandelowski and Barroso (2007) situate or classify the findings of included studies on a continuum to understand how researchers analyzed the primary data. The continuum indicates the degree of data transformation during the analysis phase (e.g., level of interpretation). The continuum runs from left to right, with the left side being the closest findings to the participant's descriptions (topical/survey data) to the far right (conceptual description/interpretative findings). This process forces the reviewers to evaluate the findings through a more critical lens, considering and selecting a description in Sandelowski and Barroso's constructed scale rather than just merely restating the methods claimed by the authors.

This study's classification was conceptual/thematic. The authors aimed to stay close to the data to highlight caregivers' experiences with a marginal amount of interpretation from the researchers using a qualitative descriptive phenomenology approach. The authors included only one or two minimally interpretive sentences in each subtheme and let numerous rich quotes for each subtheme speak for themselves.

Quality Assessment & Data Extraction

Study characteristics and outcomes (Table 1), highlighting key study details. Sixteen participants (13 mothers and three fathers) were recruited. Data was collected through in-person and online semi-structured interviews ranging from 20-60 minutes (10 in-person and six recorded WeChat interviews). The recordings were transcribed verbatim shortly after each interview and analyzed using content analysis. Three themes were identified with 1 to 5 subthemes nested within each category. The themes were: 1) weakened family socialization, 2) experience of five psychological stages, and 3) family management dilemmas.

Both reviewers (CC, KS) completed the quality appraisal using the Joanna Briggs Institute (JBI) qualitative checklist.[20] The concise 10-item checklist evaluates a study's rigour, epistemology, and ontology.[24] Sandelowski and Barroso (2007) suggest that the purpose of critical appraisal is to provide information about the quality of the evidence rather than exclude the papers, as exclusion may introduce bias.[17] Furthermore, due to a lack of consensus, widespread debate exists about rigour within qualitative research, so it is more cautious about including all qualitative studies.[17]

Both reviewers scored the study, agreeing it had many rigorous qualities (Table 2). The study provided excellent congruity between the philosophical perspective, research methodology, and objectives. Ethics were also considered and obtained. The only aspects not stated in the study were elements relating to locating the researcher culturally or theoretically and their influence on the researcher's findings, which may have introduced some bias. Overall, this study withheld a high level of methodological quality.

Metasummary and Metasynthesis

No synthesis could be completed since only one study was included in our review. It was impossible to complete either the metasummary (e.g., effect size calculation) or metasynthesis (e.g., new interpretations of the included studies) steps outlined in Sandelowski and Barroso's handbook.

Discussion

The primary objective of this qualitative synthesis was to uncover and synthesize literature relating to caregivers' information needs and experiences for a child with chronic HF. To our knowledge, no previous synthesis has been completed. Our research uncovered only one study by Zhang et al (2023) that met inclusion criteria, highlighting a significant knowledge gap about caregivers' information needs and experiences caring for a child with HF. The study included 16 participants, uncovering three themes and ten subthemes relating to caregivers' family management who have a child with chronic heart failure (Table 2).

Zhang et al. (2023) concluded that families who have a child with chronic heart failure experience difficulties with socialization and economic burden, imposing psychological repercussions on caregivers. This problematic situation is very taxing on families and requires constant monitoring for adverse symptoms or clinical deterioration, leading to adverse effects on families. This paper also highlighted participants' perception of low social awareness of this disease due to its rarity and feelings relating to a lack of educational information due to this gap.

Impact of Caregiver Knowledge Gaps

Caregivers become responsible for the daily management tasks when their children are diagnosed with chronic HF. Healthcare providers who practice in this area receive detailed education about the care needs of children with heart failure; therefore, a parallel focus needs to be placed to continue providing safe and adequate decision-making in the home environment. Caregivers are expected to understand and become proficient in highly complex medical knowledge about their child's HF in a short period, making critical day-to-day decisions. Caring for a child with chronic HF differs from caring for a child with CHD, [25,26] and needs its own research base to generate relevant knowledge about this complex population.

Adult HF Caregiver Experience

Literature on adult HF caregiver experience has been broadly documented. A state of science review by the American Heart Association suggests that unpaid support from caregivers of the adult HF population imposes a high level of strain on their caregivers.[27] Caregivers can experience feelings of doubt and anxiety, the need for constant guidance and support from healthcare providers, unmet personal needs, the continuous juggling of caregiving tasks, and the continual adaptation of strategies to normalize their lives.

A second study by Kitko et al. (2020) suggests adult HF treatments delivered by family members in the home setting have become more intensive and increasingly precarious. Tasks now performed in the home are ones that healthcare professionals have previously provided in the hospital environment, signifying that patients are being discharged into the community earlier. Adult HF caregivers spend an impressive average of 22 hours per week providing care.[27]

Kitko et al. (2020) also state that caregivers are forced to handle some complex tasks simultaneously, requiring an increased ability to think critically. They also suggest that caregivers' roles are invaluable in preventing costly hospital readmissions, which could unarguably be a factor in the pediatric context.

Another adult-based study by Sedlar (2020) highlights that caregivers felt they mostly take on practical tasks (e.g., medication administration and meal preparation) with 33% of caregivers also providing emotional support to their spouses with HF.[28] Half of the informal caregivers reported experiencing anxiety related to the future and their ability to manage sudden deterioration. Most (90%) of informal caregivers reported changes in their family roles and relationships after the diagnosis, forcing them to change their lifestyle to adapt to the patient's limitations. Notably, a third of the caregivers described their needs as less important than their spouse's needs with HF. Thankfully, two-thirds of informal caregivers felt acknowledged and ‘part of the team’ at a medical appointment.

The Importance of Knowledge Gaps

Further research is critical since our study identified a single study with 16 participants. The findings presented in this knowledge synthesis are congruent to other reviews that uncover no studies, called empty reviews.[29,30] Empty reviews were first mentioned by Lang et al. in 2007, who suggested they were rare.[30] Yaffe et al. (2012) conducted a systematic review in the Cochrane Database for Systematic Reviews, concluding that they were not as rare as once thought, occurring in 1 in 10 reviews.[29] Arguments in the literature state that empty reviews may appear to offer no conclusions as there is no evidence, leading to an overall general disappointment in the absence of recommendations or guidance.[23,29] However, alternative arguments support the importance of empty reviews because authors acknowledge a critical knowledge gap exists for a specific topic, validating the need to prioritize future research.[31] So, while no synthesis could be conducted, this finding highlights the need for further research.

Practice Implications & Future Research

It is known that evidence-based treatment guidelines for this population have rapidly evolved within the last decade;[3,4] however, our review demonstrates an evident lack of qualitative research exploring caregivers' information needs and experiences to base care and create relevant educational tools. Qualitative research is needed to uncover and truly understand the depth of caregiver experience when faced with such a complex medical diagnosis. Previous educational tools and care recommendations have been primarily designed based on limited caregiver input (e.g., parent focus groups) and the clinician lens. Therefore, our study supports our next research endeavour of completing qualitative interviews with this population to provide improved, more relevant care and education.

Study Limitations

Like all studies, this study is not free of limitations. The reviewers with advanced clinical knowledge through years of practice experience in pediatric chronic HF anticipated limited to no included studies, potentially leading to some confirmation bias. To mitigate this factor, a comprehensive search and screening strategy was undertaken. No date limits were applied to identify in hopes of identifying data on the topic. The included studies reference list was also hand-searched for potential further included studies. Furthermore, any papers about caregiver experience in congenital heart disease were carried forth to full-text screening to ensure no elements about chronic heart failure were missed.

Conclusion

Through this QES, we uncovered two critical findings. First, this review was the first of its kind in the rapidly evolving field of pediatric HF, looking to synthesize caregivers' information needs and experiences caring for a child with HF. Second, only one study met our inclusion criteria, highlighting a considerable knowledge gap in the qualitative evidence. Highlighting this opportunity for future research is critical to optimizing care experiences and providing relevant educational material through research knowledge.

Figure 3.1. PRISMA Diagram

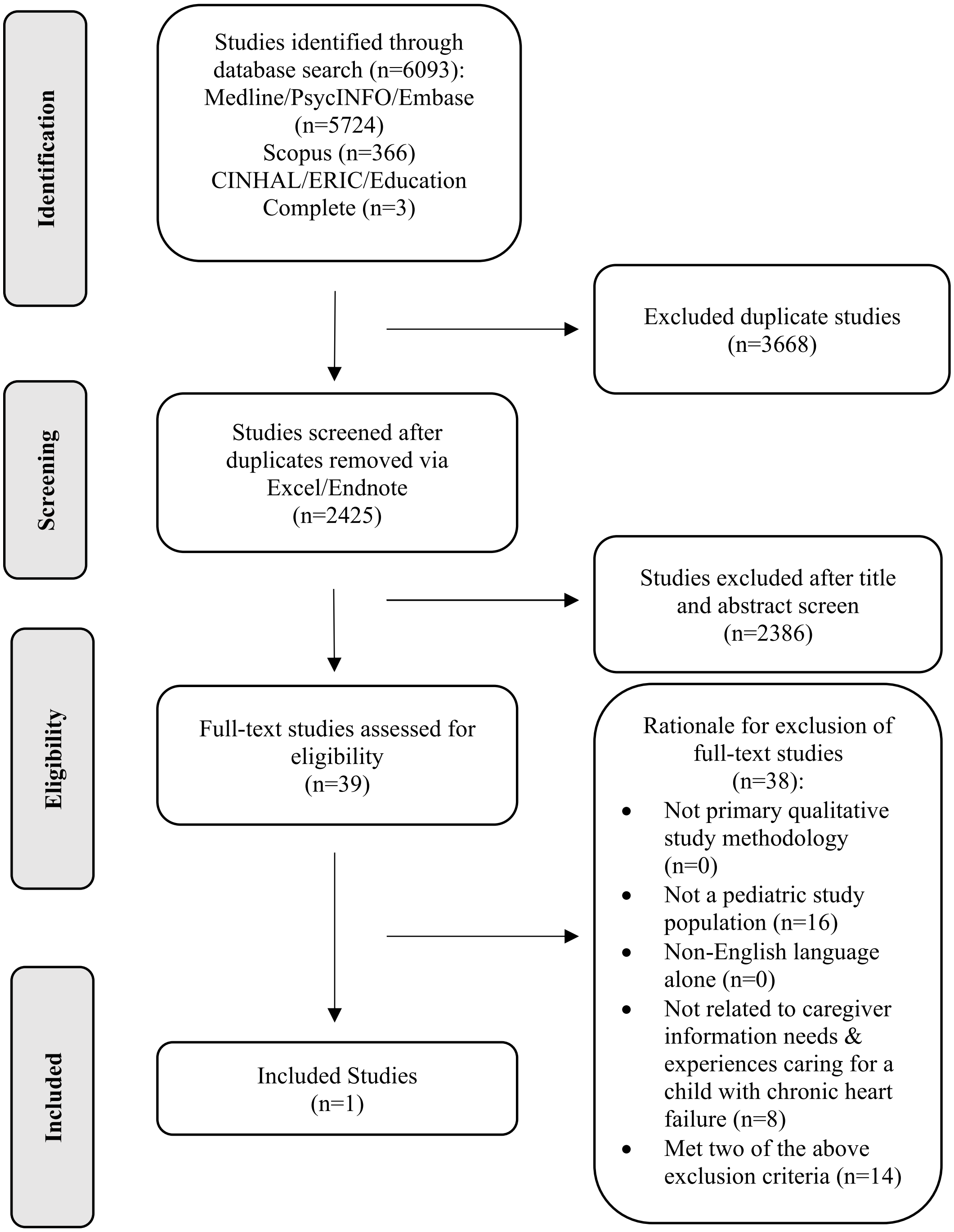

Table 3.2. Study Characteristics and Outcomes

Author/Year/Title/DOI	Study Design/Aim	Classification of Findings	Location/Context	No. of Participants/Reported Sexes/Race & Ethnicity
A. Z. Zhang, X., Shen, Q., Zhang, Q., Leng, H. 2023 Family management experience of parents of children with chronic heart failure: A qualitative study doi.org/10.1016/j.pedn.2023.07.006	Husserl's Phenomenological Theory (Descriptive Phenomenology) using semi-structured interviews (10 face-to-face, 6 WeChat video) Duration of each interview: 20 - 60 minutes Aim: This study explored the experience of family management from the perspective of the parents of children with CHF and may provide a reference for pediatric nursing staff to develop family management intervention programs.	Conceptual thematic description (bordering left on the grey towards thematic survey)	Parents of hospitalized children with CHF in the cardiovascular department in Chongqing, China from April 2021 to 2022	16 parents (purposive sampling), no breakdown of male vs. female Sex not reported, only identity (13 mothers, three fathers) Race & Ethnicity: Not reported Participant Ages (Years): • Overall Parent Age Range: 25 - 56 • Mothers Age Range: 25 - 48 (mean 36.8) • Father Age Range: 33 - 56 (Mean 42)

Study Outcomes		
Theme 1: Weakened Family Socialization	Theme 2: Experience of Five Psychological Stages	Theme 3: Family Management Dilemmas
2 Sub-themes: 1. Diminished Parental Role in Social Education: Some parents react with a mindset of compensating for the child, resulting in a lack of restraint regarding the child's behaviour and guidance related to the child's emotional regulation. Over time, children with CHF experience a range of psychological,	5 Sub-themes: 1. Exhaustion: In the process of medical treatment, family management, and uncertainty, parents often experience psychological pressure and even criticism, thus making them sensitive to sadness and Resistance: Little knowledge about the disease among parents made it difficult for parents to accept the reality	3 Sub-themes: 1. Low Social Awareness of the Disease: Awareness of CHF among parents, the public, and grassroots pediatric nursing staff is low, and that creates many challenges in the family management of the disease. Parents have inadequate disease management ability, which is mainly manifested in insufficient

behavioural, and social adaptation problems. 2. Insufficient Socialization of Children: Children with CHF have delayed growth and development and decreased activity endurance, which limits or even blocks their social activities.	of their children's illness at the time of initial diagnosis. 2. Self-blame: When parents begin to acknowledge that their children are ill, some of them feel guilty and blame themselves for their children's illnesses. Similarly, during medical treatment, unintentional blame by people nearby can intensify this sense of self-blame. 3. Worry: Parents' desire for medical treatment increased after they adjusted their emotions. During this time, parents were worried about their child's prognosis and future. 4. Exhaustion: In the process of medical treatment, family management, and uncertainty, parents often experience psychological pressure and even criticism, thus making them sensitive to sadness and even exhaustion. 5. Acceptance: During a protracted time of care, parents started to accept the significant changes the disease had caused in the family. Several parents lost confidence and felt helpless. Nonetheless, other parents persisted in changing their perspective, regaining their confidence, and embracing their children's illnesses with optimism.	medication management at home, irregular management, such as a low-salt diet, and a lack of scientific disease monitoring techniques. 2. Heavy Economic Burden: When a child becomes unwell, the family's financial burden increases due to the cost of medical care. One parent must quit his/her job to care for the sick child at home, which reduces economic resources. The disease treatment is a long process, and the expenditure is unpredictable, which makes the economic situation in the family extremely burdensome. 3. Limited Coping Styles: During the entire process, the parents tried to keep the family stable but often ignored their health and other children's feelings.

Table 3.3. Independent Reviewer JBI Quality Appraisal Comparison

Question	Reviewer #1 Responses (CC)	Reviewer 2 Responses (KS)
1. Is there congruity between the stated philosophical perspective and the research methodology?	☒ Yes ☐ No ☐ Unclear ☐ Not Applicable	☒ Yes ☐ No ☐ Unclear ☐ Not Applicable
2. Is there congruity between the research methodology and the research question or objectives?	☒ Yes ☐ No ☐ Unclear ☐ Not Applicable	☒ Yes ☐ No ☐ Unclear ☐ Not Applicable
3. Is there congruity between the research methodology and the methods used to collect data?	☒ Yes ☐ No ☐ Unclear ☐ Not Applicable	☒ Yes ☐ No ☐ Unclear ☐ Not Applicable
4. Is there congruity between the research methodology and the representation of results?	☒ Yes ☐ No ☐ Unclear ☐ Not Applicable	☒ Yes ☐ No ☐ Unclear ☐ Not Applicable
5. Is there congruity between the research methodology and the interpretation of results?	☒ Yes ☐ No ☐ Unclear ☐ Not Applicable	☒ Yes ☐ No ☐ Unclear ☐ Not Applicable
6. Is there a statement locating the researcher culturally or theoretically?	☐ Yes ☒ No ☐ Unclear ☐ Not Applicable	☐ Yes ☒ No ☐ Unclear ☐ Not Applicable
7. Is there influence of the researcher on the research, and vice-versa addressed?	☐ Yes ☒ No ☐ Unclear ☐ Not Applicable	☐ Yes ☒ No ☐ Unclear ☐ Not Applicable
8. Are participants, and their voices, adequately represented?	☒ Yes ☐ No ☐ Unclear ☐ Not Applicable	☒ Yes ☐ No ☐ Unclear ☐ Not Applicable
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	☒ Yes ☐ No ☐ Unclear ☐ Not Applicable	☒ Yes ☐ No ☐ Unclear ☐ Not Applicable
10. Do the conclusions drawn in the research report flow from the analysis or interpretation of the data?	☒ Yes ☐ No ☐ Unclear ☐ Not Applicable	☒ Yes ☐ No ☐ Unclear ☐ Not Applicable

Overall Appraisal: Include: ☒ Exclude: ☐ Seek further Information: ☐

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CHAPTER 4. Paper 3: Exploring Caregiver Learning and Experiences Caring for a Child with Heart Failure: A Qualitative Study

This paper is published as:

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Abstract

Background: PHF poses life-long, burdensome symptoms for the healthcare system and families. Diagnosis and discharge are stressful and anxiety-provoking for caregivers. They face uncertainty about their child's health and become responsible for administering complex care in the home. Little is known about this topic. Our study aimed to explore caregiver learning and experiences caring for a child with heart failure to design and implement a knowledge translation tool.

Methods: QD guided our study. Recruitment occurred in a tertiary cardiac centre in Edmonton, Alberta, Canada. Data collection and analysis occurred concurrently until data redundancy was achieved. Inductive conventional content analysis was used to develop categories.

Results: Eleven interviews identified two main categories. One related to how traumatic life experiences impact learning (e.g., new diverse ways of learning, stress steepens the learning curve, learning heart failure takes time). The other relates to families' new life reality after diagnosis (e.g., emotional distress and the new reality).

Conclusions: This study provides insight into caregivers' learning needs and experiences caring for a child with heart failure. Caregivers describe how the trauma of having their child diagnosed with heart failure negatively and the negative impacts it has on their learning and ways of life going forth. Knowledge about caregiver learning experiences and preferences for digital platforms are also highlighted. This knowledge will inform an online tool for caregiver audiences that empowers caregivers to make improved decisions in managing their child's heart failure while enhancing the means for improved clinical education in this context.

Keywords: Pediatrics, qualitative, caregivers, heart failure, nursing

Introduction

PHF is a burdensome condition for the healthcare system and families. PHF accounts for an estimated 11,000 - 14,000 hospitalizations annually in the United States.[1,2] It is a factor in many chronic health conditions, such as children with cardiomyopathy, neuromuscular, metabolic, genetic, and oncologic conditions, among other chronic etiologies.[3] A subset of children with heart muscle disease will experience a more chronic heart failure phenotype, facing a more uncertain and burdensome trajectory with a tendency for repeated exacerbations requiring prolonged, specialized home and hospital care.[4] Children with heart muscle disease exhibit systolic or diastolic dysfunction, manifesting with cardinal symptoms varying across age groups and health conditions with limited surgical treatment options.[3,4]

Over the past two decades, PHF has gained more attention from clinicians, and as a result, treatment recommendations have evolved from collaboration and knowledge-sharing.[3,4,6] Daily management for children with chronic heart failure symptoms in the home environment includes frequent medication administration, vigilant fluid management, symptom recognition, clinic appointments, and specialized diets.[3,6] When discharged from the hospital setting, implementation, monitoring, and minor adjustments of therapies fall largely on the caregivers, which are all key components of the information needs of caregivers in the home setting. Care responsibilities for a child with heart failure also include physiological pediatric growth and development needs that caregivers alone can find stressful.[7] These combined factors provide challenges for caregivers related to treatment regimes, social and financial constraints and overall family functioning.[8]

Implementing effective knowledge translation strategies geared towards caregivers is key to improving their ability to provide daily management to a child with heart failure, which also results in improved outcomes and less healthcare system burden.[9] With effective KT strategies and learning, caregivers will elicit positive behaviour change through better decision-making and participation in their child's health.[9] For caregivers to be more proficient in daily management and decision-making in the context of PHF, evidence-based information must be relevant, understandable, timely and truly based on caregiver perception and need.[10] It is known that caregivers with access to understandable, evidenced-based information feel more empowered to make decisions regarding their child's health care needs more confidently.[10] Research knowledge about caregivers' information needs and experiences in specific chronic illness contexts can assist healthcare providers in better supporting them in their difficult role as care managers.[8]

It is known that a limited number of educational tools exist for caregivers who have a child affected by heart failure.[11] Understanding caregivers' information needs and experiences through qualitative exploration has been beneficial in other chronic pediatric conditions;[12,13] However, this knowledge has been scarce in the context of chronic children's heart failure. KT strategies should be based on the caregiver's learning needs and experiences, not clinician perceptions. The foundation for the Knowledge-To-Action Framework outlines this notion, starting with tailored knowledge creation employing methods that enable participant engagement.[14]

Therefore, this study aimed to explore caregiver learning and experiences relating to caring for a child with heart failure through a qualitative approach. Knowledge generated from this study will be used to guide clinical practice and aid in the design of educational tools about PHF targeted at caregiver audiences in the future.

Methodology

A QD approach is used to gain insight into this complex topic.[15,16] This method is best applied when straightforward participant descriptions are desired to develop interventions related to specific populations' needs or understanding of human behaviour.[15-18] QD also provides data interpretation by the researcher, keeping it true to the participants' perspective.

This study was underpinned by the Knowledge-to-Action (KTA) Framework that was developed on 31 planned action theories.[14] Based on the knowledge creation funnel of the framework, this study appropriately explores caregiver learning and experience to inform an evidence-based intervention (e.g., educational tool for caregivers about children's heart failure). Understanding gaps and creating knowledge about caregivers learning and experiences (i.e., knowledge creation) to tailor future educational tool development targeted at caregivers' learning and experience is critical before KT tool development (i.e., Action Cycle).

Sample

Recruitment strategies aimed to achieve a purposeful, diverse sample.[19] Purposeful sampling was conducted in the Stollery Children's Hospital from May to December 2022. This recruitment venue was ideal as it is a main tertiary care center for children diagnosed with chronic heart failure from five Canadian jurisdictions. Participants were recruited if they met the study inclusion criteria (Table 1) and were willing to participate in an interview with the primary researcher (C. C.). Due to a limited number of pediatric patients with advanced heart failure, we included both groups, C and D, despite some nuances in the complexity of care. Recruitment happened at a minimum of two weeks or later after discharge to ensure caregivers had some independent experiences in care. Interview coordination also took up to a few weeks due to caregivers' busy care schedules, providing participants with more time to provide to gain insight.

The sample size was estimated to be approximately 10-20 participants to reach data redundancy.[17] The first author contacted participants up to three times via email, modelled after evidence-based surveying methods.[20]

Ethics

Our relevant research ethics board granted ethical approval before participant recruitment (ID PRO00106559, ARISE, University of Alberta). Eligible participants recruited in the clinic were approached initially by clinic nurses not associated with the study to seek their interest in obtaining more information. If they agreed, the primary researcher (C. C.), a clinician on their care team, explained the study to participants and obtained signed consent. Before each interview with the primary researcher (C. C.), the consent form (e.g., the purpose of the interview, data storage, confidentially, how the research would not impact their child's care, and voluntary participation). Each participant was willing to proceed with each interview. Enrolled participants received a $25 gift care for their time.

Several steps were identified beforehand to ensure that ethics and rigour were withheld. The primary researcher (C. C.) did not initially approach families about participation. Second, a modest research incentive ($25.00) was provided after consent was obtained. Lastly, interviews were completed in a virtual setting apart from the clinical environment. A review of confidentiality prior to commencing the interview occurred, emphasizing that research is voluntary. Participants were also reminded that the researcher could not address clinical needs during interviews.[21,22]

Data Collection

The primary researcher (C. C.) interviewed all participants. The researcher has a 12-year clinical background as an Advanced Practice Nurse in Children's Heart Failure and is a 5th-year doctoral student trained in qualitative methods, supervised by a senior qualitative researcher (S. D. S). The interview guide was developed by the first author (C. C.) in consultation with senior members of the research team (J. C. and S. D. S.) (Table 2). Interviews were conducted virtually through a secure online interview software account and recorded directly onto the University of Alberta's secure Local Area Network (LAN) portal. Recorded audio files were transcribed verbatim by a professional transcription service. Field notes were also recorded after each interview. Data collection and analysis were an iterative process to achieve data redundancy. Analysis started immediately after the second interview and was conducted during all stages of recruitment under data redundancy (e.g., no new categories emerged) identified by the study team.

Analysis

Our analysis used conventional content analysis to uncover categories and sub-categories.[23] Two researchers (C. C. and Z. Z.) independently completed initial coding and collapsed codes into categories using a qualitative software platform (NVivo). Codebooks with detailed definitions were sent to the senior researcher (S. D. S), who oversaw the coding process. Weekly meetings were held to discuss definitions, add or modify codes, and collapse existing codes into overarching categories. Versions of the code were saved onto the study team's LAN to document the evolution of the categories and research decisions.

Trustworthiness

Lincoln and Guba's (1985) four trustworthiness criteria (credibility, dependability, confirmability, and transferability) guided our study.[24-26] Credibility was established by investigator triangulation, where a senior author (S. S.) read all transcripts during the interview and analysis to ensure that interview data generated thick, rich descriptions. The senior author also verified all of the codebook definitions. Prior to starting all interviews, it was also explicitly stated to participants that the motivation behind the interviews was to create an educational tool for caregivers about heart failure so that participants felt open to speak freely and naturally about their experiences to help facilitate the collection of rich data. Caregivers were highly engaged and eager to share their experiences, resulting in rich, detailed data. A third strategy to ensure trustworthiness was peer debriefing, where a senior, experienced researcher verified quotations, definitions & codes warranted to establish a category. Lastly, field notes and reflexive journaling were completed following each interview to examine researcher bias. All methodological decisions were recorded. Standards for Reporting Qualitative Research (SRQR) was used to ensure comprehensive reporting.[27, 28]

Results

Demographics

Fourteen participants who identified as caregivers (mothers and fathers) caring for a child with chronic heart failure participated in the study. Three participants withdrew from the study (e.g., no response via repeated email requests for an interview from the primary researcher after recruitment). Eleven caregiver interviews were conducted. Demographic data is provided in Table 3.

Interview lengths ranged from 25 to 84 minutes (average 43 minutes) with large chunks of participant text. Two categories were identified with 2-3 sub-categories nested within each. Category 1, titled 'The Traumatic Diagnosis of Heart Failure Influences Learning,' relates to how receiving a traumatic diagnosis in their child can impact caregiver learning needs. Sub-categories were titled: 1) new diverse ways of learning, 2) stress steepens the learning curve, and 3) learning heart failure takes time. The second category related to how caregivers' experience is termed ‘A New Life Reality After Diagnosis.’ Two sub-categories shaped this category: 4) the Emotional Rollercoaster and 5) Always on the Clock: caring for a child with heart failure (Table 4).

Category #1: The Traumatic Diagnosis of Heart Failure Influences Learning

Sub-category# 1: New Diverse Ways of Learning

Caregivers described four ways of learning that emerged after their child was diagnosed with heart failure: 1) tangible educational information, 2) independent online research, 3) healthcare providers' support during care by caregiver tasks, and 4) hearing other’s stories. Tangible information sources are hard copies of information, like printouts or pamphlets, provided as tangible sources, generally in the initial stages after diagnosis. This type of information was generally not as favored for several reasons (e.g., misplacing their copy, only remembering a fraction of the information). For example, one caregiver shared, “Um, I think it was easy to forget a lot of the stuff that was in the booklet” (P1, mother). Other caregivers agreed, sharing, “I didn’t find [printouts] helpful. I preferred just going online and trying to do my own research online like for [their] specific heart stuff.” (P11, mother). Similarly, another caregiver shared they found handouts overwhelming:

> No, generally, I find you get a ten- or fifteen-page handout at the end of the doctor visit; that’s the last thing you want to look at when I’m leaving the hospital from a visit. It’s the last thing I want to do. So, no, I don’t really enjoy those. (P8, father)

Independent online research was most preferred. Caregivers could complete it independently, at their own pace, using their mobile or electronic device when it was most convenient. Search engines were cited by participants, “I just Googled stuff. That was our main source of getting that information" (P4, father). Online searches were also tailored to find information specific to their current challenges. One caregiver expressed, "And with feeding, we had to do so much independent research, on our own, about offering food…" (P3, mother).

Care by parent is a term coined by healthcare professionals when caregivers complete a dry run of care tasks in the hospital environment to assess their overall readiness for discharge and fill knowledge gaps. Attributes were described as a "hands-on approach or giving of examples by healthcare staff" (P4, father). Another caregiver shared how it gave them the "opportunity to ask questions." (P6, mother). Caregivers highlighted how it improved their confidence, expressing, "They taught us the essential basics, but at the same time, it made us feel confident. We were ready to go home is what we felt" (P7, father). Others described similar perceptions, "…they came in three or four times to make sure we were doing it right. They let us do it a few times to the point where we were comfortable" (P5, mother). Interestingly, caregivers with a healthcare background learned information at a quicker pace. One caregiver illustrated, "It was easier for [spouse's name] because [they are] a nurse, but I had to repeat it again, and again, and again until I was comfortable before they allowed my child to go home" (P10, father).

The fourth way of learning encompassed hearing stories from other caregivers. Participants felt comfort and could relate to other caregivers in a similar context, which helped them feel less isolated, navigate challenges and foster coping. One caregiver shared:

> …someone that you could relate to who is going through the same troubles. They would talk about their child, and you'll talk about yours. And it was just a good common ground to relate to somebody else, you know (P4, father)

Caregivers valued hearing stories of survival, signifying hope. For example, one caregiver stated, "I was reading up on others' experiences with heart transplant. I found that to be really helpful” (P11, mother). Another caregiver described, “…I connected with some other families dealing with the same situation. That kind of helped a little bit. Some kids were surviving” (P10, father).

Sub-category #2: Stress Steepens the Learning Curve

Hearing that their child was diagnosed with heart failure was overwhelmingly debilitating for caregivers. This affected their ability to effectively learn during times of heightened stress. Caregivers typically experienced an inability to understand new information, especially after the initial diagnosis or if their child had a decline in health, both being at times of heightened stress. One caregiver illustrated this by sharing:

> Um, so I think that the learning curve has been steep. On top of dealing with, accepting, and coming to terms with the fact that [child’s name] has heart failure, you're also simultaneously moving along that learning curve, which you know, you're being thrown in the pool, in the deep end of the pool, right? (P1, mother)

Two other caregivers described this phenomenon:

> Because when you get a new diagnosis, you can't think. It's like time freezes. You're observing your life instead of living it. And it’s hard, it's hard to remember <Tearing up>… But, in the beginning, I felt like we were probably just a deer, deer in the headlights, like totally overwhelmed being first-time parents and then even more overwhelmed by the fact we have a kid that was really sick and, uh, trying to navigate that… And so, the rest was kind of a blur after that. (P4, father)

> If there is a new diagnosis, somebody came in and talked about all the facets of

> what that means. Sometimes at rounds, people are just like spitting things off and you don't really, you don't really understand, like, I heard that they were gonna give her formula and it made me really emotional. Like, I was very upset, but now obviously looking back [child's name] had chylothorax and needed the formula (P3, mother)

Sub-category 3: Learning Heart Failure Takes Time

Caregivers discussed that understanding information about their child's heart failure eventually became easier over time. Factors that allowed caregivers to better uptake information over time were lessened stress levels and repeated exposure to information. One caregiver describes this experience:

> Now, I feel like every time she has a blip or gets sick, I start to realize – I can see it better after, once she's doing better and I reflect back, then I see more clearly kind of what was happening or that it was, you know, if she was sick because of an infection or just sick in general like a normal kid. Looking back, you can see how hard it probably was – or it was on her heart failure as well, whereas during the time, you don't see it. (P9, mother)

Similarly, other caregivers described that repeated exposure to information was essential:

> …I don't think [feeding] quite clicked until there was an online feeding therapy conference. And I watched like the first 30 minutes of that and just like cried <Laughs> and I was like, "Oh my god, I probably made my kid sicker, like…." It was really hard to wrap my head around that before… I just wish I had understood the repercussions of that when it was happening because I think, um,

> we probably would've done things a little bit differently if that had been the case. (P3, mother)

> So, I think over time it [learning about their child’s heart failure] got better. I got a better understanding and that learning curve was a little less steep... <Laughs>… I had no concept of what was being talked about, and I didn't even know where to start asking questions. Um, so I would say the biggest challenge would be that I didn't know what I didn't know. And so when I was asked, “What questions do you have?” It's like, “I probably have a thousand questions, but I just don't know what they are. (P1, mother)

Another caregiver also shared a similar experience:

> Yeah, just too like re-go back to it, to reference it, if that make sense. Especially as you go through learning, so when you're given some information in the hospital, it doesn't make a whole lot of sense at first, but then as you, as time progresses, when you revert back to it, it's like, oh yeah, this makes sense... (P4, father)

One caregiver described how repeated exposure to information over time allowed them to retain smaller components of complex information. They shared, “Oh, that's what they've been talking about this whole time. Okay, this little piece makes sense. Now I'm gonna store that away. And now I know something a little bit more” (P1, mother).

Category #2: A New Life Reality after Diagnosis

Sub-category 1: The Emotional Rollercoaster

All caregivers described accounts of experiencing emotional distress. Varying feelings of emotional distress were highest following the initial diagnosis. For example, caregiver descriptions included the feelings of “denial” (P3, mother), “loss of control” (P4, father), the situation being “overwhelming” (P1, mother), or “difficult to accept” (P10, father). One caregiver described their “whole world was turned upside down” (P6, mother). Caregivers shared that it was difficult to hear such traumatic information about their child’s health. Another participant stated, “I don’t think you can ever be completely prepared” (P11, mother).

Feelings of emotional distress stemmed from the uncertainty of their child’s survival. One caregiver stated, "Uncertainty is the hardest part” (P9, mother). Another caregiver described:

> He’s very sick. He’s dying really to put it bluntly. And I know that a transplant too is just a Band-Aid. He’s always going to be sick. And then there’s a risk later on too that he would reject that heart and he needs another transplant. There’s definitely days where it’s a lot harder and it kind of hits all at once. (P11, mother)

Another caregiver experienced feelings of uncertainty. They expressed, “The other part that wasn’t easy was we never knew if what was going to be the outcome. We didn’t know if [our child] was going to survive the situation or not.” (P10, father)

Another example of participants feeling emotional distressed related to descriptions of denial. One caregiver stated:

> I think [my spouse] has definitely been more accepting and understanding of the situation. Whereas I have been like, “She’s not sick, she doesn’t need this.” Like even, when we did the write-up for transplantation. I couldn’t wrap my head

> around the fact that she needed a heart transplant, and I still, to some degree, don't really believe it <Shaking Head>. (P2, father)

Sub-category 2: Always on the Clock: Caring for a Child with Heart Failure

Caregivers expressed instances of difficulties with managing their care schedule. This was a new way of living for caregivers, with restrictions on caregivers' socialization. Stress and constant self-sacrifice were described due to always having a scheduled medical task, highlighting the negative impact the prescribed regime had on their health and family functioning. Caregivers always felt they were on the clock for tasks all throughout the day. For example, one caregiver described:

> Physically, [my child] is doing fantastic. They are on five different types of medications, not including vitamin D drops. Um, that's been slightly difficult. I feel like I'm torturing [my child], even though I know I'm really not <Laughs>. (P5, mother)

Caregivers described challenges relating to a cumbersome, regimented schedule, describing their daily routine as 'following an instruction manual.' They shared:

> Because she was given such strict feeding volumes, feeding schedule and meds schedule and everything. So it was it, you know, off the start, it really felt like we were, you know, I felt like the whole time kind of following an instruction manual right?... things have to be step one, step two, step three all throughout the day and then repeat, right? And it, um, you know, made it very hard to, um, kind of do anything normal, right? (P2, father)

Another caregiver shared feelings of anxiety related to meeting their child's fluid requirements. They stated, "Um, well, actually, when she was very young, she wasn't too bad cause she would finish most of her bottles. Um, but it was always sort of this anxiety around, um, you know, if she doesn't." (P1, mother)

Another caregiver described feelings of anger when their child had difficulties meeting prescribed feeding volumes.

> I just found myself getting frustrated and even angry sometimes when she would have a bad day. Whereas with our son, it's like, whatever, he didn't eat today, he just wasn't hungry. Who cares? Right? He'll do good the next day, but that was never the case with her. …And I know she's not doing as good as she could and that it almost makes me get angry at her, but I don't know if that's really right. I mean, she's the focus of things. And if I'm angry, she's the reason. <Laughs> (P2, father)

Caregivers also described instances where the prescribed home regime strained their parent-child relationship. The description below signifies the strain caregivers feel when trying to balance prescribed care regimes. They shared:

> I think she knows she can't manipulate me as easily, so I don't think I'm her biggest target in that, in that sense. I think if she wants water <Laughs> she will ask her dad. To be honest with you. Uh, which also is like really funny, how she's already figured out that like, dad will bend, mom will not. So let's go, where we know our, our effort will be recognized, I guess… It's like having a little heroin addict but like the water is the heroin. Cause she's just like "water, water?" And she will manipulate the hell out of you to get water. (P3)

Discussion

Our paper provides new findings related to caregivers' learning and experiences caring for a child with heart failure. Zhang et al. (2023) uncovered similar findings related to challenges families experience when they have a child with chronic heart failure within their family, uncovering three key themes.[29] Themes were titled 1) weakened family socialization, 2) the five psychological stages, and 3) family management dilemmas. Each theme had 2-5 subthemes supporting the development of each main theme. These themes are relatable in our second category, a new life reality after diagnosis shaped by emotional distress and challenges associated with caring for a child with heart failure. Four of Zhang's (2023) psychological stages theme (i.e. resistance, worry, exhaustion, and acceptance)[29] were consistent with caregivers in our study who described these feelings in our category, 'The Emotional Rollercoaster.' Caregivers in our study explicitly stated all these feelings in our interviews. Zhang also highlighted that children who were diagnosed with heart failure had insufficient socialization following diagnosis, whereas our study indirectly suggested this notion in our second subcategory (Always on the Clock: Caring for a Child with Heart Failure) as caregivers describe little reprieve and time to socialize with other children and adults and complete self-care tasks as they are focused on providing complex daily management for their child. Our paper provides new knowledge concerning the unfolding of caregiver preferences for learning and challenges. Zhang suggests insufficient social knowledge on the topic but provides no further detail. Caregiver's in Zhang's study also described the heavy economic burden they faced after their child was diagnosed, but our study did not have those findings. This could be related to the differences in support each healthcare system and government provides to families.

Aside from Zhang's paper, a rapid review by Smith et al. (2015) about families with chronically ill children examined caregiver experience with 34 included studies.[8] No caregivers who cared for a child with heart failure were included in this study, but the concept was similar regarding caring for children with a chronic illness. Three main themes were identified in Smith's paper: (1) parental impact, (2) illness management, and (3) social disruption. Smith's themes were strikingly similar to our categories, as all elements in our findings related to Smith's in the same way. The impact on caregivers described by Smith was that caregiver's felt a range of emotions, such as confusion, disbelief, and anxiety. Caregivers in our study felt these emotions, highlighted in our first subcategory, termed the emotional rollercoaster, especially in the early stages following diagnosis. Smith's review also discusses how caregivers need to learn how to manage the illness and experience social disruption, all described by caregivers in our findings. While there is little research published specific to caregiver PHF, it can be concluded that findings from caregivers who have children with chronic illness share similar aspects of their experiences simply due to the effects that chronic illness imposes on caregiving and family dynamics.

Caregiver Learning Considerations PHF

This study highlights challenges related to caregivers' limited ability to uptake and retain information after a stressful event. Compelling evidence relating to congruent learning and testing environments by Schwabe and Wolfe (2009) resonates with our study.[30] Integrating and storing new information into an individual's memory happens during learning. Learning can be impaired if an individual is exposed to a stressful event before undergoing the learning activity,[30] similar to our study. In our first category related to traumatic experiences impairs learning, we noted that caregivers are exposed to an extreme stressor (e.g., being told their child has heart failure) that immediately impairs the caregivers' ability to retain or place new information into their memory. Hence, there is a need for further digital education platforms that are tailored to caregivers about their child's heart failure to improve learning and outcomes.

Secondly, our study highlights the same phenomena as Schwabe and Wolf (2009) called context-dependent memory.[30] They defined testing as memorization of information in one environment (e.g., hospital) that needs to be recalled and applied to another environment (e.g., home). We noted that caregivers described feelings of confidence while receiving support from caregivers in the hospital environment before discharge but then felt stressed again when at home or when their routine needed to change. This may be due to the effects of learning in one environment and then needing to apply the same knowledge in a different environment, which seemed to be another stressor for caregivers in this context.

Caregivers preferred digital educational tools as a source of learning compared to tangible educational materials. Digital tools provide a portable source of relevant information that can be repeated as needed. These tools also provide easy access to certain types of information (e.g., floating menu tabs with headings for topics) to access specific types of information conveniently. Most caregivers have access to a mobile device, compared to tangible educational resources (e.g., paper copies), which caregivers found cumbersome to sort through and did not provide a constant source of information (e.g., misplaced after some time). Knowledge translation strategies that employ a digital approach alleviate these issues for caregivers, fostering more effective health consumers who are better equipped to make decisions.[31]

Clinical Implications

Important clinical implications exist. First, this work supports healthcare practitioners' ability to provide relevant care and information to families through an improved understanding of their lived experiences. Knowledge gained from this research provides clinicians with insight into families' learning needs and experiences, providing an evidence-base to improve the provision of information for caregivers faced with the difficult and complex task of caring for a child with heart failure. This research can also be used to inform and design educational tools that are relevant to caregivers in the clinical context (knowledge translation through patient-engaged methods). As the KTA framework highlights, initial steps in knowledge creation are to understand the knowledge gaps in certain contexts and are used to inform the design of interventions targeted for end-users (e.g., caregivers). This work links theory and clinical practice to help practitioners provide improved information to complement the teaching in the clinical setting with health care practitioners (e.g., experiential guidance and emotional support). It also provides knowledge for practitioners to examine their own practice of educating families. Acknowledging that caregivers have different styles and paces of learning is important and may change how a practitioner interacts with families at different stages of their health journey. Having access to both interactive and accessible knowledge along with clinician support will help facilitate better learning for diverse learning styles that be repeated reviewed when needed to garner an understanding of complex information. It is important for clinicians to acknowledge that caregivers will have a difficult time learning about their child's heart failure in the early stages and to recognize that they need to show more support during this time of steep learning. When this is acknowledged families will feel more comfortable and supported to engage in learning and dialogue with practitioners, which upholds family centered-care values, a cornerstone of pediatric care.

Limitations

One limitation is that all the participants were recruited from a single center, perhaps affecting the overall external validity. Due to practice variation from centres and population cultural differences, this study’s findings may be difficult to generalize to all North American populations. Further studies are needed to encompass a border population; however, this was difficult given the limited resources in this doctoral dissertation work. Further work also needs to be done to include non-English speaking participants as health information developed in English may not readily transfer over to other languages and cultures, limiting who benefits from this knowledge.

The primary researcher in this study is also a practicing clinician in the area where the families were recruited. First, this may have affected the data obtained in the interviews because participants thought it would affect care or healthcare providers' perceptions of patients or families. Second, bias may have been introduced into the analysis. Before the interviews commenced, the researcher discussed the implications of being a clinician-researcher and explicitly stated that this would not affect care and that all information would be kept confidential. The primary researcher also completed reflexive journaling to help mitigate researcher bias in the analysis process.

Conclusions

Our qualitative interviews uncovered two categories with five subcategories that describe how the traumatic experience of a child being diagnosed with heart failure impacts caregiver learning and poses challenges for their life following diagnosis. Similar toa previously published study highlighting caregivers’ stressful lived experiences that highlights having a child with heart failure drastically changes a family dynamics and way of life, our study adds foundational knowledge from the North American perspective about how traumatic events shape and change learning after a child is diagnosed with heart failure. It also details information uptake, retention challenges, and ways to enhance caregiver learning. Our study was a much-needed step in improving the provision of information to caregivers who are faced with this incredibly difficult situation. Furthermore, we will use this knowledge in designing a digital education tool for caregivers and future research areas.

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Ethical Approval

This study was approved by the University of Alberta Ethics Board (ARISE ID Pro00106559).

Statement of Human and Animal Rights

All procedures in this study were conducted in accordance with the approved protocols of the University of Alberta Ethics Review Board (ARISE ID Pro00106559).

Statement of Informed Consent

Written informed consent was obtained from the participants(s) for their anonymized information to be published in this article.

Table 4.1. Participant Inclusion and Exclusion Criteria

Inclusion Criteria

1. Adult caregiver(s) (> 18 years of age) who is responsible for providing daily management & financial responsibilities for a child with chronic heart failure within the last year.
2. A child is defined as any person (< 18 years of age)
3. Child must be diagnosed with heart failure is defined as American College of Cardiology (ACC)/American Heart Association (AHA) ‘category C and D’
    a. Stage C definition is heart disease with prior or current symptoms of heart failure.
    Typical therapies for Stage C include, but are not limited to:
        - Diuretics and goal-directed medical therapy
    b. Stage D definition Patients with refractory heart failure requiring advanced intervention (i.e., biventricular pacemakers, considering left ventricular assist device but not yet implanted, transplantation)
4. Care must be current or within the last year to limit recall bias (e.g., if the child was transplanted or dies)
5. Caregivers must have completed a two-week period where the child is discharged home into the outpatient setting under their care.

Exclusion Criteria

1. Non-English speaking participant
2. No access to reliable internet to complete interview

Table 4.2. Semi-Structured Interview Guide

1. Tell me about your experience of your child having heart failure. (How old was your child when they were diagnosed? How was your child ill? Has your child previously had heart failure?)
2. How did you feel during this experience? Start from when your child was first diagnosed.
3. What did you do to manage the symptoms of your child’s heart failure?
4. What strategies were put in place by healthcare professionals to help your child? (for example, creating detailed care plans, ordering blood work or echo)?
5. How did your child manage the experience? How did you feel about the outcome of this situation?
6. If presented with the same situation again, would you do anything differently?
7. Tell me about strategies that worked well to help this situation and strategies that did not.
8. Has or did your child get sicker? If so, did you feel prepared for them to get sicker?
9. What types of health information/training did you receive about PHF? Did you receive all the information you needed to care for your child? Is there any further information you would have liked to have received?
10. What electronic platform do you prefer to learn about your child’s heart failure? (e.g., video, infographic, whiteboard animation, website)

Table 4.3. Summary Caregiver Sample (N=11)

Variable	Type	N
Gender	Male	5
	Female	6
Primary language	English	13
	Southeast Asian Language	1
Average Number of additional adults in the home	Number of Adults	1.9
Highest level of education	College/technical school	5
	Bachelor's degree	5
	Post-graduate training	1
Current working status	Full-time	9
	Part-time	1
	Not in the Labor Force/Mat Leave	1
Annual household income	\$60, 000 - \$100, 000	2
	\$100, 000 - \$150, 000	3
	≥ \$150,000	6
Health care professional experience	Yes	6
	No	5
Average Number of children in the home (including child with heart failure)	Number of Kids	1.9
Age of the child diagnosed with heart failure	Infant (0-12 m)	4
	Child (1-5 y)	7
Child's heart condition	Cardiomyopathy	9
	Congenital heart disease	2
Average Number of heart surgeries	Number of Surgeries	0.92
Average Age of Heart Failure Onset	Days	192
Listed for heart transplantation (Average Number of Days: 150)	Yes	4
	No	7
Implanted Ventricular Assist Device	Yes	1
	No	10
Average Number of Days Since Heart Failure Diagnosis/Onset	Days	195

Table 4.4. Category Labels

- Category #1: The Traumatic Diagnosis of Heart Failure Influences Learning
    - Sub-Category 1: New Diverse Ways of Learning
    - Sub-category 2: Stress Steepens the Learning Curve
    - Sub-category 3: Learning Heart Failure Takes Time
- Category #2: A New Life Reality After Diagnosis
    - Sub-category 4: The Emotional Rollercoaster
    - Sub-category 5: Always on the Clock: Caring for a Child with Heart Failure

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CHAPTER 5. Paper 4: Development, Evaluation and Refinement of an Online Educational Infographic for Caregivers about PHF

This paper is under review in *J Med Internet Res: Cardio* as:

Cunningham C, Conway J, Schroeder K, Khoury M, Urschel S, Haykowsky M, Scott SD. Development, Evaluation and Refinement of an Online Educational Infographic for Caregivers about pediatric heart failure. April 7, 2024. (Submission ID#59748).

Abstract

Background: PHF is an arduous disease that requires complex and ongoing management strategies. Often, caregivers do not have previous knowledge of this health condition and must acquire a substantial amount of information quickly to care for their child. While there have been advances in treatment guidelines for clinicians in this area, knowledge translation strategies for caregivers have lagged. A limited number of online tools have previously been created, rarely using patient-engaged methods to design, create, and refine a knowledge translation tool. This study aimed to describe the design and evaluate with caregivers through usability and knowledge acquisition, testing how the interactive web-based tool changed caregivers' knowledge and how usable they found the tool.

Methods: Several methods, including an ES, qualitative knowledge synthesis, qualitative interviews, and development with a graphic design team, informed the design of a web-based tool tailored for caregivers of children with HF. Caregivers were recruited from a tertiary outpatient cardiology department. Participants completed a demographic survey, a 5-point Likert scale usability survey with the opportunity for open-ended feedback, and a true and false pre-and post-knowledge test score to measure a change in knowledge after viewing the tool. Descriptive statistics (frequencies) were reported for demographics and usability, and a Wilcoxon rank signed test compared knowledge scores.

Results: Forty-seven surveys were completed. Mean usability scores ranged from 4.45 (SD 0.72) to 4.77 (SD 0.43). Caregivers also experienced a statistically significant overall change in knowledge. The mean correct pre-intervention score for each topic was 9 (73%), and the post-intervention mean score was 10 (83%). For each topic, significant increases in knowledge scores after viewing the infographic compared to before were documented in the areas of medication information (z=-1.51, P=.02), clinical testing (z=-2.84, *P*=.02), activity considerations (z=-2.84, *P*=.02) and emergency care (z=-2.00, *P*=.05). One topic that caregiver's knowledge decreased was the impact of dietary sodium and the impact on child's HF symptoms. Qualitative content findings included mostly positive comments (N=8) compared to areas for refinement (N=6). Areas for refinement included clarifying a child's sodium intake and some minor graphic design aspects.

Conclusions: We created and evaluated a digital knowledge translation tool for caregivers of a child with pediatric HF, employing multi-research methodologies and caregivers-engagement techniques. This resulted in an educational tool rated as favourable to caregiver audiences, demonstrating a predominant knowledge improvement and requiring minimal refinements.

Keywords: caregiver, education, knowledge translation, usability, heart failure, knowledge testing, multi-methods, pediatrics

Introduction

Heart failure (HF) is estimated to occur in 11,000-14000 children in the United States annually.[1] It is broadly defined as a clinical and pathophysiological syndrome resulting from heterogeneous factors that lead to ventricular dysfunction, volume or pressure overload, in combination or alone.[2,3] A more chronic subtype of HF due to heart muscle disease results in long-term systolic and diastolic dysfunction and symptoms of HF (e.g., cardiomyopathies, myocarditis, toxin-induced HF, genetic/metabolic diseases, infectious states, nutritional and neuromuscular conditions).[4] Characteristic symptoms of HF exhibited by children, no matter the etiology, include stagnant growth, impaired exercise tolerance, dyspnea, and anasarca.[2] Children with this phenotype experience an arduous life-long trajectory of burdensome symptoms, requiring recognition and management, as well as the risk of sudden death.[2] Oral therapy is the mainstay of treatment with a limited number of high-risk surgical options for specific disorders or at more advanced stages (e.g., septal myocardectomy cardiac resynchronization therapy, ventricular assist devices and cardiac transplantation).[2,3]

Improved outcomes for children with chronic HF are occurring due to earlier recognition and advancements in evidence-based treatment strategies.[5,6] Despite the encouraging clinical gains, patient-centred knowledge translation strategies have lagged behind for caregiver audiences, postulating a gap in care. This is problematic as caregivers for children with chronic HF are vital for providing complex therapies and identifying exacerbations of symptoms that require timely medical care, which can have an impact on health outcomes. Within the congenital heart disease population, a distinct call to improve knowledge translation strategies targeting caregivers has been suggested,[7,8] which is now similarly needed for caregivers in the chronic HF population.[9]

When few educational materials of limited value are available for caregivers, feelings of stress and anxiety surface, often with issues related to adherence.[10] Empowering caregivers through the provision of accessible and understandable research information is associated with improved caregiver resilience.[11] Relevant educational material enhances caregivers' problem-solving and decision-making abilities by enhancing cognition and competence, promoting resilience and improved decision-making. Caregivers are proxy or surrogate seekers of knowledge on behalf of the child. It is imperative that they understand their child's medical condition and associated treatments.[12]

Heightened in the COVID-19 pandemic, strategies for improving information uptake for pediatric caregivers have been optimized through online digital technologies (e.g., web-based interactive tools or applications).[12] Combining digital technologies with evidence from patient-centred experiences and learning needs enhances the ability to create relevant tools for caregiver audiences.[13] Searching for online information has become a standard way to garner health information for the general population, as it provides convenient and varied ways of presenting health information.[14] Therefore, the aim of this study is to provide an overview of the development of an infographic prototype (intervention), report caregiver knowledge change and their evaluation of usability and proposed refinements.

Methods

A three-phased, multi-method approach was used to design a caregiver-targeted knowledge translation (educational) tool about pediatric HF. A suite of patient-engaged research techniques was critical to developing, evaluating, and refining the usability of this knowledge translation tool to ensure its relevancy and suitability to caregiver audiences. Phases 1 and 2 sought to understand knowledge gaps and preferences about caregivers' information needs and experiences. Also identified in phases 1 and 2 were the caregiver's preferred educational platform (e.g., hard-copy, storybook, digital online web-based or app) and integrating evidence-based content through qualitative interviews in phase 2. Phase 3 is related to design and evaluation. The first author (CC, trained in qualitative methods and supervised by the senior author, SDS) conducted qualitative interviews about caregiver information needs and experiences caring for a child with chronic HF, which was key to the design of our tool. Ethical approval was provided by the University of Alberta ethics board (Pro00106559).

Phase 1. ES for Online Pediatric HF Education Tools Caregiver Audiences

The ES was conducted (July 2020 to March 2021), to identify publicly available North American resources that provided educational information about pediatric HF found on the internet using an advanced Google search and two application (app) stores (Google Play and Apple).[9] Qualitative interviews were conducted with key informants who were involved in development. No apps were found, and 17 educational websites were identified. Suitability of Assessment of Materials (SAM) evaluation was undertaken on all 17 relevant online educational tools, giving each tool its own score (2 pts = superior, 1pt = adequate or 0 pts = not suitable).[15] Results demonstrated that no tools were in the superior range, scoring well in layout and type but lower in readability and graphics. Key informants described essential aspects of tool development, including timely, introductory, credible, and trustworthy information, along with crucial development challenges (e.g., search engine optimization, translation into languages other than English, inclusion of citations, and dedicated time to update tool information).[9] The full results of this ES can be retrieved from the publication by Cunningham et al., 2022.[9]

Phase 2a. QES

A QES was completed in November 2023. The search aimed to identify published qualitative literature related to caregiver knowledge needs and experiences caring for a child diagnosed with chronic HF. The PICOS search was structured by two librarians, searching seven health-related databases (Medline, Psych INFO, Embase, Scopus, CINHAL, Eric and Education Complete) using three concepts: caregivers or parents, heart disease, information needs and experiences. After duplicates were removed, 2425 papers underwent title and abstract screen, using the PICOS inclusion guide designed in relation to our research question. Thirty-nine papers were carried over to the full-text screening phase, with only one paper meeting the inclusion criteria. Zhang et al. (2023) highlighted three main themes with subthemes for each category.[10] Themes related to weakened family socialization, experiences of five psychological stages, and family management dilemmas.[10] The full study results are currently under journal review.[16]

Phase 2b. A Qualitative Descriptive Study Exploring Caregivers' Learning and Experience Caring for a Child with Chronic HF

Recruitment occurred at a tertiary care pediatric cardiology clinic in Western Canada from May 2022 to December 2022. Eleven caregivers participated in the semi-structured interviews. The interview duration was an average of 42 minutes (25-130 minutes). Data collection and analysis were concurrent until data redundancy was apparent. Using conventional content analysis,[17] two categories were identified (the first category had three subcategories; the second category had two subcategories). Caregivers identified an overall lack of knowledge on the topic of pediatric HF and difficulties understanding terminologies, especially early on following diagnosis. They provided details about the design of an educational tool that would help augment their learning.

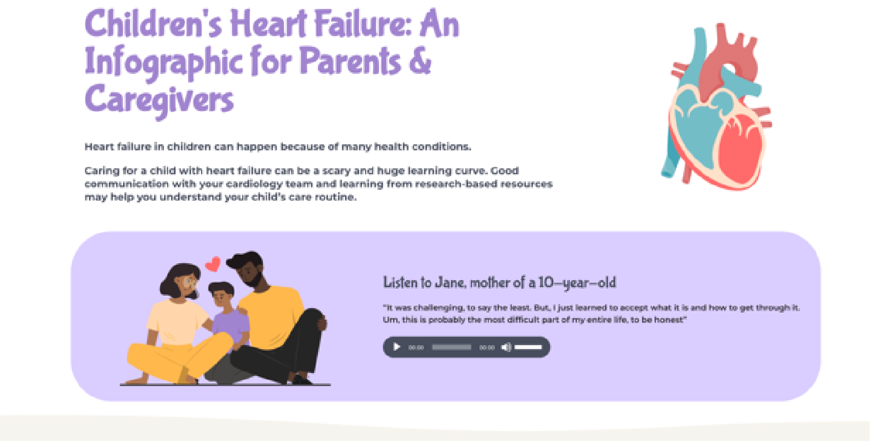
One caregiver suggested an app as their preference for learning to keep track of fluids and medications (streamline communication with other caregivers). The rest of the participants were generally interested in an online digital tool as an accessible platform to obtain knowledge. An overall dislike towards papers or pamphlets was also evident in the interviews. Caregivers also expressed positive past experiences using online digital formats, highlighting that an online infographic tool was a feasible and appropriate educational platform for this specific population of caregivers. One caregiver shared, “I have lots of apps for everything. I think that would be really helpful. Um, I like visual simulation, or even infographics are good” (P3, mother). Another caregiver stated, “For me, probably either an app or a website or video education tool, something like that, yeah” (P9, mother).

Caregivers' descriptions of favorable attributes to enhance the digital delivery of information were also asked in the semi-structured interviews. Specifically, the use of graphic illustrations, understandable or defined terminology, other families’ stories, repetition of information, and quick access to applicable information in the design. For example, one caregiver stated, “… I would like something that is put together online to just do a refresher, especially with maybe signs and symptoms or different things about HF or when something is happening when the heart isn’t so good” (P7, father). Another caregiver favored illustrations as they provided an additional means of helping them understand the complex information. They shared, “And then for me, I’m a digital learner, so I like pictures too” (P11, mother).

Phase 3. Prototype Infographic Development

The initial design of the online infographic prototype involved the creation of an infographic skeleton with a professional graphic design team in July 2023, with refinements being completed in April 2024 (Figure 1-3). The content for the skeleton was knowledge integrated from the previous two phases of treatment guidelines,[2,3] along with Phases 2a/b described above. The first author (CC) led the development of the infographic with ongoing input from the senior scientist (SDS), an experienced researcher who designs educational tools for caregiver audiences. A professional graphic design team was hired to create the prototype's graphic images and layout, which underwent four rounds of detailed revisions before it was scored and piloted with families in a cardiology clinic at the Stollery Children's Hospital in Edmonton, Canada.

Figure 5.1. Sample Introduction Section



Children's Heart Failure: An Infographic for Parents & Caregivers

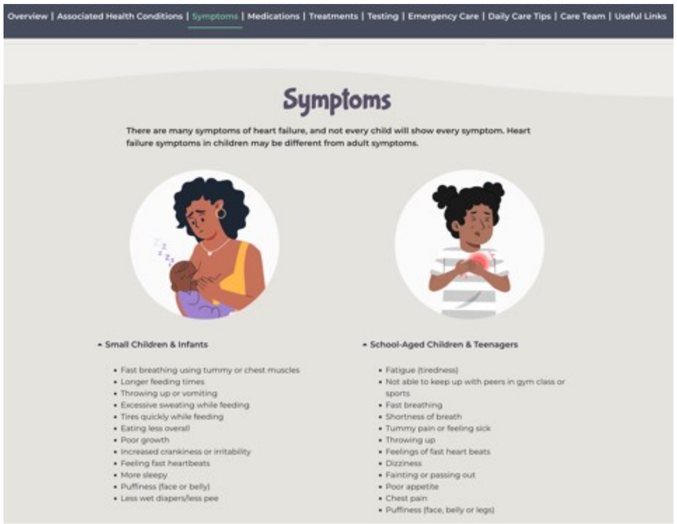
Heart failure in children can happen because of many health conditions.

Caring for a child with heart failure can be a scary and huge learning curve. Good communication with your cardiology team and learning from research-based resources may help you understand your child's care routine.

Listen to Jane, mother of a 10–year–old

"It was challenging, to say the least. But, I just learned to accept what it is and how to get through it. Um, this is probably the most difficult part of my entire life, to be honest"

Figure 5.2. Sample Symptoms Section



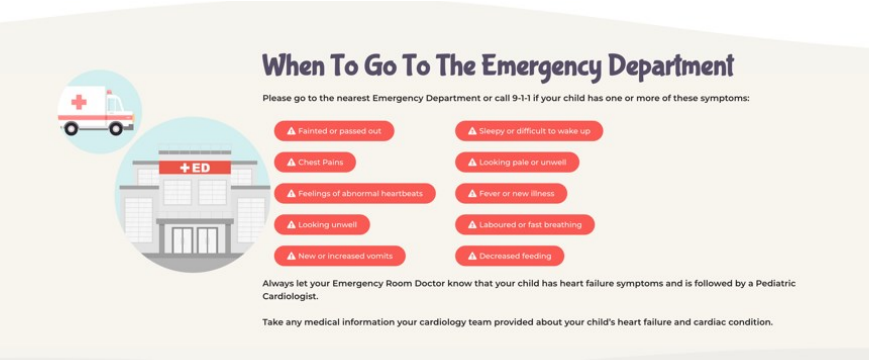
Symptoms

There are many symptoms of heart failure, and not every child will show every symptom. Heart failure symptoms in children may be different from adult symptoms.

- Small Children & Infants
  - Fast breathing using tummy or chest muscles
  - Longer feeding times
  - Throwing up or vomiting
  - Excessive sweating while feeding
  - Tires quickly while feeding
  - Eating less overall
  - Poor growth
  - Increased crankiness or irritability
  - Feeling fast heartbeats
  - More sleepy
  - Puffiness (face or belly)
  - Less wet diapers/less pee

- School-Aged Children & Teenagers
  - Fatigue (tiredness)
  - Not able to keep up with peers in gym class or sports
  - Fast breathing
  - Shortness of breath
  - Tummy pain or feeling sick
  - Throwing up
  - Feelings of fast heart beats
  - Dizziness
  - Fainting or passing out
  - Poor appetite
  - Chest pain
  - Puffiness (face, belly or legs)

Figure 5.3. Sample of When to Go To the Emergency Department Section



When To Go To The Emergency Department

Please go to the nearest Emergency Department or call 9-1-1 if your child has one or more of these symptoms:

- ⚠ Fainted or passed out
- ⚠ Chest Pains
- ⚠ Feelings of abnormal heartbeats
- ⚠ Looking unwell
- ⚠ New or increased vomits
- ⚠ Sleepy or difficult to wake up
- ⚠ Looking pale or unwell
- ⚠ Fever or new illness
- ⚠ Laboured or fast breathing
- ⚠ Decreased feeding

Always let your Emergency Room Doctor know that your child has heart failure symptoms and is followed by a Pediatric Cardiologist.

Take any medical information your cardiology team provided about your child's heart failure and cardiac condition.

Similar to the evaluation of educational tools conducted in the ES (phase 1), CC evaluated the PHF tool before the pilot study began, using the SAM score criteria (Table 1).[15] The SAM score comprises 6 SAM factors with subfactors, totalling 22 items. The score is calculated by scoring each item (superior = 2 pts, adequate = 1 pt, and not adequate = 0 pts) and calculating a percentage from a total score of 44 points.[15] The tool is then rated as superior (70–100%), adequate (40–69%) and not superior (0-39%). The tool scored in the superior range (95.4%) for every item except for the reading level. The Flesh-Kincaid reading level of the tool was graded as a Grade 8 reading level, which was a score of adequate (1 pt). With the four revisions, it was difficult to achieve superiority in this section due to the complex cardiology terminology (e.g., cardiomyopathy, echocardiogram, etc.). To mitigate this issue, audio clips were created with visible phonetic breakdowns of words with multiple syllables. There were no changes to the number of image captions in the tool, as captions were only provided to explain more complex images.

Expert Feedback and Prototype Piloting

Throughout and upon completion of the infographic prototype, it was thoroughly reviewed by two additional substantive experts (JC, KS). The content expert (JC) was a suitable candidate to provide feedback, as evidenced by many years of clinical experience and leadership within North America in children's HF A second allied health professional with experience in pediatric HF and caregivers' education provided feedback on each prototype iteration (KS), and a senior author with extensive experience developed educational knowledge translation tools for children who visit the emergency department (SDS). Minor revisions were made to some content and graphics at this stage. All eligible participants were approached for recruitment. Eligible caregivers of children were assessed in the cardiology clinic for any health condition, ranging from new consults to children who visit the clinic frequently. This provided the opportunity to varied samples with a wide range of feedback for refinements.

The survey format included a demographic survey, a pre-knowledge test with knowledge acquisition questions, and an intervention (infographic tool), followed by usability and post-knowledge test questions. Knowledge acquisition questions were created by the primary author (CC) (Table 2). JC and SDS reviewed the 12 questions (two questions per topic) for clarity and to ensure they captured all topic information provided in the tool (e.g., the number of questions and questions related to each section). The initial draft included five questions. However, the number of questions was increased to 12 to capture questions to assess each section. The research group's standard usability question, developed from 180 surveys, was applied (Table 3).[19] The usability survey included 9 Likert-scale questions related to the usability of the tool developed based on 180 usability surveys.[19] Participants could rate the tool from 1 (strongly disagree) to 5 (strongly agree). One open-ended question at the end of the survey provided an opportunity for any additional feedback.

Other usability surveys were explored (e.g., User Experience Questionnaire and System Usability Scale).[19] However, they were deemed not as applicable for adequately evaluating the usability of a caregiver-targeted PHF tool. Most usability surveys are designed to be applied to test computer software apps, are often adapted for use (affects their validity), have no existing comparator, and involve complex survey terminology or scoring methods.[21,22] Therefore, this supports our decision to use our research team's own previously designed study usability for caregiver audiences.

Analysis

Data were analyzed using SPSS (Version 29; IBM Corporation).[24] Descriptive statistics (e.g., frequencies), variability (e.g., standard deviation), and statistical inferences were completed. An a priori sample size calculation was completed using G*Power 4 software[25] based on a power of 90%, medium effect size of 0.5 and a significance level of 0.05 (2-tailed), resulting in a sample size calculation of 47.

Results

Piloting took place in the Cardiology Clinic using two password-protected iPads, with a sample of 5 caregivers (approximately 10% of the estimated sample).[20,23] No changes were made to the survey sequence, questions, or format, as no caregiver's feedback seeking clarity on any of these items was obtained.

Survey data were collected from Jan 22 – February 8, 2024, using the Canadian web-based electronic platform SimpleSurvey. SimpleSurvey is a secure platform (e.g., firewall technology) and adheres to Canadian privacy laws.[24] The data collected were also completely anonymized, only collecting their email for research incentive purposes. All incomplete survey data was discarded.

To assess for normality with a small sample size (<50 scores) and alpha of 0.05, a Shapiro-Wilks calculation indicated a non-normal distribution of our sample data (P=.002);[27] therefore, the Wilcoxon signed-rank test was used to compare pre-and post-intervention scores.[27] We compared overall pre-intervention and post-intervention scores for each topic to assess for knowledge change after participants were exposed to our infographic. Items were scored either true or false. Response data was transformed into 1 for correct and 0 for incorrect scores. The open-ended text was compiled into a table, and refinements were considered based on the feedback.

Web-based Infographic (Intervention)

Collaborating with a creative design expert, we developed an educational web-based infographic constructed on a previous qualitative synthesis and 11 caregivers qualitative interviews about caring for a child with chronic pediatric HF (both currently under review for publication).[16] The decision for an online infographic was made as caregivers mentioned they preferred an educational tool online as they found tangible products (e.g., pamphlets) cumbersome, inconvenient to have on them when needed, and overwhelming to sort through.[16] While no applications (apps) are targeted at educating caregivers about children's heart failure,[9] the design decision of an online website was made due to the complexity, time and costs involved in app design. The tool was developed over six months (May – November 2023). The infographic aims to educate caregivers with evidence-based information used by healthcare professionals but in a more understandable format that can be repeatedly accessed. The infographic includes key topic headings, labelled overview, associated health conditions, symptoms, medications, treatments, testing, emergency care, care team, and useful links. At the end of the infographic, a summary of daily care tips for caregivers integrates information from the previous section, summarizing previously included information (repetition) and explicitly stating care tips (behaviour change), highlighted in our qualitative interviews. We simplified the language in the infographic to be congruent with a Grade 8-10 Flesch-Kincaid reading level. Words with more than three or more syllables were assigned professionally recorded phonetic pronunciations to mitigate including complex medical terminology that increased reading level. Cartoon characters were of a diverse, inclusive population. Given the chronic and complex nature of pediatric HF and the large amount of information provided in the infographic, it was anticipated the caregivers would take approximately 30 minutes to read and review the infographic on average. Data excerpts from families that participated in the qualitative interviews were also included in the infographic with text and professionally recorded voiceovers from other caregivers, embedding the lived experiences of other caregivers in a similar situation and relatable feel.

A total of 63 surveys were started, but only 47 (75%) were complete and included for analysis. Any survey with missing data was excluded surveys from the analysis. Table 4 provides the demographic characteristics of the study participants.

Usability Evaluation Results

As the usability survey used was not validated, a Cronbach α coefficient was calculated to assess its psychometric quality.[23] The r Cronbach coefficient calculation was reported within a 'good' parameter (α=.87), indicating high-scale reliability and valid internal consistency of the employed usability survey. In addition, this survey has been adequately utilized in other child health conditions without any modifications.[28]

Using a 5-point Likert scale, mean scores ranged from 4.45 (SD 0.72) to 4.77 (SD 0.43) (Figure 4). Open-ended feedback on the tool's content and design was also very positive

(Multimedia Appendix 1). Only one caregiver disagreed that it would help with their decision-making. Participants' open-text comments indicated that the tool was “very useful,” “engaging and informative,” “looks great,” and “clear graphics and content, which can be easily understood by most people.” Areas for infographic refinement included bolder topic headings, interactive videos, and more explicit labelling of complex heart images.

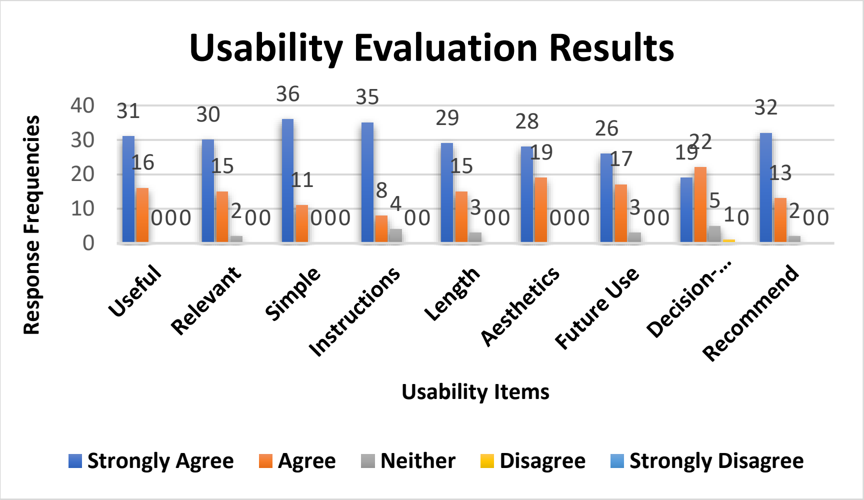


Figure 5.4. Usability Evaluation Results

Knowledge Acquisition Testing

Overall, the average correct mean pre-intervention score was 9 (73%), and the correct post-intervention mean score was 10 (83.0%), signifying a positive increase in caregivers' overall knowledge after viewing the tool (Table 5). Wilcoxon signed-rank testing indicated a statistically significant finding in pre-post-intervention scores (z -3.50, *P*<.001). Individually, statistically significant knowledge scores before and after viewing the infographic were in the areas of medication information (z=-1.51, *P*=.02), testing (z=-2.84, *P*=.02), activity considerations (z=-2.84, *P*=.02) and emergency care (z=-2.00, *P*=.05). No significant increases in knowledge scores that were not found to be statistically significant were observed in several topics (e.g., 1, 2, 3, 4, 5, and 11). Topic 7, related to sodium intake, was the only topic that showed a nonsignificant decrease in participants' knowledge, highlighting another area for tool refinement (e.g., wording revisions). Participants surveyed all scored perfect (12/12) on topic 12 about informing emergency physicians that the child has HF before and after the intervention.

Discussion

This study describes creating, evaluating, and refining an educational tool with caregivers of children with pediatric HF through patient engagement, usability evaluation and knowledge testing after tool exposure. The findings of this study are caregivers scored the tool positively, indicating that they agreed or strongly agreed with each usability item. Including the component of usability testing ensures that tools are usable for health consumers.[19,29] Based on open-text usability suggestions, tool refinements included modifying headers to be more noticeable and adding links to videos about congenital heart disease and cardiomyopathy images. The section outlining recommendations for a regular salt diet was made more explicit based on knowledge scores.

Caregivers' education in pediatric HF is critically important, as delays in symptom recognition can result in delayed delivery of medically complex care, affecting outcomes. With the advancement in treatments, children with chronic HF are surviving and being discharged from the hospital. The onus has now shifted onto caregivers to provide medical care in the home environment. Caregivers must quickly become proficient in symptom recognition, treatment, medication administration, fluid targets and dietary considerations,[2,3] often this is evaluated by clinical teams as a criterion for being discharged home. Ideally, these requirements should be met to promote a safe discharge; caregivers have no medical background, making acquiring this knowledge stressful and overwhelming. Previous studies have outlined that caregivers must learn about and apply HF information, which requires time and repetition.[16] Hence, there is a need for accessible and relevant information that is tailored to their information needs and experiences and refined with caregivers' input.[13]

Digital KT tool development is best developed with input from the target population and based on medical guidelines, which was the aim of this study. Our study supported the notion that qualitative interviews can be used in the pediatric cardiology population to design education tools. Another recent pediatric heart transplant population study employed qualitative interviews to inform the style and content of an educational graphic highlighting discrepancies between health information priorities between teenagers, healthcare providers, and caregivers.[30] Our tool was solely based on research guidelines, expert opinion, and qualitative interviews with caregivers. While not every aspect of information could be included in our KT tool, it gives caregivers the most information they need to learn at their own pace and convenience in an appealing and motivating format. This digital aspect also provides a technologically advanced platform to update the tool when required (e.g., new medical guidelines or medical therapy). This format is also accessible to families with mobile devices, compared to paper copies that need to be physically present.

Limitations

Research on caregiver knowledge needs is limited in this clinical population, so the developed knowledge questions used in this study needed to be validated. Steps were taken to ensure appropriate knowledge design and piloting.[20,31] Before constructing the knowledge questions, the primary researcher thoroughly searched for previously constructed and validated knowledge questions that applied to the tool; however, given the specific nature and lack of research evidence, no appropriate previous knowledge test questions were available. The primary research developed questions based on the tool content (i.e., content validity) and the design recommendations published in the literature (e.g., assesses the minimum amount of data, questions based on previous qualitative studies, verified by substantive (JC) and methodology experts (SDS), appropriate, articulate wording).[31] The questions were also test-piloted with 10% of the estimated sample to assess for data and ask caregivers for feedback regarding question clarity.[32]

Our study relied on self-reported data, which can introduce bias[33]. Furthermore, since the primary researcher was a care provider, there is always a concern that participants would not want to rate our tool negatively. First, self-reported bias was likely minimal in our study as the topics were not sensitive compared to other research topics (e.g., domestic violence, drug use, or diets), and the cohort surveyed was motivated to provide honest feedback to assist in refinements targeting other future caregivers in this difficult situation. Our consent form also included a section where this research would not impact their clinical care. To help mitigate self-report bias, survey data was collected anonymously online using SimpleSurvey, which was also explained to the participants during the consent phase. Feedback was highly encouraged at recruitment as a means of helping future families.

Knowledge testing occurred immediately after reviewing a large amount of complex information. A statistically significant change was reported, highlighting that the tool positively influenced knowledge. Future research considerations could test the same set of caregivers after a longer time of using the tool to see if there is a change in knowledge after a longer time period. Caregivers are undoubtedly our partners in care, with more children with HF requiring care in community settings.

Conclusions

This method of knowledge translation tool development increased caregivers' knowledge about their child’s HF, which signifies an effective way to produce educational materials for caregivers of children with chronic HF. Our results demonstrate that caregivers positively rated a web-based infographic about children’s HF created using a combination of patient engagement, research evidence, and clinician expertise. While employing patient-engaged methods to develop educational tools is time-consuming, our study provides further evidence to support that these tools can positively impact caregiver knowledge and outcomes.

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Conflict of Interest

None

Table 5.1. Suitability of Assessment Materials Score

SAM Factor	Score	Comments
3. Content		
(a) Purpose is evident.	2	
(b) Content about behaviors.	2	
(c) Scope is limited.	2	
(d) Summary or review included.	2	
4. Literacy Demand		
(a) Reading Grade Level	1	*Flesh-Kincaid Reading Score: Grade 8
(b) Writing style, active voice	2	
(c) Vocabulary uses common words	2	
(d) Context is given first	2	
(e) Learning aids via "road signs," subtitles, and captions	2	
5. Graphics		
(a) Cover graphic shows purpose	2	
(b) Type of graphics	2	
(c) Relevance of illustrations	2	
(d) Lists and tables explained		
(e) Captions for graphics	1	*Captions only used with complex graphics
6. Layout and Typography		
(a) Layout factors	2	
(b) Typography	2	
(c) Subheads ("chunking") used	2	
7. Learning Stimulation, Motivation		
(a) Interaction Used	2	
(b) Behaviors are modeled and specific	2	
(c) Motivation, self-efficacy	2	
8. Cultural Appropriateness		
(a) Match in logic, language, and experience (LLE)	2	
(b) Cultural Images and examples	2	
Score: 22 (of possible 44 pts) (95%, superior score)		

Table 5.2. Pre-Post Knowledge Acquisition Questions (N=12)

Topic #1: Physiology & Definition

1. Heart defects can cause symptoms of heart failure.[T]
2. Heart failure symptoms are a result of enough blood being pumped out to the body with each heartbeat.[F]

Topic #2: Symptoms

3. Poor growth is a sign of heart failure in an infant.[T]
4. Heart failure symptoms in children are the same as in adults.[F]

Topic #3: Medications

5. Lasix helps keep the extra fluid stored in a child's tissues.[F]
6. A beta-blocker medication slows down the heart rate.[T]

Topic #4: Treatments

7. A high salt diet helps decrease symptoms of heart failure.[F]
8. All children with heart failure should try to stay active.[T]

Topic #5: Testing

9. An exercise stress test uses sound waves to look at the heart squeeze.[F]
10. An electrocardiogram measures the squeeze power of a child's heart.[F]

Topic #6: Emergency Care

11. If your child has chest pain, they should visit the Emergency Department.[T]
12. It is important for the Emergency Department Doctor to know your child has heart failure.[T]

Correct Answer: [T]True, [F]False

Table 5.3. Usability Evaluation Items (N=12)

1. Is it useful. (5-point Likert Scale)
2. It provides information that is relevant to me as a parent. (5-point Likert Scale)
3. It is simple to use. (5-point Likert Scale)
4. I can use it without written instruction or additional help. (5-point Likert Scale)
5. Its length is appropriate. (5-point Likert Scale)
6. It is aesthetically pleasing (i.e., images, colors, etc.). (5-point Likert Scale)
7. It helps me to make decisions about my child's health. (5-point Likert Scale)
8. I would use it in the future. (5-point Likert Scale)
9. I would recommend it to a friend. (5-point Likert Scale)
10. List the most negative aspects. (open text)
11. List the most positive aspects. (open text)
12. Any additional comments or feedback. (open text)

5-point Likert Scale: Strongly Agree, Agree, Neither Agree Nor Disagree, Disagree, Strongly Disagree

Table 5.4. Demographic Characteristics (N=47)

Variable	N (%)
Gender	
Woman	33 (70.2%)
Man	14 (29.8%)
Transgender	
No	45 (95.7%)
Yes	1 (2.1%)
Missing/Not Specified	1 (2.1%)
Race & Ethnicity	
White	38 (80.9%)
South Asian	3 (6.4%)
Latino	4 (8.5%)
Southeast Asian	1 (2.1%)
Missing/Not Specified	1 (2.1%)
Age	
51 years+	1 (2.1%)
41-50 years	21 (44.7%)
31-40 years	19 (40.4%)
20-30 years	6 (12.8%)
Second Supportive Adult in the Home	
Yes	42 (89.3%)
No	5 (10.6%)
Annual Household Income (CA	
$150K+	13 (27.7%)
$100K - 149K	14 (29.8%)
$75K - $99,999K	8 (17.0%)
$50k - $74,999K	3 (6.4%)
$25K - $49,999K	6 (12.8%)
<$25K	1 (2.1%)
Prefer Not to Say	2 (4.2%)
Highest Level of Education	
Some Highschool	3 (6.4%)
High school diploma	8 (17.0%)
Some post-secondary	5 (10.6%)

Post-secondary certificate/diploma	13 (27.7%)
Post-secondary degree	13 (27.7%)
Graduate degree	5 (10.6%)
Household Location	
City	9 (19.1%)
Town	10 (21.3%)
Suburb	18 (38.3%)
Farm/Rural	9 (19.1%)
Missing/Not Specified	1 (2.1%)
Total No. of Children in the Home	
1	5 (10.6%)
2	18 (38.3%)
3	17 (36.2%)
4 or more	7 (14.9%)
Affected Child Cardiac Lesion	
VSD/ASD/PFO	9 (19.1%)
Screening, heart murmur	5 (10.6%)
Cardiomyopathy/Myocarditis	5 (10.6%)
Hypoplastic Ventricle	3 (6.4%)
Pulmonary Stenosis/Atresia	4 (8.5%)
Pericarditis	1 (2.1%)
Arrhythmia	1 (2.1%)
Tetralogy of Fallot	2 (4.2%0
Transposition of the Great Arteries	1 (2.1%)
AVSD/Valve Lesion	9 (19.1%)
Complex cardiac (>3 abnormalities)	1 (2.1%)
Missing/Not Specified	5 (10.6%)
Primary Language	
English	42 (89.4%)
Spanish	2 (4.2%)
Malayalam	1 (2.1%)
Thai	1 (2.1%)
Gujarati	1 (2.1%)
Age of Child with Cardiac Condition	
Infant (0-12 months)	4 (8.5%)
Toddler (1-4 years)	9 (19.1%)

School Aged Child (4-12 years)	16 (34.0%)
Teenager (13-18 years)	17 (36.2%)
Missing/Not Specified	1 (2.1%)
Listed for Heart Transplant	
Yes	1 (2.1%)
No	46 (97.9%)

Table 5.5. Pre-Post Intervention Topic Scores

Topic	Correct Pre-Intervention Responses N (%)	Correct Post-Intervention Responses N (%)	p value (Z)
1. Heart defects can cause symptoms of heart failure.^{T}	43 (91.5%)	46 (97.9%)	0.18 (-1.34)
2. Heart failure symptoms are a result of enough blood being pumped out to the body with each heartbeat.^{F}	33 (70.2%)	34 (72.3%)	0.71 (-0.38)
3. Poor growth is a sign of heart failure in an infant.^{T}	41 (87.2%)	45 (95.7%)	0.10 (-0.63)
4. Heart failure symptoms in children are the same as in adults.^{F}	39 (83.0%)	43 (91.5%)	0.10 (-1.63)
5. Lasix helps to keep extra fluid stored in a child's tissues.^{F}	29 (61.7%)	31 (66.0%)	0.59 (-0.54)
6. A beta-blocker medication slows down the heart rate.^{T}	36 (76.6%)	42 (89.4%)	**0.03 (-2.12)**
9. A high salt diet helps decrease symptoms of heart failure.^{F}	40 (85.1%)	35 (74.5%)	0.13 (1.51)
10. All children with heart failure should try to stay active.^{T}	29 (61.7%)	36 (76.6%)	**0.02 (-2.84)**
11. An exercise stress test uses sound waves to look at the heart squeeze.^{F}	18 (38.3%)	29 (61.7%)	**0.01 (-2.84)**
12. An electrocardiogram measures the squeeze power of a child's heart.^{F}	19 (40.4%)	24 (51.0%)	0.13 (-1.51)
13. If your child has chest pain, they should visit the Emergency Department.^{T}	41 (87.2%)	45 (95.7%)	**0.05 (-2.00)**
14. It is important for the Emergency Department Doctor to know your child has heart failure.^{T}	47 (100.0%)	47 (100.0%)	1.00 (0.000)

Correct Answers: ^{T}True, ^{F}False; Statistical significance p=<0.05

Table 5.6. Open-ended Caregiver Feedback Responses

Positive Comments (N=8)	Constructive Feedback (N=6)
• Very useful • Engaging and informative • The colors are very inviting. • I really like how it's more in bullet form than just a long write up. • It's very engaging by having to click to get more information and it's not long and drawn out and boring. • Clear graphics and contents, which can be easily understood by most people. • Very user friendly. Images and extra links kept it interesting.	• Though animated characters are well done, actual pictures have merit and can help clarify things. • Moving from one 'topic' to another so frequently can be a bit confusing. Adding more headers to each topic may help. The cardiomyopathy section is a bit confusing; how can it be both thick and thin? More audio of personal accounts may be nice/reassuring. • Contains info I already know or that can be easily captured or inferred via online tools. • I would have interactive videos. • A lot of information, while helpful, can be overwhelming the first time the resource is used. • Shapes in the reasons to go to emergency reacted to click (changed state) without any pop up or new information.

Additional Comments (N=4)

- Possibly a search tab for key letters to bring direct to a question or even a "frequently asked questions" section.
- Looks great!
- I think it is very useful, it's almost like the AHS heal website but for cardiac parents. It's nice that if a family member needed information, it's very well laid out for anyone to read.
- Graphics on various heart conditions could be better labeled, or videos to better demonstrate the features of concern.

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CHAPTER 6. Conclusions: Final Thoughts and Scientific Contributions

Overview of Findings

My research situates PHF as a complex, burdensome condition that some families encounter throughout their lifetime, causing stress and uncertainty while also being difficult to learn. Guided by the KTA Framework, this work sought to 1) understand knowledge gaps in caregiver learning tools and 2) create and tailor an evidence-based educational tool for caregivers about their child's heart failure. The purpose is to create positive behaviour change, reduce stress levels, enhance communication with healthcare providers, and improve their decision-making with daily care tasks and adherence. This dissertation was guided by the KTA framework, mainly guided by the three steps of knowledge creation (e.g., knowledge inquiry, knowledge synthesis, and product/tool development) and three iterative steps in the action cycle (e.g., identify a problem, adapt knowledge to the local context, and select, tailor, and implement interventions). This work combined the caregiver voice, substantive expert opinion and knowledge from clinical practice guidelines to produce a relevant, informative and empowering educational infographic. The overarching purpose of this dissertation was to address the clinical question that I had when I embarked on my PhD work about how to understand factors relating to caregivers' information needs and experiences caring for a child with chronic heart failure. During the dissertation, I used integrated KT strategies (e.g., conference presentations, posters, and educational sessions with frontline nursing and medical staff) to disseminate new knowledge created through this research. The post-dissertation additional diffusion and dissemination strategies will incorporate posting the education tool broadly on the web (www.trekk.ca, www.echokt.ca), presenting at relevant conferences, embedding the KT tool in pediatric cardiology clinical practice (Stollery Children's Hospital), networking in North American groups who have an interest in PHF (e.g., ACTION) and evaluating the impact the KT tool has on patient care.

Three main phases were designed and conducted based on the KTA Framework (Figure 1.1),[1] depicting knowledge creation in chronic PHF. The knowledge creation funnel was designed to create an educational tool based on research and patient engagement (Figure 1.2), outlining a 3-phased approach to tool development. The first phase employed the ES approach to uncover publicly available North American caregiver-targeted educational resources on the web that were sources of information for caregivers of a child diagnosed with heart failure.[2] The 17 identified educational resources were evaluated using a validated tool that effectively and systemically assesses the suitability of health information materials for a particular audience (i.e., caregivers) (Chapter 2). This ES contributed to providing a comprehensive list of 17 heart failure educational tools posted on the internet (N=17) and in application stores (N=0) that targeted caregiver audiences.[3] The ES evaluation using the SAM evaluation highlights gaps in design and content that guided the semi-structured interview guide in the subsequent qualitative interviews (Phase 2b) and tool strategies for tool design (Phase 3).[4,5] The qualitative interview portion of the study also shed light on key design elements, both barriers and facilitators, that were also considered in the tool design phase (i.e., language, graphics, layout).[5]

Phase 2a employed a qualitative synthesis guided by the Handbook for QES, written by Sandelowski and Barroso.[6] The original search was run in August of 2023. The search was guided by two different librarians (KS and TP), and screening was completed by two independent reviewers with clinical experience in PHF nursing (CC and KS), supervised by my primary supervisor and senior scientist (SDS). The search resulted in an empty review with no included studies. Empty reviews are a rare finding in research.[7-9] While highlighting a significant knowledge gap, this posed difficulties in publishing this work as no journals would publish an initial 'empty' review (i.e., no studies were included).[7-9,] The search was re-run for currency in November of 2023, resulting in one new included study.[10] Data extraction and critical appraisal were undertaken;[6,11] however, no synthesis could be completed with a single study. Given its increased recognition and burden on the healthcare system and caregivers, this highlights the crucial need for more research on caregiver experience in PHF.

Phase 2b employed a qualitative descriptive approach to examine caregivers' learning needs and experience caring for a child with heart failure.[12,13] This study resulted in a published paper.[14] The detailed descriptions from the 11 participant semi-structured interviews provided reached data redundancy, uncovering two major categories: 1) The traumatic diagnosis of heart failure impacts learning and 2) A new life reality after diagnosis. Each category had codes grouped into sub-categories by two independent reviews (CC, ZZ) that shaped each category's meaning. Codebook definitions and groupings were overseen by a senior researcher (SDS). Credibility, transferability, and dependability were steps to enhance trustworthiness in this qualitative study.[15] Researcher triangulation (e.g., review of transcriptions, verifying code book definitions and shaping of categories), interview transcription that reflected resulted in thick, rich descriptions of participant lived experience. Caregivers were also motivated to openly and honestly share their knowledge to help future families in this challenging situation. The research consent was also reviewed with participants, stressing that it would not affect the care their child received. Also, to ensure dependability, the transcripts were transcribed verbatim by a human transcriptionist, leaving all nonverbal communication data.

Phase 3 employed developing and refining a KT tool about PHF targeted at caregivers, integrating all the results from the subsequent phases. (Chapter 5). The qualitative interviews decided that a digital educational tool would be the best platform for translating research evidence to caregivers. While no applications were identified in our ES,[4] producing an app as part of a dissertation was not feasible for a doctoral dissertation due to limitations in design expertise, time and financial commitments. Instead, this study outlined how research, patient engagement, and expert opinion were married to co-create a tool for a complex health condition to support caregiver educational needs through an interactive web-based tool favoured by caregivers. Included in this study was how caregivers evaluated the usability and demonstrated a change in knowledge after viewing the tool before dissemination on the internet. The significance of these findings is that even after a short period of time and limited repetition of information, this tool successfully changed their knowledge in many areas about childhood heart failure. Some minor refinements were also made to the tool before it was posted before widespread dissemination.

This body of work was guided by applying the KTA Framework,[1] which was demonstrated in a multi-phase, multi-method study that employed caregiver-targeted knowledge translational strategies to generate knowledge. Given the scarcity of literature on this topic, the methods undertaken in this dissertation were coherent with the knowledge creation funnel and the first box in the action cycle (e.g., identified, reviewed and selected knowledge in the action cycle). Iteratively, some parts of the action cycle were also considered (e.g., adapt knowledge to local context; and select, tailor, and implement interventions). Further work could be to evaluate this tool's outcomes within the healthcare setting, completing the rest of the action cycle. This work contributes to nursing and KT science within the PHF context, using a modest approach to patient engagement. Each phase had unique and significant contributions that were integrated into the tool design:

Phase 1: ES. The need for a more relevant and understandable tool with improved graphics was highlighted in this study, as it is known that caregivers search the internet for information. Seventeen tools were identified. During the evaluation stage of this study, no tools scored within the superior range (70-100%), with needed improvements to reading level and graphics, that I applied to my tool design. The need for tools was also highlighted, given that no tools relevant to PHF caregivers were identified. Themes recognized in key stakeholder interviews highlighted areas for improvement in search engine optimization, tools being available in other languages, time for refinements/updates, and how to include credible references.

Phase 2a: QES. A significant knowledge gap exists in PHF about caregiver information needs and experiences. Designed using PICOS for his comprehensive approach,[16] the initial search (August 2021) resulted in an empty review. The study was re-run (November 2023) to keep the search current and re-examine the state of the literature, with only one included study. This search again highlighted the knowledge gap and the need to understand caregivers' perceptions in this context through scientific research. Despite non-significant findings that could not be published in the journals chosen for submission, this still suggests a significant knowledge gap and that tools are primarily being developed based on other avenues other than research knowledge.

Phase 2b: QD. Two categories were uncovered from interviews with 11 caregivers who cared for a child with heart failure. Due to the COVID-19 pandemic, holding virtual interviews was a cost-effective and convenient way to ensure interviews met strict social distancing guidelines while continuing to be productive during the dissertation.[17] The first category describes challenges faced by caregivers when learning new, complex information about PHF.

This category was shaped by three subcategories (new diverse ways of learning, stress steepens the learning curve and learning heart failure takes time). The educational platform parents mentioned in interviews was they wanted to see this complex knowledge placed on a digital platform, as it was more convenient to access with the bonus of providing privacy and repetition when trying to uptake knowledge. The second category relates to how caregivers' life profoundly changes after their child is diagnosed with heart failure. This category was shaped into two sub-categories (the emotional rollercoaster and always on the clock: caring for a child with heart failure).

Interestingly, caregivers need time to learn and master the care routines when under tremendous stress. It was also identified that caregivers prefer online digital tools. Digital platforms are convenient, provide repetition for caregiver learners, and can be a quick reference to specific chunks of information. Caregivers wanted friendly digital graphics, more understandable cardiology terminology, and family stories with lived experience highlighted. Hearing stories of others who have experienced this journey provided hope and relatable element (Cunningham, 2024).

It was decided to develop a website to translate the knowledge found in clinical practice guidelines.[18,19] Caregivers in the interviews voiced preferences for a digital educational tool in the first category (sub-category one termed new diverse ways of learning).[14] They found tangible material (e.g., paper-based educational material) too cumbersome and overwhelming to look through and preferred the convenience of accessing an online digital tool. One parent mentioned the need for an app, which was also supported by findings in paper one; however, this option required significant financial support and programming expertise that were unavailable during this dissertation. These elements would have dramatically lengthened this dissertation process.

Furthermore, an app requires frequent updates that an expert programmer needs to design and push out to end-users. End-users need to acknowledge and update their app, whereas website updates are immediately available. An app design is a future research consideration when more time and finances are available to support such a project adequately.

Phase 3: KT Tool Co-development and Refinement. Integrating all the knowledge generated from the first three caregiver-engaged phases, along with the most recent research-based guidelines, expert input and a professional graphic design team, resulted in the KT tool. Within the tool, there is an interactive feature that embeds further information (e.g., What is heart failure?) if caregivers choose to access more in-depth information, provides quotes from caregivers in the qualitative interviews (e.g., relatable and human aspect to the tool), a daily care section that provides repetition of information, and is specific to caregiver daily care tasks (e.g., caregiver behaviour change) and also provides links to other evidence.

Relevance to Nursing Science

Nursing science is rooted in and continues to evolve from theoretical and practical knowledge.[20] Through nursing inquiry, improved principles and laws that govern life processes and the well-being of individuals and families during illness and health while also seeking to understand patterns of human behaviour within the health context and environment.[21] The overarching goal of nursing science is to improve and positively impact an individual's health trajectory.[21] This dissertation met those objectives for caregivers of children who are diagnosed with heart failure, as the overarching goal was to fill a knowledge gap that would improve caregiver decision-making, reduce stress and improve outcomes for children with this diagnosis.

Within pediatric cardiology, similar work completed in a different population (e.g., single ventricles) aligned with what was found in my work. Rempel et al. (2012) report that parents who have children with congenital heart disease that can be life-threatening are parenting under pressure that emerges in her work with four themes (e.g., realizing and adjusting to the inconceivable, growing increasingly attached, watching for and accommodating the unexpected, and encountering new challenges).[22] A second paper on the population suggests that living in these circumstances leads to parent hypervigilance.[23] While not the same population of children, both populations face a chronic trajectory of uncertainty, which aligns with a nursing scholar's previous work in the single ventricular population. Treatment strategies and health trajectories of both populations are very different approaches, as single ventricle physiology often encompasses numerous surgical interventions in a potentially life-threatening condition. However, children with heart failure are managed with medical therapy until they have advanced refractory symptoms that require mechanical support or cardiac transplantation, if deemed to be suitable candidates. The two categories found in paper three of this dissertation discuss the challenges of learning new complex information and how their life becomes challenging following diagnosis, which aligns with Rempel's previous work in pediatric cardiology.

This work also contributes to pediatric nursing and family-centred care. Pediatric nursing integrates improving the lives of children and families they encounter in healthcare context and emphasizes the family's role in promoting the child's health.[24] The family is the child's source of strength and impacts the child's outcome as they are the primary care provider and proxy decision-maker.[24] Nurses seek to educate families with evidence-based educational materials to improve the outcomes of pediatrics every day. This work draws on all these concepts and delivers an evidence-based educational tool relevant to promoting the child's health through information provision. The resulting tool can be applied in clinical nursing care, enhancing pediatric nursing through a family-centered care approach.

Exploring the lived experiences of children and families with PHF through research methods is congruent with the science of nursing and family-centred care underpinnings. Modelling both the practice and research epitomizes and amalgamates theoretical and clinical nursing care. Including the family in the process of tool development and refinement resulted in a tool that was relevant and applicable to the family's needs, as they are a pillar in the child's care that can drastically affect the outcomes if not educated in a meaningful way. Nurses are in an ideal position to educate caregivers and enhance their educational experiences by applying research methods (i.e., patient engagement and knowledge translation). The digital tool created through this dissertation research will help meet learning needs during their encounter with heart failure. This work is a pragmatic contribution to nursing science that nurses can apply to promote the health of pediatric children with heart failure and their families.

Relevance to Knowledge Translational Science

A straightforward definition of knowledge translation science is the enhanced use of research knowledge, including the design, conduct of studies, and the dissemination and implementation of findings.[25] The Canadian Institutes of Health Research defines it as a dynamic and iterative process that includes synthesizing, disseminating, exchanging, and ethical application of research knowledge to provide a more effective and strengthened healthcare experience.[26] Knowledge translation aims to improve the healthcare experience and reduce adverse events.[27] This body of work advances and embodies the essence of KT science by developing a multi-method tool about PHF that collaborates with caregivers, research knowledge and key stakeholders, upholding the principles of KT science. Traditionally, KT efforts have mainly targeted the healthcare profession,[28,29] but this dissertation work applies a unique focus on bringing research knowledge to healthcare consumers (i.e., caregivers) in the context of PHF.

The environmental scan identified a modest amount of KT tools (n=17), but none were truly co-developed based on research findings, specifically caregiver information needs or experiences, evaluated using research-based tools (e.g., SAM, usability and knowledge acquisition evaluation), making this tool's ability to educate caregivers more robust.

Within the scope of this dissertation, we applied KT science throughout this dissertation research process to create, enhance, and apply research within the context of PHF. The first steps were designed to understand current tools and previously published knowledge to inform the development of our tool using patient-engaged methods, which also incorporated the most current clinical practice guidelines and combined with the knowledge of the caregiver's lived experience. The evaluation reflected that applying this research knowledge produced a tool that caregivers met their needs and could also learn complex knowledge, further contributing to the work in KT that art-based tools effectively meet caregivers' learning needs and styles. This work also integrated KT and was woven throughout as it was shared at several national and international conferences during its undertaking (e.g., Women and Children's Research Institute, PHF Summit).

Relevance to Patient Engagement

Patient engagement is a collaborative approach to incorporating patients and families into the research process.[30,31] The approach seeks to produce research informed by end-users (i.e., patients and their families) to enhance uptake, applicability, and success.[28] Collaboration must occur from the inception of the research idea to the end for it to be informed, meaning there is an interaction between the family and the researcher. Despite this notion, patient-engaged research strategies have continued to lag,[30,31] and no formal evaluation exists to improve the process.[30] Besides a process, patient engagement also seeks to change behaviour.[30]

As outlined in the introduction of this thesis, a purposeful approach to involvement for families was taken as outlined by the IAP2 spectrum[32] due to the demand that heart failure management places on caregivers. The qualitative interviews supported our careful but strategic approach to including caregivers' voices in phases 2b and 3 as caregivers are very overwhelmed with care, especially in the beginning phases due to the several daily tasks. Therefore, strategically choosing this level of patient engagement on the spectrum avoided not overburdening participants while still achieving a caregiver's voice. Furthermore, there is no standardized consensus about the definition of patient engagement. This approach was feasible and acceptable as the literature supports qualitative interviews as a means of patient engagement.[33]

This research embodied a collaborative approach to patient engagement, with elements woven throughout this research.[34] This work is closely connected to these principles, encompassing patient engagement throughout all stages. The phases of 2b and three actively engaged families in qualitative interviews and the evaluation process of tool development. Phases one and 2b sought to understand caregiver experience and understand gaps in knowledge on this subject. This collaborative effort resulted in a tool rated positively by caregivers and demonstrated a change in knowledge, signifying the importance of patient engagement when designing tools for caregiver audiences.

Overall Implications for PHF Nursing Practice

PHF is becoming more prevalent due to increased improved surgical procedures in children with congenital heart disease, recognition, detection and management, imposing a larger burden on more families and the healthcare system. More nurses are encountering and caring for pediatric patients who have this condition. It is the nurse's responsibility to uphold evidence-based practice standards and provide the most recent evidence. The context of PHF is no exception and requires knowledge generation in this niche area, but through this work, it was recognized that there is little evidence to base clinical practice. The tool designed from this work will enhance nursing's ability in clinical practice to improve family education of complex medical information through modern, digitalized means.

Within the research context, this work has uniquely contributed by employing the methodology of the ES to understand what publicly available tools are available, how they are evaluated, and design aspects by key stakeholders for caregivers in this difficult situation, which has not been conducted in this context before this work. Furthermore, this research filled key knowledge gaps with a qualitative knowledge synthesis, uncovered an appropriate multi-media platform preferred by caregivers and evaluated its ability to translate complex information into a caregiver-friendly tool design.

This tool's unique contribution to PHF clinical practice is significant. Given our knowledge testing and usability results, with future implementation, this tool could decrease caregiver stress by empowering them with research-based knowledge uptake to improve decision-making and better adherence to complex management strategies (e.g., fluid targets). The result will be an improvement in the healthcare system burden and improved clinical outcomes. When caregivers are armed with research-based knowledge on this topic, this can help caregivers seek health care professional assessment sooner, potentially avoiding clinical decompensation. Caregivers can easily use this online educational tool since it will be disseminated online in any circumstance (e.g., early after diagnosis or if a refresher is needed).

Strengths and Limitations

The greatest strength of my dissertation is the significant contribution of this multi-method research approach, with each phase informing the next phase of the research. The resultant tool makes a substantial contribution to knowledge translation science, the field of PHF, and patient engagement. As alluded to above, care and outcomes are improved when caregivers have access to research knowledge. An overall understanding of the current tools created and their strengths and limitations, the understanding of the current knowledge gap in PHF and filling this gap with qualitative interviews with caregivers to investigate their lived experiences. This research has produced an online, evidence-based tool that is the only tool currently based on qualitative interviews. This tool can be updated as new guidelines to align with current practices in PHF for caregiver learning. Specifically, below, each phase is discussed with its unique limitations.

Phase 1: ES. This paper's strengths include that it is the first scan within the context of PHF looking to identify tools in this topic.[4] One limitation is that information posted on the Internet changes rapidly and is likely not reproducible. Despite acknowledging this limitation, it provided a starting point for knowing what tools were available and the design aspects and challenges, which provided vital information that informed the design of our KT tool.

Phase 2a: QES. This was the first review paper to understand current qualitative literature on this topic. A qualitative focus was taken as thick descriptions, quotes, and context provide more insight into lived experience and more effectively serve as a foundation to design educational tools rather than survey data better. This study initially resulted in an empty review, and then after updating the search, only one study was included. The resultant review with only one included study posed a challenge as several journals did not want to publish nonsignificant findings (i.e., publication bias). One consideration is reconducting the review using a systematic approach that includes all methodologies, which could result in more findings and mitigate publication bias. Studies applying a quantitative approach were also excluded for another exclusion criteria. Despite this limitation, highlighting this evidence gap was still critical for this dissertation work, justifying that qualitative interviews needed to be completed next and were essential to designing an evidence-based tool.

Phase 2b: QD. This study was also the first North American study examining caregiver lived experience and learning in the context of caring for a child with heart failure. One limitation of this study is that all participants were recruited from a single center. The goal for recruitment in qualitative research is to define and describe in detail the sample so that other healthcare providers and researchers can determine the transferability of this work to their own population of families affected by heart failure (e.g., external validity). Online recruitment was attempted, but no participants reached out to the study team, perhaps due to the sensitive nature of this topic. Despite this limitation, participants were recruited from several Canadian provinces who sought care from a significant tertiary center where recruitment occurred, helping to mitigate this limitation. This was also the only sample available to the research team at a single center.

One limitation of this study could be the social desirability of participants to answer in specific ways, especially as participants were recruited in the center where they received clinical care. In some instances, the participants received care from the primary researcher (doctoral student), which could have impacted their responses to the survey. To mitigate this limitation, the research team did not approach the participants about the study; instead, they were approached following initial contact with non-study clinic healthcare providers and the consent form was reviewed before each recorded interview, highlighting key aspects (e.g., confidentially, voluntary participation, benefits to future families in this context, and to effect on care). In the future, when not part of a dissertation work, it would be ideal to have a research manager conduct the interviews. Having to balance meeting my doctoral training and ethical standards, this was the best approach in conducting qualitative interviews.

Phase 3: Development and Evaluation Using Usability and Knowledge Acquisition Testing. The KT tool was evaluated using the unique usability and knowledge acquisition testing approach. Two surveys were used that were not validated; rather, the surveys were constructed in our research lab. This could affect the internal validity of this study. It was determined that previously validated usability surveys were unsuitable for measuring caregiver perspectives on using an educational tool that communicates complex health information to caregivers. The other tools that were considered were the System Usability Scale and User Experience Questionnaire.[35,36] The System Usability Scale is dated (created in 1986), uses the term system in the questions, which may confuse participants, and employs complex, complicated calculation instructions.[35] The User Experience Questionnaire employs complex language (i.e., perspicuity) that is not within an appropriate reading level for end-user healthcare consumers, is lengthy (i.e., 26 items) and has components that are not applicable (i.e., stimulation).[36] The usability scale used in this work has been successfully used in previous studies, has a significant Cronbach alpha coefficient, and was designed based on a systematic review of 180 usability surveys.[37]

A second limitation of this study was that the post-knowledge acquisition test was conducted shortly after the initial testing and after viewing the tool. Participants could have remembered the 12 test questions while reviewing the tool. To mitigate this, it was kept from the participants that they would complete an identical post-test. We could have considered sending the test questions to the participants, but then the study would have been at risk for attrition, which would have lengthened the study duration and the number of participants needed.

Considerations for Future Research

Future research on this topic should include a more widespread recruitment effort to truly provide a broader view of family experience in this complex context to uncover and bring forth new knowledge to improve and identify more ideas for further research. A more extensive research endeavour within North American jurisdictions (i.e., other Canadian Provinces or the United States) have unique nuances, which may also identify more variations in experience. More widespread recruitment efforts would need to be completed and examined to ensure a more widespread documented lived experience about caregivers' experiences and learning needs.

A second consideration for future research will be re-running the QES when more research is available to provide a significant synthesis of a research repository on caregiver experience. Knowledge syntheses aggregate global evidence about a topic or area to inform KT interventions (e.g., policy, patient decision aids, clinical practice guidelines).[38] The ability to synthesize findings would produce a more concrete foundation on which to base clinical practice and more certainty of the family's experience. Aspects to enhance PHF education and facilitate learning in this complex setting may also be uncovered. The research conducted in this dissertation is the foundation of much more work that can be done to enhance knowledge translation, nursing science, and patient engagement.

Another consideration for future research is examining and developing a rigorous approach to conducting ES methodologies. A systematic review underway by Charlton et al., 2019 could be applied to further Ess approaches when published.[39] The ES is an extremely useful means of providing knowledge of what is available in real-world contexts, informing change and identifying gaps in knowledge.[41] In our study, this method was used to inform what tools or apps were available and how enhancements could be completed to enhance caregiver learning. Without this knowledge, this dissertation would have no evidence base to understand the number, type and quality of tools available to caregivers, which may have resulted in duplicate tool development. Furthermore, this method also provided other ideas for future research (e.g., application development).

Another future KT tool that could be developed and evaluated was an application targeted at caregivers about their child's heart failure, where caregivers could include avenues to communicate about their child's daily health status with the other caregiver(s). For example, the organizer or primary caregiver could check medications given, feeds the child took, vomits, or other care-related activities. This would streamline communication, provide trends or caregivers about the child's care, ease stress and provide a platform for a daily diary of the child's health status. Identified as a gap in the ES (Phase 1) with no apps being identified, and the qualitative interviews (Phase 2b), caregivers talked about how they were always on the clock and how they communicated with the other caregiver who had to spend periods of time away from the child (e.g., work). An application that communicates complex medical information and key information about their child's daily progress (e.g., medications given, feed volumes taken) would help make this process more efficient and relieve stress in caregivers. This will be considered the next step in KT strategies for caregivers when more funding and resources can be secured.

The last area for future research relates to validating the usability tool used in our study. It was developed by the PI (Dr. Shannon Scott) to address the need to assess the usability of caregiver-targeted educational tools within a healthcare context. It has been applied in other contexts in our research laboratory before this dissertation.[41] The survey was also used to the third phase of this dissertation work. There was no feedback about the questions during piloting, and the Cronbach alpha coefficient was reassuring. Future research validating this survey tool would provide another means of measuring caregiver perceptions about usability. The other options for measuring usability are the System Usability Scale[37] and User Experience,[36] which are validated but are grounded in measuring the useability of computer systems or websites within the Information Technology context and not educational health care contexts. This rationale justified using other developed scales in the context of caregiver learning needs. Generally, these surveys need to be adapted specifically for caregiver education in healthcare, which inhibits their validity if adaption is needed.

Conclusion

Through a three-phased progressive approach, this dissertation has documented a foundational understanding of caregivers' information needs and experiences when caring for a child with heart failure. Despite advancements in clinical care and knowledge, KT strategies for caregivers have lagged, posing an issue for advancing outcomes in this vulnerable population. This knowledge generation has resulted in developing patient-engaged methods to co-create and refine an educational tool on this topic targeted at caregiver audiences, underpinned by a theoretical framework. The research approaches were ES, QES, QD, usability and knowledge acquisition testing. This knowledge and tangible output make a substantial contribution to the field of PHF, the discipline of nursing, KT science and patient engagement. Furthermore, it identifies future research opportunities that can continue to enhance the knowledge of caregivers' needs in this area as healthcare is now shifting to require advanced knowledge for caregivers of children diagnosed with heart failure. Finally, this dissertation has positively influenced my nursing practice and worldview as I examined how families impacted by such an uncertain and chronic disease state must cope and live their lives.

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