



Original Article

Exploring Caregiver Learning and Experiences Caring for a Child With Heart Failure: A Qualitative Study

Chentel Cunningham, MN, NP, PhD Candidate,^{a,b} Jennifer Conway, MD, MSc,^{b,c}
Ziad Zahoui, BScN Student,^a Mark Haykowsky, PhD,^a and Shannon D. Scott, PhD, RN^a

^a Faculty of Nursing, University of Alberta, Edmonton, Alberta, Canada

^b Division of Pediatric Cardiology, Stollery Children's Hospital, Edmonton, Alberta, Canada

^c Faculty of Medicine and Dentistry, University of Alberta, Edmonton, Alberta, Canada

ABSTRACT

Background: Paediatric heart failure poses life-long, burdensome symptoms for the health care 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: Qualitative description 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 2 main categories. One relates to how traumatic life experiences impact learning (eg, new diverse ways of learning, stress steepens the learning curve, and learning heart

RÉSUMÉ

Contexte : L'insuffisance cardiaque pédiatrique entraîne des symptômes qui durent tout au long de la vie et qui pèsent lourd sur le système de santé et les familles. Le diagnostic et le congé de l'hôpital causent tous deux un stress et de l'anxiété pour les proches aidants, qui doivent composer avec l'incertitude liée à la santé de leur enfant et prodiguer des soins complexes à la maison. Notre étude visait à faire la lumière sur cette question en explorant le processus d'apprentissage et les expériences vécues par les proches aidants d'enfants atteints d'insuffisance cardiaque afin de proposer un outil sur l'application des connaissances.

Méthodologie : Nous avons basé notre étude sur une description qualitative. Les participants ont été recrutés dans un centre de soins cardiaques tertiaires d'Edmonton, en Alberta (Canada). La collecte et l'analyse des données ont été réalisées au même moment, jusqu'à la redondance des données. Une analyse thématique inductive classique a permis d'en extraire des catégories.

Paediatric heart failure (PHF) is a burdensome condition for the health care system and families. It 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 cardiomyopathy, neuromuscular, metabolic, genetic, and oncologic conditions, among other chronic etiologies.³ A subset of children with heart muscle disease 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 2 decades, PHF has gained more attention from clinicians, and as a result, treatment recommendations have evolved from collaboration and knowledge-sharing.^{3–6} 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.^{5,6} 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 paediatric 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

Received for publication March 3, 2024. Accepted May 23, 2024.

Corresponding author: Dr Shannon D. Scott, Faculty of Nursing, University of Alberta, 5-187 Edmonton Clinic Health Academy, 11405 87 Ave NW, Edmonton, Alberta T6G 1C9, Canada. Tel.: +1-780-492-1037.

E-mail: shannon.scott@ualberta.ca

<https://doi.org/10.1016/j.cjpc.2024.05.003>

2772-8129/© 2024 The Authors. Published by Elsevier Inc. on behalf of the Canadian Cardiovascular Society. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

failure takes time). The other relates to families' new life reality after diagnosis (eg, 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 impacts their learning capabilities and way of life going forward. Caregiver learning experiences and preferences for digital platforms is also highlighted. This knowledge will inform the design of an online educational tool about pediatric heart failure for caregiver audiences. This tool will empower and improve caregiver decision-making related to their child's daily heart failure management, with the goal to positively impact clinical outcomes, lessen stress and anxiety.

Implementing effective knowledge translation (KT) 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 health care 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 health care providers in better supporting them in their difficult role as care managers.⁸

It is known that a limited number of educational tools are available for parents who have a child affected by heart failure.¹¹ Understanding caregivers' information needs and experiences through qualitative exploration has been beneficial in other chronic paediatric conditions.^{12,13} However, this knowledge has been scarce in the context of children's chronic 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 (KTA) framework outlines this notion, starting with tailored knowledge creation using 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.

Résultats : Deux grandes catégories se sont dégagées des onze entretiens réalisés : 1) les répercussions des expériences de vie traumatisantes sur l'apprentissage (p. ex. le recours à des modalités d'apprentissage nouvelles et diverses, l'effet du stress sur la courbe d'apprentissage et le temps requis pour comprendre l'insuffisance cardiaque), et 2) la nouvelle réalité des familles après le diagnostic (p. ex. détresse émotionnelle et bouleversement des habitudes).

Conclusions : Notre étude offre un aperçu des besoins d'apprentissage et des expériences des proches aidants qui prennent soin d'un enfant atteint d'insuffisance cardiaque. Les proches aidants décrivent le traumatisme lié au diagnostic d'insuffisance cardiaque de leur enfant et les répercussions négatives sur leur capacité d'apprentissage et sur leur mode de vie à partir de ce moment. L'étude fait également le point sur les expériences d'apprentissage des proches aidants et leur préférence pour les plateformes numériques. Ces renseignements guideront la conception d'un outil pédagogique en ligne sur l'insuffisance cardiaque pédiatrique destiné aux proches aidants. Cet outil permettra et améliorera la prise de décision des proches aidants concernant la prise en charge quotidienne de l'insuffisance cardiaque de leur enfant, dans le but d'avoir un impact positif sur les résultats cliniques, de réduire le stress et l'anxiété.

Methods

A qualitative description 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 Qualitative description also suggests minimal data interpretation by the researcher, keeping it true to participants' perspective.

This study was underpinned by the KTA framework that was developed on 31 planned action theories.¹⁴ On the basis of the knowledge creation funnel of the framework, this study appropriately explores caregiver learning and experience to inform an evidence-based intervention (eg, educational tool for caregivers about children's heart failure). Understanding gaps and creating knowledge about caregivers' learning and experiences (ie, knowledge creation) to tailor future educational tool development targeted at caregivers' learning and experience is critical before KT tool development (ie, 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 centre for children diagnosed with chronic heart failure from 5 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.). Because of a limited number of paediatric 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 2 weeks or later after discharge to ensure that 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

Table 1. Participant inclusion and exclusion criteria

Inclusion criteria	
1.	Adult caregiver(s) (>18 years of age) who is responsible for providing daily management and 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 as defined as American College of Cardiology/American Heart Association “categories C and D” <ol style="list-style-type: none"> 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, <ul style="list-style-type: none"> • diuretics and goal-directed medical therapy Stage D definition: Patients with refractory heart failure requiring advanced intervention (ie, biventricular pacemakers, considering a left ventricular assist device but not yet implanted, and transplantation)
4.	Care must be current or within the last year to limit recall bias (eg, if the child was transplanted or dies)
5.	Caregivers must have completed a 2-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

participants to reach data redundancy.¹⁷ The first author contacted participants up to 3 times via email, modelled after evidence-based surveying methods.²⁰

Ethics

Our relevant research ethics board granted ethical approval before participant recruitment. 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 (including details such as the purpose of the interview, data storage, confidentiality, how the research would not impact their child's care, and voluntary participation) was signed by the participants. Each participant was willing to proceed with each interview. Enrolled participants received a CAD\$25 gift card 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 before 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 fifth-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

Table 2. Semistructured 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 health care professionals to help your child (eg, creating detailed care plans and 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 paediatric heart failure? 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 (eg, video, infographic, whiteboard animation, and website)?

online interview software account and recorded directly onto the University of Alberta's secure local area network 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 (eg, no new categories emerged), as identified by the study team.

Analysis

We inductively employed conventional content analysis to uncover categories and subcategories.²³ Two researchers (C.C. and Z.Z.) independently completed initial coding and collapsed codes into categories using a qualitative software platform (NVivo, Limivro, Denver, CO). 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 local area network to document the evolution of the categories and research decisions.

Trustworthiness

Lincoln and Guba's²⁴ 4 trustworthiness criteria (credibility, dependability, confirmability, and transferability) guided our study.^{25,26} 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. Before 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, and

codes warranted to establish a category. Lastly, field notes and reflexive journaling were completed after each interview to examine researcher bias. All methodological decisions were recorded. Standards for Reporting Qualitative Research was used to ensure comprehensive reporting.^{27,28}

Results

Demographics

A total of 14 participants who identified as caregivers (mothers and fathers) caring for a child with chronic heart failure participated in the study. Of them, 3 participants withdrew from the study (eg, no response via repeated email requests for an interview from the primary researcher after recruitment). Therefore, 11 caregiver interviews were conducted. Demographic data are 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 subcategories 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. Subcategories 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 caregivers’ experience, was termed “a new life reality after diagnosis.” Two subcategories 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

Subcategory 1: new diverse ways of learning. Caregivers described 4 ways of learning that emerged after their child was diagnosed with heart failure: (1) tangible educational information, (2) independent online research, (3) health care providers’ support during care by parent tasks, and (4) hearing others’ stories. Tangible information sources are hard copies of information, such as printouts or pamphlets, provided generally in the initial stages after diagnosis. This type of information was generally not as favoured for several reasons (eg, 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 that 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

Table 3. Summary caregiver sample (N = 11)

Variable	Value (n)
Gender	
Male	5
Female	9
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
Postgraduate training	1
Current working status	
Full-time	9
Part-time	1
Not in the labour force/maternity 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 mo)	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

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 health care 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

Table 4. Category labels

Category 1: The traumatic diagnosis of heart failure influences learning
Subcategory 1: New diverse ways of learning
Subcategory 2: Stress steepens the learning curve
Subcategory 3: Learning heart failure takes time
Category 2: A new life reality after diagnosis
Subcategory 4: The emotional rollercoaster
Subcategory 5: Always on the clock: caring for a child with heart failure

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 health care 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, 1 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).

Subcategory 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 ... 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)

Subcategory 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 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..... 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 eventually retain and understand components of complex information overtime. 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

Subcategory 1: the emotional rollercoaster. All caregivers described accounts of experiencing emotional distress. Varying feelings of emotional distress were highest after 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 emotionally distressed relates 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. (P2, father)

Subcategory 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 their socialization. Stress and constant self-sacrifice were described due to always having a scheduled medical task, highlighting the negative impact the daily management had on their health and family functioning. Caregivers always felt that 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. (P5, mother)

Caregivers described challenges relating to a cumbersome, regimented schedule, describing their daily parenting 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 difficult, you know, off the start, it really felt like we were 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 and stress related to meeting their child's fluid management and nutrition. Caregivers equated feeding and nutrition as a measurement of the child's health status. If their child was not able to feed well, this stressed families as they knew their child could be getting sicker or they could not adequately fulfill their caregiver role. 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 feeding volumes. Feelings of anger were described by some caregivers when their child would not feed properly, as a key parenting task in society is to ensure a child is fed.

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. (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 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.²⁹ uncovered similar findings related to challenges families experience when they have a child with chronic heart failure, including 3 key themes titled (1) weakened family socialization, (2) the 5 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 et al.'s psychological stages (ie, 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 et al. also highlighted that children who were diagnosed with heart failure had insufficient socialization after diagnosis, whereas our study indirectly suggested this notion in our second subcategory (always on the clock: caring for a child with heart failure) as parents experience 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 parent preferences for learning and challenges. Zhang et al. suggest insufficient social knowledge about the topic but provide no further detail. Parents in Zhang et al.'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 health care system and government provides to families.

Aside from Zhang et al.'s paper, a rapid review by Smith et al.⁸ about families with chronically ill children examined caregiver experience with 34 included studies. No caregivers who cared for a child with heart failure were included in this study, but the concept was similar and relatable regarding chronic childhood illness and round-the-clock daily management duties. Three main themes were identified in Smith et al.'s paper: (1) parental impact, (2) illness management, and (3) social disruption. Smith et al.'s themes were strikingly similar to our categories, as all elements in our findings were related to Smith et al.'s in the same way. The impact on parents described by Smith et al. was that parents felt a range

of emotions, such as confusion, disbelief, and anxiety. Parents in our study felt these emotions, highlighted in our first subcategory, termed the emotional rollercoaster, were especially prominent early after diagnosis. Smith et al.'s review also discusses how parents need to learn to manage the illness and experience social disruption, all described by caregivers in our findings. Although 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 with caregiver of a child affected by heart failure due to the effects that chronic illness imposes on caregiving and family dynamics.

Caregiver learning considerations in 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 Wolf³⁰ resonates with our study. 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 impairing learning, we noted that caregivers are exposed to an extreme stressor (eg, being told that their child has heart failure) that immediately impairs their 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 Wolf³⁰ called context-dependent memory. They defined testing as memorization of information in one environment (eg, hospital) that needs to be recalled and applied to another environment (eg, 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 with tangible educational materials. Digital tools provide a portable source of relevant information that can be repeated as needed. These tools provide the benefit to quickly and conveniently access specific subtopics or chunks of information related to an aspect of a health condition (eg, heart failure) through advanced digital capabilities (eg, floating menu tabs with topic headings) to access specific types of information conveniently. Most caregivers in today's society have access to a mobile device with internet access that they can use to refer to digital information. This is more convenient than tangible educational resources (eg, pamphlets or hard copies of paper information); which were often described to be misplaced, not always on hand for reference and find cumbersome to sort through. KT strategies that use a digital art-based 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 health care 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 (KT 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 (eg, 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 (eg, 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 information along with clinician support will help facilitate better learning for diverse learning styles. Information and tasks can be repeatedly reviewed when needed to gain an understanding of complex information. It is important for clinicians to acknowledge that caregivers will have a difficult time to learn 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 centred-care values, a cornerstone of paediatric care.

Limitations

One limitation is that all the participants were recruited from a single centre, 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 health care 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 2 categories with 5 subcategories that describe how the traumatic experience of a child being diagnosed with heart failure impacts caregiver learning and poses challenges for their life after diagnosis. Similar to a previously published study highlighting parents' stressful lived experiences, our study adds foundational and additional 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.

Acknowledgements

The authors of this study would like to thank all the participants who shared their impactful experiences with the research team.

Ethics Statement

This study was approved by the University of Alberta Ethics Board (ARISE ID PRO00106559).

Patient Consent

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

Funding Sources

C.C. is funded by the Canadian Institute of Health Research Doctoral Fellowship (RES0056719), a previous graduate studentship from the generous support of the Women's and Children's Health Research Institute, Alberta Registered Nurse Educational Trust award, Canadian Nurses Foundation, the University of Alberta, Edmonton, AB, Canada Faculties of Nursing and Graduate Student and Postdoctoral Studies. Z.Z. was generously funded by the Women's and Children's Health Research Institute, Edmonton, AB, Canada. S.D.S. is a distinguished researcher at the Stollery Children's Hospital (RES0044689) and a Canada Research Chair. S.D.S. is also funded by CIHR, Ottawa ON, Canada (RES RES0044689).

Disclosures

The authors have no conflicts of interest to disclose.

References

1. Amdani S, Marino B, Rossano J, et al. Burden of pediatric heart failure in the United States. *J Am Coll Cardiol*. 2022;79:1917–1928.
2. Rossano JW, Kim JJ, Decker JA, et al. Prevalence, morbidity, and mortality of heart failure-related hospitalizations in children in the United States: a population-based study. *J Card Fail*. 2012;18:459–470.
3. Kantor PF, Lougheed J, Dancea A, et al. Presentation, diagnosis, and medical management of heart failure in children: Canadian Cardiovascular Society guidelines. *Can J Cardiol*. 2013;29:1535–1552.
4. Das BB. Current state of pediatric heart failure. *Child*. 2018;5:88.
5. Bansal N, Burstein DS, Lorts A, et al. Heart failure in children: priorities and approach of the ACTION collaborative. *Prog Pediatr Cardiol*. 2020;59:101313.
6. Kirk R, Dipchand AI, Mertens L, et al. The International Society for Heart and Lung Transplantation guidelines for the management of pediatric heart failure: executive summary. *J Heart Lung Transplant*. 2014;33:888–909.
7. Kepreotes E, Keatinge D, Stone T. The experience of parenting children with chronic health conditions: a new reality. *J Nurs Healthc Chronic Illn*. 2010;2:51–62.
8. Smith J, Cheater F, Bekker H. Parents' experiences of living with a child with a long-term condition: a rapid structured review of the literature. *Health Expect*. 2015;18:452–474.
9. Hartling L, Elliott SA, Buckreus K, Leung J, Scott SD. Development and evaluation of a parent advisory group to inform a research program for knowledge translation in child health. *Res Involv Engagem*. 2021;7:38.
10. Hummelinck A, Pollock K. Parents' information needs about the treatment of their chronically ill child: a qualitative study. *Patient Educ Couns*. 2006;62:228–234.
11. Cunningham C, Sung H, Benoit J, Conway J, Scott SD. Multimedia knowledge translation tools for parents about childhood heart failure: environmental scan. *JMIR Pediatr Parent*. 2022;5:e34166.
12. Gates M, Shulhan-Kilroy J, Featherstone R, et al. Parent experiences and information needs related to bronchiolitis: a mixed studies systematic review. *Patient Educ Couns*. 2019;102:864–878.
13. Meherali S, Campbell A, Hartling L, Scott S. Understanding parents' experiences and information needs on pediatric acute otitis media: a qualitative study. *J Patient Exp*. 2019;6:53–61.
14. Field B, Booth A, Ilott I, Gerrish K. Using the Knowledge to Action Framework in practice: a citation analysis and systematic review. *Implement Sci* 2914;9:172.
15. Sandelowski M. Focus on research methods: whatever happened to qualitative description? *Res Nurs Health*. 2000;23:334–340.
16. Sandelowski M. What's in a name? Qualitative description revisited. *Res Nurs Health*. 2010;33:77–84.
17. Kim H, Sefcik JS, Bradway C. Characteristics of qualitative descriptive studies: a systematic review. *Res Nurs Health*. 2017;40:23–42.
18. Neergaard M, Olesen F, Andersen R, Sondergaard J. Qualitative description—the poor cousin of health research? *BMC Med Res Methodol*. 2019;9:52.
19. Suen L-JW, Huang HM, Lee HH. [A comparison of convenience sampling and purposive sampling]. *J Nurs*. 2014;61:105–111 [in Chinese].
20. Dillman DA. *Mail and Internet Surveys: The Tailored Design Method*. 2nd ed. New Jersey: John Wiley & Sons Inc; 2007.
21. Yanos PT, Ziedonis DM. The patient-oriented clinician-researcher: advantages and challenges of being a double agent. *Psychiatr Serv*. 2006;57:249–253.

22. Largent EA, Lynch HF. Paying research participants: regulatory uncertainty, conceptual confusion, and a path forward. *Yale J Health Policy Law Ethics*. 2017;17:61–141.
23. Hsiu-Fang H, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15:1277–1288.
24. Lincoln YS, Guba EG. *Naturalistic Inquiry*. Thousand Oaks, CA: Sage Publications; 1985.
25. Morse JM. Critical analysis of strategies for determining rigor in qualitative inquiry. *Qual Health Res*. 2015;25:1212–1222.
26. Stahl NA, King JR. Expanding approaches for research: understanding and using trustworthiness in qualitative research. *J Dev Educ*. 2020;44:26–28.
27. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med*. 2014;89:1245–1251.
28. Dossett LA, Kaji A, Cochran A. SRQR and COREQ reporting guidelines for qualitative studies. *JAMA Surg*. 2021;156:875–876.
29. Zhang A, Zheng Z, Shen Q, Zhang Q, Leng H. Family management experience of children with chronic heart failure: a qualitative study. *J Pediatr Nurs*. 2023;73:e36–e42.
30. Schwabe L, Wolf OT. The context counts: congruent learning and testing environments prevent memory retrieval impairment following stress. *Cogn Affect Behav Neurosci*. 2009;9:229–236.
31. Albrecht L, Scott SD, Hartling L. Knowledge translation tools for parents on child health topics: a scoping review. *BMC Health Serv Res*. 2017;29:686.