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Original Article

Growing Up With Congenital Heart Disease: A Qualitative Research Study of Parents' and Clinicians' Experiences and Perspectives

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ABSTRACT

Background: Families of children with congenital heart disease (CHD) may experience a range of challenges, such as interactions with the medical system, parental stress, and the child's physical activity (PA) participation. The aim of this study is to explore how those with CHD and their families experience childhood based on parents' and clinicians' experiences and perspectives. The ultimate goal is to identify lacking supports (if any) and when children and their parents may be most amendable to receive them.

Methods: We recruited parents/guardians of children with CHD and clinicians involved in care provision for children with CHD. Participants completed life story interviews, with key events from parent/guardian interviews mapped to a timeline. Data were analysed using reflexive thematic analysis.

Results: Twelve parents of 11 children with CHD, with diagnoses spanning from mild to complex, and 12 clinicians (42% paediatric cardiologists, 33% nurses, and 25% other) were interviewed. Three

RÉSUMÉ

Contexte : Les familles dont un enfant est atteint de cardiopathie congénitale peuvent avoir à gérer des situations complexes comme les interactions avec le système de soins de santé, le stress parental et la participation de leur enfant à des activités physiques. Notre étude visait à porter un regard sur l'enfance des patients atteints de cardiopathie congénitale à partir du point de vue et de l'expérience des parents et des cliniciens. Le but ultime était de cerner les possibles lacunes en matière de soutien, le cas échéant, et de déterminer à quel moment les enfants et leurs parents seraient le plus susceptibles de recevoir de l'aide.

Méthodologie : Nous avons recruté des parents/tuteurs d'enfants atteints d'une cardiopathie congénitale et des cliniciens qui fournissent des soins aux enfants atteints d'une cardiopathie congénitale. Des entrevues ont été réalisées auprès des participants qui étaient invités à parler de leur expérience personnelle. Les événements marquants relevés lors des entrevues étaient consignés de manière

Congenital heart disease (CHD) is a common birth defect, affecting approximately 1 in every 100 children.[1,2] Advancements in medical treatment and surgical interventions have greatly reduced the mortality of the condition in infants and children, and people with CHD are living longer, with as many as 97% of children with CHD now surviving to adulthood.[3−5] However, raising children with CHD continues to be a unique and complex challenge. Parents of children with CHD face numerous hurdles as they learn to care for their children and must lean on a variety of personal and clinical supports to provide for their family's needs.[6,7] There is increasing evidence that addressing family adjustment, by teaching active coping techniques or providing psychoeducation, and reducing stress are the most effective ways to improve psychological and behavioural outcomes in children with CHD.[8,9]

Caring for children with CHD is a challenging experience for parents, who must juggle managing finances and complex childcare, along with the emotional toll of their child's diagnosis.[10] Parents experience significant levels of stress, regardless of whether their child's diagnosis is made prenatally or postnatally,[11] and are at a greater risk for depression and

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themes were identified: (1) overwhelmed—the relationship between parents and the health care system, (2) trauma and resilience—the emotional side to raising a child with CHD, and (3) PA … more than just fun. Subthemes explored challenges of education, communication, and living away from the hospital, traumatic experiences, the need for parental support, different approaches to PA counselling, providing role models, barriers to successful PA promotion, and tools for improvement.

Conclusions: This study highlights the need for changes to how and when information is communicated to families of children with CHD and an increase in the number and types of support mechanisms available.

chronologique. Les données ont ensuite été évaluées dans le cadre d'une analyse thématique réflexive.

Résultats : Douze parents de 11 enfants ayant reçu un diagnostic de cardiopathie congénitale légère ou complexe et 12 cliniciens (cardiologues pédiatres, 42 %; membres du personnel infirmier, 33 %; autres, 25 %) ont été interrogés. Trois thèmes se dégageaient : 1) sentiment d'être dépassé – la relation entre les parents et le système de soins de santé, 2) traumatisme et résilience – l'aspect émotionnel lié à l'éducation d'un enfant atteint de cardiopathie congénitale, et 3) activités physiques… pas seulement pour le plaisir. Plusieurs sous-thèmes ont été explorés, dont les suivants : défis en matière d'éducation et de communication, vie hors de l'hôpital, expériences traumatiques, besoins en matière de soutien parental, différentes approches liées aux conseils sur l'activité physique, modèles de comportement, obstacles à la promotion efficace de l'activité physique et outils utiles.

Conclusions : Cette étude montre à quel point il est nécessaire de changer la façon dont nous communiquons l'information aux familles d'enfants atteints d'une cardiopathie congénitale, de choisir le bon moment pour transmettre cette information, et d'accroître le nombre et le type de mécanismes de soutien offerts.

anxiety than the general population.[10] This in turn contributes to an increased risk of psychological and behavioural disorders in their children.[12,13] Common sources of stress may include inadequate knowledge of their child's condition, self-blame, problems with the support network, and insufficient resources.[14] Common sources of support may include doctors and nurses, community resources, family, friends, neighbours, and peers with children with chronic disease.[14] However, there remain questions as to when and how to best incorporate these supports into the parents' lives.

In addition to managing parental stress, ensuring that children with CHD engage in physical activity (PA) is essential for their health and development. Research has shown that PA is associated with improved cardiometabolic health, cognition, and better mental health;[15] however, rates of participation in PA remain low in children with CHD, with less than half meeting the Canadian daily PA guidelines.[16–18] Although Canadian children without CHD do not meet Canadian PA guidelines at a similar rate,[16,19] addressing PA in children with CHD is particularly important, because abnormal heart anatomy or function places people with CHD at an increased risk of acquired cardiovascular disease.[20] Identifying strategies to address these challenges is crucial for enhancing the quality of life in children with CHD.

Clinicians agree that children across the spectrum of CHD complexity should generally not restrict their PA, especially after surgical correction.[21,22] Therefore, to improve their quality of life and reduce the mortality from their increased risk of acquired heart disease, PA should be promoted in children with CHD. Attempts to design effective PA interventions have yielded underwhelming results, and there is no consensus on the optimal method of promoting activity.[23–25] Existing methods target school-aged and adolescent children, after activity habits have already formed.[24,26] A change in the way we approach PA promotion for children with CHD is clearly needed.

The present study explores how those with CHD and their families experience childhood, including key developmental and/or clinical milestones, PA participation, and how they experience their interactions with the medical system. The ultimate goal is to identify what supports—if any—may be lacking, and when children and their parents may be most amendable to receive them. Therefore, the aims of this study were (1) to gain insight into parents' experiences and perspectives about what it is like for them and their children as they grow up with CHD; (2) to document clinicians' experiences and perspectives regarding key clinical, behavioural, and developmental milestones that generally apply to children growing up with CHD; and (3) to identify major trends within the patient journey that help us understand when and how to best support the paediatric CHD population.

Methods

Approach and design

We adopted an interpretivist constructionist approach using life story interviews,[27] timeline mapping,[28,29] and analysing the data using reflexive thematic analysis.[30] Within an interpretive constructionist paradigmatic approach, there is an understanding that people make sense of their experiences in multiple ways, and that reality is contextual and subjective.[31] Guided by these underpinnings, the purpose of our study was to gain an understanding of how parents made sense of their experiences with their children who were growing up with CHD over time and within the context of the family's everyday lives. We sought to understand the subjective, contextual meanings parents assigned to their experiences, to cast light on how to better understand when and how to promote PA in the paediatric CHD population.

Sample and recruitment

Parents/guardians (from here on out "parents" for brevity) of children, adolescents, or adults with CHD (any type, any age) living in British Columbia, Canada (BC) were invited through email distribution lists of the provincial CHD parent network and via REACH BC (https://reachbc.ca/). Although the focus of the study is on children with CHD, parents of adult children were included to provide insights into their experiences as their children transitioned from birth to adulthood. Clinicians, including paediatric cardiologists, nurses, exercise physiologists, social workers, and echocardiography technicians, who provide care for children with CHD in BC, were recruited from the only paediatric tertiary care centre in BC: BC Children's Hospital (BCCH).

Data collection

Participants completed an electronic demographic survey, followed by life story interviews. The purpose of the surveys was to describe the sample and contextualize the participants' accounts. Parent surveys captured information about themselves and their child, including details regarding their CHD diagnosis and brief treatment history. Clinicians reported relevant information regarding the scope of their work, including years of experience and annual patient volumes. Survey data were collected and managed using REDCap electronic data capture tools, hosted at the University of British Columbia (UBC).[32] Data collection took place between October 2023 and May 2024. Participants had the option to receive a CAD$25 gift card to a vendor of their choice, or to have a $25 donation made to a charitable organization of their choice. The study was approved by the UBC Okanagan Behavioural Research Ethics Board (H23-00114), and all participants provided written informed consent. In addition, written informed consent was obtained from one parent participant and their child (now adult) with CHD whose timeline map is included in this publication (Supplemental Fig. S1).

Life story interviews. Interviews were conducted over institutional Zoom for parents and in person or over Zoom for clinicians (Zoom Video Communications Inc, San Jose, CA). The interview guide for parents was scaffolded as a life story interview,[27] with a focus on the parent's account of significant clinical and developmental milestones, and participation in and capacity for PA, in their child's early/mid/late childhood/adolescence (as applicable). A life story interview allows participants to speak for and about themselves and encourages participants to provide the relevant context that surrounds their life experiences.[27] This method allowed for a more holistic understanding of how clinical and developmental milestones in the life of their children fit into the bigger picture of the parents' lives, and provided additional nuance to address our research questions, such as why certain supports available to parents were not used, and how and why PA was incorporated into their lives. The interview guide for clinicians was similar but asked for a generalized account of their paediatric patients' journey during childhood and adolescence, and what role—if any—PA plays.

Timeline mapping. Timeline mapping is a qualitative research tool involving the generation of visual timelines of significant events in a participant's life from an interview.[29] Timeline maps help focus the interview on the chronological dimension of their story, enabling extraction of events associated with specific times or ages, and may enhance interview data quality.[28,29]

In our study, maps of the patient story were written out by the interviewer, while the parent dictated their experiences and those of their child and served to help guide the interview; maps were only made for interviews with parents and not clinicians. After the interview, a timeline map was digitally generated from each parent interview about their child's journey using Microsoft Visio (Microsoft Corporation, Seattle, WA). Timeline maps were later augmented by reviewing audio transcripts to confirm the order of events, then reviewed, and—if applicable—further edited by the parents for accuracy. Timeline maps were reviewed during the analysis process to further understand the chronological relationship between life events. An example of one person's timeline map is found in Supplemental Figure S1 (published with participant permission).

Analysis

Descriptive statistics (mean ± standard deviation, frequency [%], and median [range]) were calculated for sample characteristics. Interview recordings were automatically transcribed verbatim by Zoom and manually verified for accuracy. Interviews and timeline maps were analysed using reflexive thematic analysis.[30] We interpreted the content and patterns of meaning within and across the parents' accounts regarding their children's experiences, as well as the clinicians' understanding of their patients' experiences. The data were coded abductively, combining a deductive approach informed by existing literature on the unique challenges of growing up with CHD, with inductive adaptation of codes using the parent and clinician experiences uncovered in the interviews. Data from both parents and clinicians were analysed collectively, such that codes generated from either group could be applied to both as relevant. NVivo 14 (Lumivero, Denver, CO) was used to record and organize codes. Codes were then sorted and amalgamated to construct 3 themes and 8 subthemes that reflect and tell an overarching story about the parents' and clinicians' accounts, which are presented in the Results section below. To protect the privacy of participants, we chose to use pseudonyms in place of real names for participant quotes.

Results

Twenty-four participants completed the study: 12 parents and 12 clinicians. Detailed demographic characteristics of the parents and their children, as well as clinicians, are presented in Tables 1 and 2, respectively. Median interview times were 55 minutes (range: 28-159 minutes) and 24 minutes (range: 14-38 minutes) for parents and clinicians, respectively.

Three main themes and 8 subthemes were identified in the data. The themes and corresponding subthemes are summarized in Table 3.

Theme 1: overwhelmed—the relationship between parents and the health care system

Parents and clinicians both recognized the common challenges associated with raising a child with CHD. First, education for parents and communication with the health care team was organized around the time of diagnosis, but often

Table 1. Sample characteristics of parent interviewees and their children with CHD

Characteristic	Value
Parent interviewees	
Mothers, n (%)	12 (92)
Age (y), median (IQR)	42 (37-48)
Highest education attained, n (%)	
High school diploma	1 (8)
College certificate or diploma	5 (32)
University degree	6 (50)
Annual household income, n (%)	
<$60,000	3 (25)
$60,000-$125,000	3 (25)
>$125,000	6 (50)
Ethnicity*, n (%)	
White	11 (85)
East Asian	2 (17)
Region of BC, n (%)	
Metro Vancouver	6 (50)
BC Interior	4 (33)
Vancouver Island	2 (17)
Parent interviewees' children with CHD	
Girls, n (%)	11 (45)
Age (y), median (IQR)	9 (3-17)
Ethnicity*, n (%)	
White	10 (85)
East Asian	2 (17)
CHD diagnosis, n (%)	
Mild	1 (9)
Moderate	7 (64)
Complex	3 (27)
Timing of CHD diagnosis, n (%)	
Before birth	6 (55)
Shortly after birth	5 (45)
Past surgical and/or interventional procedures, n (%)	
Yes	9 (82)
No	2 (18)
Current formal physical activity restrictions, n (%)	
None	11 (100)

CHD, congenital heart disease; BC, British Columbia; IQR, interquartile range.

* Proportions for this category may exceed 100% as participants could select more than one option. All participants were parents; 1 parent-pair was included (interviewed separately), resulting in 12 parents of 11 children.

Table 2. Sample characteristics of clinician interviewees

Characteristic	Value
Women, n (%)	12 (58)
Age (y), median (IQR)	42 (37-50)
Ethnicity*, n (%)	
White	7 (58)
East Asian	2 (17)
South Asian	3 (25)
Clinician type, n (%)	
Paediatric cardiologist	5 (42)
Cardiology nurse clinician	4 (33)
Other†	3 (25)
Primary location for CHD-related clinical care delivery, n (%)	
BC Children's Hospital (BCCH), Vancouver	12 (100)
Additional CHD-related clinical care delivery through provincial outreach clinics, n (%)	
Yes	5 (42)
No	7 (58)

CHD, congenital heart disease; IQR, interquartile range.

* Proportions for this category may exceed 100% as participants could select more than one option.

† "Other" clinician types included echocardiography technicians, social workers, and exercise physiologists.

became overwhelming and disconnected after birth. Parents were struck with the reality of having to advocate for themselves and their children to stay well informed. And for families receiving care away from BCCH, there were additional challenges that complicated their caregiving experience.

Subtheme 1: education and communication—the cornerstones of care. Parents reflected on the enormity of the learning required to best care for their child after diagnosis. Clinicians understood the magnitude of the education required of parents, empathized with their situation, and explained how they did their best to prepare parents for what to expect when raising a child with CHD. After diagnosis, the meetings provided by the health care team provided a roadmap for parents to set expectations for their child's care and reduce their stress. Information packets in the form of booklets or binders provided during these early meetings were cited as particularly helpful to understand their child's diagnosis and expected health care needs. Although the resources were useful, one mother explained that she still felt that the health care team could have provided more guidance. She felt underprepared after her discharge from hospital, stating:

> *… the piece where I feel like things were hard, was when they give you your heart baby and they send you home. They say … now you just deal with whatever comes.*

Many parents took education into their own hands by using the internet. Unfortunately, some parents found that doing their own searching led to more stress through exposure to potential complications that they may not have otherwise been exposed to and often ended up confused and scared. Diane (mother) described the experience generated by these internet searches as being sent to "the realm of the fear that [their] baby was going to die." To stop parents finding irrelevant and traumatizing information about their child's condition online, some clinicians offer digital resources. For Shelly, having her internet education curated by her paediatric cardiologist made the process clearer and increased her rapport with her paediatric cardiologist.

With the variety of approaches to learning about their child's condition available to parents, one clinician suggested that:

> *maybe it isn't for [the health care] team to decide how we provide [education], maybe the question is, how do we ask our families how they want information provided to them.*

Many parents struggled with trying to remember all the information provided to them during their visits with cardiologists. Parents cited the importance of having a nurse around to help clarify what they had just been taught, as described by Kimberly (mother):

> *we would have our own sort of debrief [with the nurse] …. if we couldn't remember, 'cause it was overwhelming with the terms, or the amount of information.*

Nurses concurred and explained that parents may not feel comfortable asking questions to their cardiologists and preferred to speak with the nurse, as explained by Monica (nurse):

Table 3. Main themes and corresponding subthemes

Main theme	Subthemes	Representative quote
(1) Overwhelmed—the relationship between parents and the health care system	Education and communication—the cornerstones of care	"I was given this big book, and this big binder … explaining kind of everything … meanwhile, your head's spinning, and you're a new mom … and you're not sleeping, and, you know, it's crazy!"—Maria (mother)
	Not in the big city? No problem ... almost	"Being not in a major center, you know, there's not a lot of supports for parents, you know, when you have a sick child."—Maria (mother)
(2) Trauma and resilience—the emotional side to raising a child with CHD	Traumatic experiences	"What I wanted to ask was, even if he survived in the NICU, you know, how long would he live? ... I know if somebody had asked me, like, 'what are you worried about for his future?' I think I would have been honest and said so. But nobody asked it, and I didn't really have the courage to ask that myself [cries]."—Sonja (mother)
	Parental support ... it takes a village	"… the support mechanisms for parents is something which I don't think we provide for very well for because, although we talk about patient centered care, it's funding is very patient centric."—Clinician
(3) Physical activity ... more than just fun	Providing role models	"We saw this Olympic athlete who had the same heart condition as [our child] and for us to see someone who has his diagnosis, to be that elite in his sport, gives us so much hope that there's no restrictions on what he can do."—Molly (mother)
	Barriers to success	"Do you have two working parents than can't get their kids to activities? Is there a financial barrier?"—Clinician
	Exercise physiology—an underused discipline	"An exercise physiology person is very good because they present exercise as being a medical management thing, versus a just get your ass off the couch and off your phone."—Clinician
	Tools for improvement	"It's about meeting them where they're at … seeing them along their own trajectory, not some made-up trajectory."—Clinician

CHD, congenital heart disease.

> *The cardiologist will come in, say a few things, ask parents if they have any questions and then the parents will go "No, nothing." … And then I always stay behind and say, did you have anything else, like anything you want and all of a sudden, they're asking you questions about what the doctor said because they didn't understand it.*

Aside from parents not being in the best place of mind to remember everything, one clinician believed that concepts could be explained to parents in a better way by paediatric cardiologists:

> *[Pediatric cardiologists] speak a different language—they don't break it down… [they] are drawing the picture of the heart facing themselves and they're pointing things out. The parents like, they don't even know what they're talking about.*

As their children get older, some parents were confused about how CHD might change as they age, with Sarah (mother) explaining that "there was never any conversation where [the healthcare team was] like, 'it's unlikely that anything is going to change.'" There was still a lack of clarity as to whether their child's CHD may cause them issues later in life, and it was a continuing source of anxiety. One paediatric cardiologist felt that parents continue to feel anxious regardless of the level of reassurance they are given, explaining that for some parents, "every time [their child] gets chest pain, they think of their heart," even after successful surgical correction. A reason for this may be poor communication; Cherise (mother) often felt that her child's health care team would often be "talking amongst themselves" and to stay informed, she and her husband would need to constantly "advocate for themselves." Another parent explained that the doctors in the Neonatal Intensive Care Unit (NICU) would often use medical terminology that they could not understand, and they would need to spend their own time looking up the definitions of the terminology used by their care team. One clinician recognized these frustrations:

> *I think a lot of it is communication … families feel very frustrated around, I think, around communication. … [It] is the biggest piece that comes back to me.*

Subtheme 2: not in the big city? No problem … almost. In BC, families living away from Vancouver and BCCH receive follow-up care from a travelling partnership clinic consisting of a paediatric cardiologist, cardiac nurse, and echocardiography technician. The service travels to a different municipality in the interior or northern regions of BC 2-3 times a month, for 3 days at a time. Parents expressed their gratitude for this service and felt that partnership clinics provided high-quality care for their children in a more accessible way. Unlike care received at BCCH, where each patient is assigned one paediatric cardiologist, patients receiving care from the travelling partnership clinic may receive care from multiple different cardiologists, depending on who is available on a given week. Two parents brought up concerns about receiving differing medical opinions, which increased their confusion and anxiety around the timing to their child's impending surgery. William (paediatric cardiologist) directly recognized the possibility for parents to receive conflicting information at a travelling partnership clinic, saying:

> *It generally occurs in situations where there's no obvious simple answer and there's certainly … variations between how people are trained*

> *and what they actually do. … Certainly, it is very important when you see the patient … to read the previous note if it's not you, because you know, not everybody does [the] same things at the same time.*

Outside of the limitations of the travelling clinic, there are other challenges associated with living away from BCCH that, parents felt, need to be addressed. The first is the limited knowledge of physicians in their area when providing care for their children. Maria explained that they would have to coach their local health care team, saying:

> *I've gotten used to being like, "No. Just call BC Children's. They'll pull his record. You'll speak with the cardiologist on call. They'll, you know, they'll go through the stuff with you." 'Cause I could see as soon as they listen to his heart, their face drops.*

Parents also spoke to the limited parental supports they have access to in their local community; parents outside of the lower mainland were familiar with a provincial nonprofit organization that offers support for families of children with CHD but felt that the events and supports offered were not helpful for them in their communities away from BCCH. This contrasts with the suggestion that clinicians made, who suggested that the organization is an effective resource for families outside of Vancouver. Clinicians did reference how accessibility to psychologists, therapists, physiotherapy, and occupational therapy is also reduced in rural communities, particularly those in the northern health region.

Katey (social worker) spoke about the large volume of paediatric patients in cardiology, and that limitations in social work staff make it difficult to offer services to every family. However, families travelling to BCCH for surgical procedures are prioritized, as these families are away from their local community and family support systems. Unfortunately, as social work is not familiar with the resources in the communities where these families travel from, after their time at BCCH is complete, social work is not able to provide much support with accessing resources specific to their community.

Theme 2: trauma and resilience—the emotional side to raising a child with CHD

As parents shared their stories of diagnosis, birth, and everything afterward, the emotional weight of their experiences became very apparent. Parents experienced significant impacts from both the imagery of their children in intensive care and the real and potential complications of their child's condition as they grow. Supports for parents are available and offered by clinicians, but there are ways to improve them.

Subtheme 1: traumatic experiences. Across all parents, there was consensus that diagnosis, surgery, and ongoing medical care were a large source of trauma. Whether it occurred prenatally or postnatally, diagnosis was always a shock to parents. This parent describes the variety of emotions they experienced simultaneously after the diagnosis, which was a sentiment shared by all the parents interviewed:

> *It's pretty shocking. I think you can process so much information in a day right, and so you kind of go through like, you're hit with different things, like, worry, fear, denial.*

Parents whose children had to spend time in the NICU were impacted by the visual of their children connected to life-saving equipment, as well as thoughts of how their child would fare after their time there. Surgery was another source of trauma, and many parents described the day leading up to surgery as one of the most difficult days in caring for their children. Collette (echocardiography technician) spoke to how imaging was also a source of trauma for patients:

> *As a parent, seeing your child just be distraught over having these tests done, I think emotionally can be quite hard … I feel really bad when we have kids who have a hard time coping … screaming or crying, or just generally trying to run out of the room.*

Parents expressed that as time passes from diagnosis and surgery, the shock of their child's diagnosis began to fade, their child's health care needs became more routine, and their stress was reduced. However, many parents were still impacted by the trauma years later. One mother spoke about suffering from worsening panic attacks after her daughter turned 2, whereas another spoke about how the possibility of her child's condition negatively impacting him was always on her mind, even many years after surgical repair, saying:

> *The other morning, he slept in really, really late, and he wasn't getting up, and I went into his room, and I had to wake him up. … He was just in a really deep sleep; he was totally fine. But you just wonder, you know, and- [participant tears up].*

Clinicians were very aware of how stressful and life changing having a child with CHD can be and empathized with the parents well during our interviews; one clinician shared how they "have to reassure parents all the time that they can cry" during their care visits.

Subtheme 2: parental support … it takes a village. Parents identified 4 key sources of support: other parents of children with CHD, family members and friends, mental health professionals such as therapists or counsellors, and their child's health care team. Consistently, parents spoke very highly of how helpful it was to have been connected to another family with a child with CHD. Most often, parents were connected to the provincial nonprofit organization that supports families of children with CHD, which acted as an initial link to the greater heart-parent community by providing opportunities for children and parents alike to connect with others in a similar situation. Parents who were not connected with this organization or a "mentor" family mentioned wanting to have that as an option for their support system.

Parents valued having a close personal network of people to rely on. Grandparents were often cited as being helpful in caring for other children, helping parents with health care visits, or giving parents time to rest by watching their newborns. Close friends were mentioned by 2 parents as being helpful. This parent expanded that while the support was beneficial, they desired greater levels of emotional support, saying:

> *I do have wonderful friends, and they would bring meals. But it wasn't like there was anybody that had the resources to provide the kind of support that I needed.*

Multiple parents spoke about seeking therapy or counselling on their own and wishing it had been offered to them earlier, as they saw great benefits. Two parents mentioned having been offered counselling and declining it, and later coming to regret it.

The final pillar of parental support comes from the child's health care team. All parents felt that the care at BCCH their children received was exceptional. However, multiple parents felt that emotional support was lacking, with one parent rating their care in the following way:

> *Personal support, emotional, probably at a 3. In terms of resources, we can put it at a 6. In terms of [my child's] support … when we're at the hospital, I would rate it at 10.*

Although parents may not have felt sufficiently emotionally supported by their health care team, clinicians across the different roles interviewed all spoke to the importance of practicing empathy and compassion in their roles. Many clinicians would directly state that they did their best to offer emotional support by listening to parents and asking about how they were feeling. When asked about parental support, one clinician recognized the lack of support by say, quote:

> *We don't have much support for the parents … the support mechanisms for parents is something which I don't think we provide for very well for because, although we talk about patient centered care, its funding is very patient centric.*

For multiple parents, a time when they felt unsupported was during the birth of their child. One clinician spoke to how the health care team does its best to "de-medicalise [the delivery] as much as [they] can… so [mothers] can still have skin to skin, and those types of moments that they would get in a typical birthing experience." Unfortunately, many of the parents interviewed did not feel that this was the case. When asked about whether there was any focus on her care during childbirth, one mother stated: "No. None whatsoever … I wasn't a priority."

Theme 3: physical activity … more than just fun

During the interviews, one of the primary goals was to get a better understanding of how PA incorporates into the lives of families of children with CHD, and how the clinical care team views and incorporates PA into their care plan. The core of this theme is the importance of PA for the health of children with CHD and to aid in their medical management. One paediatric cardiologist explained:

> *I use PA very much as an indicator of whether the child needs an intervention or not. So, it's helpful for me to know if the child is thriving based on what they are doing physically.*

Participants weighed in on how powerful role models, both familial and famous, were for encouraging PA to children with CHD, as well as the challenges that exist to increasing PA. Clinicians then also dove into how best to address the issue of low PA participation rates.

Subtheme 1: providing role models. Parents and clinicians perceived that the provision of diverse role models could have an important effect on PA in children with CHD. The biggest role models in the lives of children are their parents; parents who have the time and financial liberty to be directly involved in their child's PA do so, and they do so early. In our interviews, there were many examples of parental PA interests dictating their child's participation in activity. The exercise physiologist we interviewed echoed the importance of parents, explaining that children "don't work in isolation … the family is a really important component of what a kid can do and [can]not do." It should be noted, however, that role models can exist outside of just the immediate family; other physically active people in their life can impact these children. One of the children would go mountain biking and "on hiking trips with [his uncle], who's sort of an outdoorsy guy," and as a result, would later grow an interest in mountain biking as an adolescent.

One paediatric cardiologist mentioned that they would tell their patients' parents that "there's no reason [their child] can't become [an] Olympic athlete just like anybody else." Interestingly, 2 different parents referenced this exact suggestion about Olympians and spoke to how inspiring that was for them. This parent explained how it empowered them:

> *We saw this Olympic athlete who had the same heart condition as [our child] and for us to see someone who has his diagnosis, to be that elite in his sport, gives us so much hope that there's no restrictions on what he can do.*

Subtheme 2: barriers to success. The second subtheme regarding PA encompasses the challenges and issues that children with CHD face when trying to be active, as well as the barriers to optimal counselling. The first challenge faced by children with CHD is physical limitations. Children who were actively experiencing symptoms were not able to exercise like their peers and would drop out of organized sport. Maria (mother) explained how these limitations looked in her son, explaining:

> *… you could notice him getting tired. He'd get really tired. … he'd be running, and then just stop. He couldn't run anymore. So, then he couldn't play soccer.*

For many of these children, surgical repair changed everything for the better. But this was not always the case; Maria explained how her son required multiple surgeries as he was growing up, and "his skill level … wasn't at the level that his peers' were at. So, he couldn't play with his peers." This resulted in her son losing interest in PA and opting to pursue sedentary hobbies instead.

Aside from the physical limitations, another obstacle cited by clinicians and one parent was the financial barriers to exercise. Many of the children who were active were active via group activities, lessons, and team sports, all of which cost money. Access to spaces to be active for free and the mindset to be active outside of planned activities is not always there.

Subtheme 3: exercise physiology—an underused discipline. There was a consensus among the clinicians that referrals to exercise physiology were helpful and underused. Some clinicians even felt that it would be useful to provide a referral to all patients if resources allowed for it. Although most clinicians spoke to the utility of exercise physiology referrals to help guide teenagers and increase their exercise as they enter the period of life when they are exercising less, some suggested decreasing the age of the first referral to try to establish communication with exercise physiology earlier and maximize impact. This clinician summarized it by saying:

> *My general feeling is that [exercise physiology] need[s] to start talking to families as preschoolers … to intervene at five years of age and then [again] in the 13-15 age group.*

Clinicians also spoke about limited access to exercise physiologists. People living outside of Vancouver have less frequent access to and a reduced variety of care; this in turn results in less referrals for testing or exercise prescriptions, as they require a visit to BCCH. At BCCH, referrals for exercise physiology can be made for exercise testing and/or exercise prescriptions. Due to the limited number of exercise physiologists, it is not possible to refer all children who are not meeting the Canada PA guidelines for exercise prescriptions.

Subtheme 4: tools for improvement. The final subtheme in "PA … more than just fun" covers the potential solutions to the problem of promoting PA. The first concept discussed by clinicians was about "meeting patients where they're at" and tailoring the discussion to their needs and preferences. The exercise physiologist explained that they found success through motivational interviewing, by assessing what the children find fun, exploring how important PA is to these children and how confident they are with being physically active, and finally, "how motivated [the] kids are to … make changes to their PA."

One clinician mentioned trying to integrate technology into PA promotion by introducing pedometer applications and tracking step goals for their patients; their hope was to engage with youth in a way they were comfortable with (eg, phone apps). Another clinician suggested providing "a handout … saying that [their] heart defect will not cause these things" so that "parents don't start pulling [their kids] out of activities." However, when asked about the utility of such a handout, a different clinician stated that they thought handouts are "kind of an old school way" and assumed that people would not engage with and read them.

Although PA promotion was clearly a part of the counselling plan that clinicians deliver to paediatric patients with CHD, there were very apparent differences in *when* PA counselling was initiated. For example, one paediatric cardiologist believed that PA counselling "has to start right from the beginning of it being known [the patient has] a heart defect," while other paediatric cardiologists claimed that "the conversation starts basically in early childhood," or "from age 3 or 4." To provide an example of why offering counselling earlier may be more effective, one parent who enrolled her daughter into organized sport starting at 20 months of age spoke about how her paediatric cardiologist's counselling helped assure her that exercise was safe for her daughter:

> *… the cardiologist told us she'll still be the same her sister [and] there wouldn't be any restriction on her activity. … So, we told everyone … that after her surgery she'll be the same as any other kid.*

Regardless of whether they began counselling at birth or later in childhood, clinicians seemed to agree that "PA declines throughout adolescence" and that they must make a point of "increasing emphasis to try and keep [teenagers] active." One clinician believed that there was a lot of opportunity for improvement in counselling frequency, stating that they "don't think most of [their] colleagues go through PA at every visit." This clinician proposed reviewing PA on every visit to provide additional opportunities to reinforce the notion that PA should not be restricted and that PA is especially important for the long-term health of children with CHD.

Table 4. Suggested improvements for paediatric CHD care

Recommendations with supporting quotes
(1) Physician curated online resources for parental education "Dr. [Jones] had … written down really great links … to go look at information … and I learned a whole bunch"—Diane (mother)
(2) Additional CHD education for families during transitions to adolescence and adulthood "We're still trying to navigate how … he's going to look after himself [in adulthood] … I'm, you know, feeling lost right now."—Maria (mother)
(3) Revisiting parental amenability to supports such as counselling or therapy in the years after diagnosis and surgery "[Counselling] was offered to us. But I think in like postpartum your first time, you don't think you need counselling, whereas I look back and I'm like … you should have just taken it."—Anne (mother)
(4) PA counselling starting shortly after diagnosis "I think [PA counselling] has to start right from the beginning of it being known they have a heart defect."—Clinician
(5) PA recommendations reinforced at every visit "… we encourage PA and … every time a child comes for a follow up in our clinic, there's an opportunity for a doctor and nurse to sit down and sort of gauge where they're at"—Clinician "We talk about what we've seen and what … literature shows [about PA] and … trying to motivate them to do so. So, it's a lot of repetition …"—Clinician
(6) Exercise physiology referrals for exercise prescriptions before beginning grade school "I think we need to intervene [with exercise physiology] at preschoolers, probably five years of age"—Clinician

CHD, congenital heart disease; PA, physical activity.

Discussion

This study explores the challenges and resilience experienced by families of children with CHD, as well as the perspectives of the clinical providers who support them. Three key themes were identified that shed light on the CHD journey: first, the theme "overwhelmed" captures the struggle parents face when learning the vast amount of information on their child's condition and managing fragmented communication with their health care team, particularly when care is provided away from BCCH. Second, the "trauma and resilience" theme highlights the emotional scars left by diagnosis, surgery, and ongoing care, while also illustrating the support system parents must access to cope with these challenges. Finally, the theme "PA … more than just fun" explores how families and clinicians encourage PA in children with CHD, and the walls that must be scaled to further increase PA participation. Together these themes provide insight into the CHD experience, offering valuable suggestions into areas where health care delivery and support systems can be improved. Our key recommendations for CHD care drawn from these themes are summarized in Table 4.

Preparing parents for a child with CHD

Participants in our study discussed the overwhelming volume of new knowledge required to learn about a new diagnosis and the tools that are offered to support this process, including accessing the internet. Parents spoke about the utility of many meetings around the time of diagnosis and educational resources, such as information booklets. Existing research on the topic of education for parents of children with CHD has shown that preparation for hospital admission, surgical course, and condition anatomy, such as what was provided for the parents we interviewed, was adequate.[33] In a study by Gramszlo et al.,[33] reputable websites for CHD information were not provided but were a desired educational resource; our research also suggests that providing a curated list of online resources for parents could improve their experience.

Translating paediatric cardiology to parents

Participants described challenges with communication between parents and clinicians, and how this impacted the experience for parents. In particular, the volume of information communicated at one time was often overwhelming, and parents felt unable to express this to their paediatric cardiologists and preferred to confide in their cardiac nurse instead. Clinicians also thought that there was opportunity to improve with regards to how details were explained when speaking with parents.

Research exploring the challenges of parental communication with care teams in the paediatric cardiac intensive care unit has found that inconsistent and incomplete communication with parents often left them confused, stressed, and feeling like information was being concealed from them.[34] This agrees with the experiences of some of the parents in our study, particularly during the birthing process and their stay in the NICU. Parents in our study struggled when care teams used medical terminology without using patient-accessible language. Medical jargon has been shown to be a source of confusion for parents but can be resolved by receiving one-on-one clarification after a health care visit.[34] In the clinic setting, parents can find themselves overwhelmed and struggling to properly communicate with their cardiologists, with some choosing to defer their questions to their cardiac nurses. This may be due to the nurses acting as a "continuity person" for the parents, acting as a constant point person to help navigate their children's care.[34] A systematic review of family preferences with regards to communication of care decisions in children with cardiac disease found that parents trusted physicians who were present and mindful during their visit, cared for the entire family's needs, and included other nonimmediate family members in the discussions of their child's condition.[35] Focusing on these strategies could help improve rapport with physicians and enhance communication during clinic visits. Finally, as children with CHD approach adulthood, the frequency of their visits decreases significantly; this may result in a lack of opportunity for parents to express their fears about their child's condition and reduce opportunities for clinicians to reinforce CHD education. In the interviews from our study, parents and clinicians alike shared that most of the resources provided for CHD education were delivered around the time of diagnosis or surgery. Providing parents with another set of resources for CHD education as their children transition into adolescence and adulthood may help offset the potential for confusion and anxiety associated with the decreasing frequency in visits with the paediatric cardiologist.

Living away from the children's hospital

For families who are not close to BCCH, the travelling clinic was a greatly appreciated benefit. The only issue parents brought up with regards to the clinic was differing clinical opinions being a source of confusion. Some clinicians in our study directly recognized how different opinions could impact a family and explained how this might be avoided. Research from Miller et al.[36] suggested that when parents of children with heart disease perceive an increased number of people providing information, it is associated with poorer evaluation of communication and a decrease in preparedness for decision-making about their child's care. As suggested by one of the clinicians in our study, we agree that better documentation and reading of notes from previous physicians is the most effective tool to minimize conflicting opinions.

Unfortunately, greater systemic issues, such as the financial challenges of travelling for care, poor local physician understanding of paediatric cardiology, and lack of parental or child support services, including those from the provincial nonprofit organization depending on the region, are resulting in a worse experience of care for families away from BCCH in our study population. Parents in our study who lived away from Vancouver mentioned that access to events by the nonprofit organization and other support groups within their local community was one of their desired supports. Existing research about accessing surgical care in rural British Columbia has shown that transportation and financial barriers are the most common barriers to accessing care outside of the local community.[37] The social worker we interviewed explained that at BCCH social work support is offered only by referral, and it is not a service offered to everyone. Considering the importance of the social work team in organizing the supports for families travelling to BCCH for paediatric cardiology care, providing everyone with a social work appointment, regardless of referral, may be an effective way to help address these challenges.

Supporting parents through their trauma

Parents in our study were deeply emotionally impacted by their child's diagnosis and surgery. Whether it was the shocking visuals of their child in the NICU, or watching their baby recover from open heart surgery, parents would carry emotional trauma into their lives going forward, which could become affective or anxiety disorders. While clinicians understood, empathized with, and offered supports, they could be mistimed or simply not the right type of support for the parent.

Our results agreed with a review of the literature by Kolaitis et al.,[38] who showed that the time of diagnosis and the weeks after surgery were stressful periods that impacted parental mental health. Parents consistently mentioned that while they felt their kids received world class care, they felt like their care was ignored. This is particularly concerning given that it is known that parents of children with CHD are at a greater risk for depression and anxiety than the general population.[10,38] In our study, multiple parents cited the birthing experience as negative. Parents who had already experienced childbirth shared that the experience with their child with CHD was different in that they felt like their own care became less of a focus of the experience. This may be related to the increase in operative vaginal deliveries in pregnancies for fetuses with CHD, as compared with the general population,[39] or a reduction in personal control during childbirth, which has been shown to be a significant predictor for women's satisfaction during childbirth.[40]

Clinicians in our study explained that while they are limited, there are some support services available for the parents of children with CHD. These include referrals to counselling, connecting families with another heart family, and a referral to social work. However, these supports are only offered to parents around the time of birth or surgical repair. Multiple parents in our study did not feel ready to access counselling services around the time of their child's diagnosis, and so declined the services. They later came to regret this decision, as they had to seek these services on their own. We suggest that it would be beneficial to offer social work referrals and explore a desire for counselling or therapy for parents a few years after diagnosis, as multiple parents reported that they did not begin to seek these services until they had settled into a routine with their child's health care needs.

Physical activity: encourage it early and often

Caterini et al.[23] suggest that physicians should implement 3 tenets when approaching PA promotion for children with CHD: (1) physicians should provide recommended physical activities and restrictions, (2) physicians should provide personalized written exercise prescription for the patient and family, and (3) they should regularly follow up to ensure adherence to the recommendations and monitor patient responses to the increased PA level.[23] Cardiologists in our study reported providing recommendations on PA and clarity on restrictions, but written exercise prescriptions were seldom used, and instead, a referrals to an exercise physiologist were made for this purpose. In addition, there were clear differences between when clinicians in our study first started discussing PA and limitations, and whether it was something that they discussed at every visit.

All parents in our study reported being told to encourage PA as much as possible for their children, but some specifically mentioned being told at the time of diagnosis. There are potential advantages to this: first, counselling on PA as early as possible can prevent parents from minimizing PA in their infants. For example, multiple parents in our study mentioned that their child's surgical repair impacted their ability to engage in tummy time, which is a form of PA recommended for infants <6 months of age that is associated with gross motor development.[41] Parents in our study explained that their child showed signs of pain while on their tummies and reported that even years after the surgical procedure, these infants/toddlers avoid tummy time. This is in line with existing research on tummy time in infants after cardiac surgery, where parents feared causing distress to their infants by lying them prone, even though parents are recommended to lie their children prone 2 weeks after surgery.[42] In addition, parents in our study described their toddler stopping to catch their breath after running around; regardless of whether these episodes of dyspnoea are related to their hearts or not, these parents did not discourage PA in their toddlers and cited that they felt comfortable letting their child play because of their cardiologist's recommendation. Cardiologists who wait until their paediatric patients reach their school-age years (ie, 3-5 years old) to begin PA counselling may be missing out on early habit formation.

In addition to PA counselling differences, paediatric cardiologists in our study referred their patients to exercise physiology at different times and for different indications; however, most of their referrals to exercise physiology were for patients who were experiencing limitations in their capacity for PA. Some of the cardiologists mentioned that they make referrals for sedentary patients to receive exercise prescriptions and felt that the exercise physiologist can provide a more tailored prescription and offer more time for counselling. Two clinicians in our study suggested that a proactive approach to exercise physiology referrals for an exercise prescription, by making them in early childhood, may be a more effective way of combatting sedentary behaviour in children with CHD, rather than a reactive approach targeting sedentary adolescents. Considering the potential benefits to starting PA counselling at diagnosis (eg, increased postsurgery tummy time and unrestricted PA for toddlers with CHD), potential downsides to waiting to change behaviour in adolescence (eg, motor development has already been delayed and interests are solidified), and some of our interviewed clinicians' recommendations, we suggest discussing PA with parents early and at every visit, and incorporating exercise physiologists and exercise prescriptions before beginning grade school.

Two parents in our study spoke about how they encourage their children to exercise without limitation because of how they were inspired by Olympians with CHD. Although professional athletes are often seen as role models in popular culture, research into the efficacy of using sport role models to encourage PA in youth is limited.[43] This is an area that requires further research before making recommendations on providing professional role models as role models for children with CHD.

Limitations and future directions

A major limitation of this study was that none of the parents included in this study lived in the northern health region, which is the largest health region in BC by area, services approximately 300,000 people, and includes the communities farthest away from BCCH.[44] Families in the north face unique challenges in receiving health care in general, and insight into their experience would be beneficial for health care administrators and providers to better optimize care.

Our sample was very affluent as 75% of parents reported an annual family income greater than $100,000, whereas the median household in BC is $85,000 as per the last census.[45] Families of children with CHD, especially those with complex CHD, face a number of expenses associated with ongoing care;[46] if the families who participated in our study were more representative of Canadian families with low socioeconomic status, we may have uncovered an alternative set of themes. This is particularly true with regards to PA participation, which has been shown to be impacted by socioeconomic status.[46] In addition, all the participants interviewed either delivered or received care at BCCH. Therefore, themes drawn from this research may not be applicable to other health regions or children's hospitals.

Conclusions

This study offers insight into the complexity of caring for children with CHD, highlighting the need for changes to how and when information is communicated to parents and the introduction of support mechanisms to help process trauma and cope with caregiving stress. In addition, we explored some existing barriers and potential solutions to the issue of low PA rates in children with CHD, with a focus on counselling earlier and more often. We are hopeful that findings can inform health care professionals, advocacy groups, and government agencies on providing education, emotional support, resources, and PA counselling more effectively.

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Ethics Statement

The study was approved by the University of British Columbia Okanagan Behavioural Research Ethics Board (H23-00114).

Participant Consent

The authors confirm that written informed consent has been obtained from all participants for this study.

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Supplementary Material

To access the supplementary material accompanying this article, visit *CJC Pediatric and Congenital Heart Disease* at https://www.cjcpc.ca// and at https://doi.org/10.1016/j.cjcpc.2024.10.006