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Parenthood against the clock: Experiences of being a parent with congenital heart disease - A qualitative study

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A R T I C L E I N F O

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A B S T R A C T

Background: Most people with congenital heart disease (CHD) now reach adulthood, and many wish to become parents. However, many in this group struggle with health challenges and are at risk for complications related to their heart disease early in life. What parenthood means for adults with CHD is still an unexplored area.
Objectives: Describe experiences of being a parent with CHD.
Methods: Ten semi-structured interviews with six women and four men were conducted using an inductive approach. Inclusion criteria: (i) visiting a CHD clinic at least once after age 18 and (ii) having biological children. Data were analyzed using qualitative content analysis, from a manifest level to deeper latent interpretation.
Results: The results comprised three themes. *The complex emotional landscape of parenthood* covered how heart disease became a tangible concern after becoming a parent, making life feel fragile. *Strategies for navigating life as a parent* illustrated how participants dealt with parenthood by adapting to their limitations and accepting their present and future. *Sharing eases life's challenges* described the participants' need to be met as whole person facing both physical and emotional challenges.
Conclusion: The heart disease became visible in the daily lives of parents with CHD, both as a tangible reminder and in a physical sense. Healthcare professionals should address physical and emotional challenges, as parenthood can heighten awareness of personal vulnerability. The study underlines the need to inquire about support and counseling needs, as parenthood for adults with CHD can add an extra dimension to life's challenges.

1. Introduction

Parenthood has been described as one of the most overwhelming experiences in a person's life, with challenges at different levels and different contexts [1]. Studies show that people with chronic ill health consider parenthood to have made their lives richer [2], but not being the primary parental caregiver in all situations can also bring sorrow [3–5]. Congenital heart disease (CHD) is a structural heart defect developed in the fetal stage, occurring in approximately 1 % of children [6]. Due to improved pediatric cardiac care, the survival rate in high-income countries has risen dramatically in recent decades, and over 95 % of children with CHD will now reach adulthood [7,8]. The increased chances of survival have led to more women with CHD choosing to become pregnant, and this trend is expected to continue [9]. Previous research on parenthood and CHD has focused on morbidity and mortality in pregnancy and childbirth [10,11], while research focusing on parenthood from a longer perspective is still limited.

How individuals are affected by their heart disease partly depends on the complexity of the lesion [12]. However, all adults with CHD can expect to need lifelong follow-up care since complications can develop later in life [13–15]. Research also shows that this group experiences accelerated aging [14,16–18], with a median age at death of 64 years [16], and those with severe CHD face an even shorter lifespan [13,16]. Despite the severity of the heart condition and the risk of facing health challenges in life, there is an increasing trend of adults with CHD becoming parents [19]; indeed, women with CHD consider parenthood to be a victory against their heart disease [20]. However, in addition to their desire to have children, adults with CHD also wish for support from healthcare professionals in the early postnatal period [20,21], and many have concerns about the transmission of genetic risks to their children [20,22].

For all these reasons, it is essential to explore the issue of parenthood

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among adults with CHD. Existing qualitative research has predominantly centered on women despite the fact that parenthood is an experience shared by both parents. This study, therefore, included perspectives from both male and female parents with CHD to provide a comprehensive understanding of parenthood within this population. Thus, the aim is to describe the experiences of being a parent with CHD.

2. Methods

2.1. Study design and participants

To explore the experiences of parenthood with CHD, semi-structured interviews employing an inductive approach were conducted and analyzed using qualitative content analysis [23]. This methodology facilitated a step-by-step progression from manifest data analysis to latent interpretation and understanding. The participants comprised six women and four men with structural CHD who had biological children, who had visited a CHD clinic in Sweden after turning 18, and who spoke Swedish. Each participant had 1–3 children aged 2–18 years (average: 8 years). The division participants' lesion complexity is based on the ESC Guidelines [12]. Participants' characteristics are summarised in Table 1.

2.2. Data collection

Participants were recruited via nurses at the heart clinics who informed patients about the study and an online announcement by the Swedish Child Heart Association. Prospective participants contacted the first author via email for more details and to schedule an interview. A total of 13 individuals expressed interest in participating. However, two decided not to proceed after receiving the study information, and one did not fully meet the inclusion criteria. Study information and consent forms were sent by email and post, with written consent obtained before interviews. The research group developed an interview guide, which was slightly adjusted after one pilot interview. After seven interviews, the data became repetitive, with no new information emerging. Nevertheless, three additional interviews were conducted to ensure the robustness of the findings [24]. Interviews were undertaken mainly digitally, except for two in-person sessions. Participants were initially asked if they had questions about the study, followed by queries about their sociodemographic background and heart condition. Recordings began after these preliminary questions, using an analog Dictaphone. Participants were asked to describe their experiences of parenthood and their future expectations (Interview guide in the supplementary material). Interviews lasted 18—56 min (average: 31 min) and were conducted and manually transcribed verbatim by the first author.

Table 1
Overview of participants' characteristics.

Characteristics	Total number of participants = 10
Gender	
Female	6
Male	4
Average age	39
Min–Max	33–48
Occupation	
Full-time	8
Part-time	2
Place of residence	
Urban area	7
Rural area	3
Complexity of lesion	
Mild	1
Moderate	4
Severe	5
Symptoms of the heart disease	7
Cardiovascular medication	6

2.3. Analytical process

The analysis started with listening to and reading the interviews to ensure accurate transcription [23]. Subsequently, meaning units were identified, condensed, and analyzed into codes using a manifest approach to preserve their sense of meaning [23]. The first author and co-authors AB and AW independently analyzed one interview and compared their findings to ensure analytical consistency. Then, the first author analyzed the remaining nine interviews with support from the co-authors. The analysis involved repeatedly referring to the original text to ensure the integrity of the interview content. Once consensus was reached on the codes, the first author sorted and further abstracted the codes into sub-themes and themes (see Table 2 for an example). These were then refined in collaboration with the co-authors until a final agreement was achieved. Codes unrelated to the study's aim were excluded from the results. Swedish was used throughout the analysis to ensure the integrity of the data and to facilitate ease of reference. For the present study, quotations were translated from Swedish to English and presented to highlight the content.

2.4. Trustworthiness

In conducting this study, we considered the four validity perspectives: credibility, dependability, confirmability, and transferability [25]. Credibility was ensured by including participants from all over Sweden and by following the same interview guide in every case except for follow-up questions. Dependability was taken into account through discussions within the research group at various stages to ensure transparency and confirmability before reaching a final agreement on the results [26]. The authors, comprising three midwives and one cardiology nurse, all had experience in qualitative research and were all aware of their pre-understanding regarding the patient group and parenting in general. The findings reflect the experience of parenthood within the Swedish context, and the reader is left to decide whether these results can be transferred to other contexts.

2.5. Ethics

Approval was granted by the Swedish Ethical Review Authority (ref: 2021-02364), and the study adhered to the principles of the Declaration of Helsinki throughout the research process [27].

3. Results

Parenthood proved to be a transformative experience for all participants, evoking a mixture of great joy and fragility. The results comprised three themes and eight sub-themes (Table 3).

3.1. The complex emotional landscape of parenthood

Parenthood profoundly changed how the participants perceived their present and future. Before parenthood, they were often less preoccupied with their future, and the heart disease had less impact on their

Table 2
Example of the analysis.

Theme: Strategies for navigating life as a parent			
Meaning unit	Condensed meaning	Code	Subtheme
When we come home from school... She gets to watch TV, and I'm sort of asleep. But then, I usually lie next to her to be close.	When we get home from school, she watches TV and I sleep, but I lie next to her to be close.	When she watches TV, I lie next to her to be close.	Finding ways to be a present parent.

Table 3
Overview of themes and sub-themes.

Themes	Sub-themes
The complex emotional landscape of parenthood	Feeling gratitude since children were not a given Experiencing a sense of loss over physical limitations Living with constant worry
Strategies for navigating life as a parent	Finding ways to be a present parent Striving to accept life and prepare for the future Holding back to defuse the children's concerns Using one's own experiences
Sharing eases life's challenges	Professional counselling facilitates acceptance

lives. Love for their children and the sense of being needed gave life greater meaning and responsibility for the future.

3.1.1. Feeling gratitude since children were not a given

The joy of parenthood was palpable among the participants, who described their intense longing for children and their children as the highlight of their lives. The participants' children became a source of vitality, shifting the focus from themself to others. Parenthood was emphasized as significant, since, for previous generations of people with CHD, even reaching adulthood was not a given. However, being a parent was also seen as a societal norm and a choice that carried great responsibility. Due to their heart condition, the gift of having children was not taken for granted. Still, this newfound responsibility also led to concerns about their own health and the inherent risks of CHD. The participants struggled with feelings of selfishness, the prospect of dying prematurely, and guilt over hereditary consequences. They felt concerned that their children might endure the same hardships they had to endure.

> Participant 4. *"It never felt like a guarantee or a given that I could have children. So, there's great gratitude in that way, too. That it's worked out!"*

3.1.2. Experiencing a sense of loss over physical limitations

Parenthood was described with mixed feelings involving great joy but also a lingering sense of sadness at the constraints imposed by CHD. However, the participants perceived themselves as typical parents, with their children as a natural and significant part of their lives. Parenthood was expressed as an unexpected but fun adventure, albeit filled with unforeseen events that could drain energy reserves and lead to increased fatigue. They reflected how complicated it was to imagine parenthood before having children and the unrealistic expectations. Parenthood ended up being more difficult than expected. Parenthood also gave hope of fitting in like everyone else in the parenting norm, but for some participants, the heart disease became more apparent instead. Dealing with young children was described as exhausting; the physical demands combined with sleep deprivation could lead to daytime tiredness and a greater tendency to arrhythmias. Teenagers were more independent, but this brought new challenges since older children followed an active lifestyle that was difficult to keep up with. The participants expressed sadness about the inability to fully engage in their children's active lives, explaining that the societal norm was to be a sporty parent, especially a sporty dad. Feelings of envy were also described, as their co-parents could participate in activities and games that they could not.

> Participant 1. *"I feel sadness that I cannot participate in some things. The other day, my daughter wanted to go out and run 5 km. It was very important, but none of her friends could go with her. I told her I really couldn't do it. And so my husband went. They were out running, and she was very happy afterward. They'd done it together, but I can't do it."*

3.1.3. Living with constant worry

The participants had a range of concerns about how heart disease could reshape their daily lives. Some of the participants were just concerned about general co-morbidities later in life and did not think their heart disease would affect them much at present. However, others worried about the potential impact of heart disease on their ability to be present in their children's future, describing thoughts of death and catastrophic feelings. The participants had been told their biological clock was ticking faster, which produced stress. The idea of additional heart medication was depressing and hard to accept, as it felt closer to the ultimate solution of heart transplantation. Surgeries were also perceived as very stressful due to the risks. Despite their fears, the participants strived to move forward in life amidst their health challenges; their main goal was to survive their children's childhood.

> Participant 6. *"I feel some concern as well. I want to be able to support my daughter in the future, too. And it doesn't always feel like I'll be able to do that."*

3.2. Strategies for navigating life as a parent

The participants managed life by adapting to their limitations and taking advantage of their heart disease experiences. Acceptance was an essential aspect of overcoming challenges and managing parenthood.

3.2.1. Finding ways to be a present parent

The participants faced different degrees of restrictions due to their heart conditions and hence followed different routes on their journey of adaption to life. However, they emphasized the importance of making the most of life and were aware of the unpredictable nature of their health. Sharing everyday moments with their children had profound meaning and was far more important than larger events. In planning their everyday lives, they strategically conserved their energy reserves for the sake of their children and sought out activities and environments that allowed them to participate actively without undue strain. Strategies included quiet pursuits, being out in nature, assuming roles like goalkeeper during football matches, or simply indulging in reading. One mother recounted the intimacy of lying beside her daughter, sharing a quiet moment while watching TV after a long day at school.

> Participant 6. *"When we come home from school... She gets to watch TV, and I'm sort of asleep. But then, I usually lie next to her to be close."*

In order to be a present parent and cope with daily challenges, the participant's partners, along with support from extended family and network, played a crucial role in coping with daily challenges. They emphasized that it was challenging to understand their need for support before parenthood, which varied depending on the condition of their heart disease. They discussed the societal aspect of support and pointed out that if they needed help, they had to take the initiative to organize it themselves.

> Participant 1. *"In parenting, you are usually two, so you can share it. The things I can't do, there is usually someone else who can do."*

3.2.2. Striving to accept life and prepare for the future

In terms of their own and their children's futures, a central aspiration among the participants was maintaining good health and prolonging their lives for as long as possible. They expressed that they did their best to live in a healthy way. However, they also stressed the importance of independence and self-confidence in their children, knowing they might not always be present as parents. Amid the uncertainties, the participants highlighted the importance of embracing the present and resisting overthinking the future. They emphasized acceptance, realizing that nobody could predict what the future held. The most important thing was to be happy with their own lives.

Participant 4. "*Nowadays, I try not to overthink the future. It feels like you need long-term planning, of course. But still try to be more present here and now.*"

3.2.3. *Holding back to defuse the children's concerns*

The participants varied in how much they told their children about their CHD, but they hoped and believed that their heart condition would not negatively impact their children. Those whose heart disease had minimal impact on their lives used a strategy of not telling their children much about it. Others also used the strategy in order to protect their children from unnecessary anxiety. One participant chose to tell very little about her heart condition, minimizing its importance and effectively navigating between two different lives: one characterized by her heart condition and one reflecting a conventional life. The participants described how their children commented on their breathlessness but usually accepted their slower pace. Events such as medical interventions raised uncertainty about how to communicate with their children, especially given the stress of the situation and concerns about their children's ability to cope in their absence. In such situations, the participants prioritized their children's well-being over their own and hence downplayed the seriousness of the situation to prevent unnecessary anxiety. One participant reassured his child that the intervention was simple despite being terrified himself.

Participant 9. "*Like, but it's not that bad. It's a standard thing... and you're extremely scared yourself. I don't want him to be stressed out.*"

3.2.4. *Using one's own experiences*

The participants' own childhood experiences with CHD also shaped their parenting style, leading them to avoid worrying about minor issues and to adopt a broader perspective on life due to past and present challenges. They also mentioned that their earlier encounters with healthcare professionals helped them support their children during their medical appointments. Living with CHD provided them with a profound understanding that life can vary significantly.

Participant 5. "*I think you become a good parent if you've had a hard time. I think you're a good parent otherwise, too, but it becomes a bit more multifaceted if you've had a bit of trouble.*"

3.3. *Sharing eases life's challenges*

Participants emphasized the importance of sharing emotional challenges and everyday life as a parent. Since parenting brought new challenges regardless of the heart disease, medical interventions such as surgery or worsening of the heart disease could become too heavy to bear alone.

3.3.1. *Professional counselling facilitates acceptance*

Emotional loneliness was recurrent in the interviews, and the participants expressed a desire to process their lives. They described a general lack of emotional support in connection with surgeries, physical limitations, and the worsening of their heart disease. Having children was explained to increase these worries. One problem was that the heart clinic was concerned with their heart, the maternity clinic was responsible for their pregnancy, and either nobody or yet another party took care of their feelings, as heart clinics did not routinely offer personal counseling. Sharing thoughts and concerns with other individuals with CHD was deemed essential. However, as everyone faces their own difficulties, it could also be challenging to open up about one's own struggles. A few participants had sought psychological support, which they found to be transformative, altering their perspective on life and influencing their approach to parenthood.

Participant 9. "*Before and after surgery, I'd have appreciated having someone to talk to. Because there's a lot going on in your head when you're having surgery, you think a lot. And there's never been anybody who was in charge of it like that.*"

4. Discussions

This study provides new knowledge regarding the experiences of being a parent with CHD. The results reveal a duality between the participants' great joy about parenthood and their sense of fragility after becoming parents. The participants described their children as something never taken for granted, which may explain their deep sense of gratitude. This sentiment aligns with earlier research on parents with cystic fibrosis, who also expressed the joy of living their dream of parenthood [2]. However, the accelerated aging faced by participants in the current study became a significant concern, mirroring previous findings that concerns about the end of life intensified with age [3]. Limitations in life were described with sadness, again in line with previous studies highlighting the challenges of fitting into children's active lives and the disappointment of not always being the most involved parent [3–5].

A strategy that was emphasized in both our results and earlier research was the importance of taking time with their children between stressful daily routines [3]. Our participants described the parental norm as being physically active; this may be due to unrealistic portrayals of parenthood in social media, as described in earlier research [28,29]. Unrealistic ideas of parenthood may occur because preparations often focus primarily on childbirth, leaving significant gaps in knowledge beyond that point [28]. Previous research from Sweden emphasizes the importance of providing access to parental information through easily accessible channels [29]. However, the current findings show that there is still a gap between individuals and eventual support.

Our results also highlight the importance of addressing both physical and mental health simultaneously to help patients cope with life challenges and the heart disease. This need for integrated support has been previously emphasized by both pregnant women with chronic disease and young individuals with heart failure, who describe a wish for physical and mental care to be provided simultaneously [30,31]. Moreover, research indicates that cognitive therapy can reduce psychological distress in adults with CHD [32]. Given these findings and recognizing that heart disease adds another dimension to parenthood, we recommend that healthcare professionals should inquire about the need for support and offer counseling to adults with CHD, particularly those who are current or prospective parents.

4.1. *Strengths and limitations*

This study used semi-structured interviews, which is a valuable method for describing experiences in a specific context [33]. To enable participants to share their unique experiences, the questions were designed to broadly address parenthood without specifically mentioning heart disease. However, as participation was voluntary, it is possible that the results primarily reflect the situation among a subgroup of the target population who have great eagerness to discuss their situation. Most of the interviews were conducted on a digital platform, which may have made communication more challenging, as subtle nuances can be missed when not meeting in person. However, the virtual setting may also have helped participants feel more at ease, making them more comfortable discussing difficulties during the interviews [34].

5. Conclusions

This qualitative study describing experiences of being a parent with CHD shows that participants felt a desire to be treated as whole persons with both physical and mental life challenges. CHD became more tangible in the participants' lives after becoming parents, causing them to reflect on their future life expectancy and instilling a sense of life's fragility. They expressed sadness at being unable to participate fully in their children's active lives but tried to find ways to participate on their own terms. Our findings underscore the importance of healthcare professionals addressing both physical and emotional challenges, as parenting can heighten awareness of one's own vulnerability. We, therefore, suggest broad collaboration between different professional groups and emphasize the need for health professionals to be aware of and inquire about the need for counseling, as parenthood may add an extra dimension to life's challenges for adults with CHD. There is a need for further research on multidisciplinary care to increase knowledge on best practices for holistic support, but also longitudinal studies on parenthood for adults with CHD as both parents and children age.

CRediT authorship contribution statement

Ylva Holstad: Writing – review & editing, Writing – original draft, Validation, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Agneta Westergren:** Writing – review & editing, Validation, Methodology, Formal analysis, Conceptualization. **Maria Lindqvist:** Writing – review & editing, Validation, Methodology, Formal analysis. **Annika Bay:** Writing – review & editing, Validation, Supervision, Project administration, Methodology, Funding acquisition, Formal analysis, Conceptualization.

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Declaration of competing interest

Ylva Holstad declares to have no competing interests.
Agneta Westergren declares to have no competing interests.
Maria Lindqvist declares to have no competing interests.
Annika Bay declares to have no competing interests.

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Appendix A. Supplementary data

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