



Navigating healthcare during a pandemic: what parents of CHD children want healthcare professionals to know

Original Article

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Abstract

Background: The COVID pandemic has had deleterious effects on the mental health of the global population. Parents of children with CHD were particularly vulnerable to negative mental health outcomes such as depression, anxiety, and perceived stress. A better understanding of the CHD parent experiences, needs, and concerns while navigating the healthcare system during a pandemic is needed. **Methods:** Online survey responses from 71 parents of young children with CHD representing families across the United States of America and Canada were analysed. Qualitative data were collected one year into the COVID pandemic. Thematic analysis was used to examine responses to the open-ended question “What would you like healthcare professionals (doctors, nurses) to know about your experience of being a parent with a child with CHD during the COVID-19 pandemic?” **Results:** Two major themes with subthemes and an umbrella theme emerged from the parents’ responses (1) Pandemic Parenting: The Emotional Toll of Hospital Visitation Restrictions, Dealing with Social Distancing, Feeling Isolated, Decision Making in Uncertainty, and Playing it Safe versus Returning to Normal and (2) Unmet Expectations of Care: Needing Information, Wanting Empathy, Requesting Respect, Questioning Care Quality, and the umbrella theme of: Our Lives were Turned Upside Down. **Conclusion:** CHD parents describe a negative impact of healthcare-related challenges during the COVID pandemic. These findings may offer insight to how healthcare professionals can better support the mental health and care burden of CHD parents during future pandemics.

Introduction

The COVID pandemic has had deleterious effects on the mental health of the global population.¹ Caregivers were particularly vulnerable to the negative impact on mental health. Approximately one year into the pandemic, parents caring for young children in the United States of America were more likely to report adverse mental health symptoms than adults without caregiving responsibilities.² Parents of children with chronic conditions such as CHD had an even higher rate of negative mental health outcomes such as depression, anxiety, and perceived stress.^{3–9} Support and respite have been identified as key protective factors against the stress from the care burden.^{2,6,10}

Navigating the healthcare system posed additional challenges for parents of children with medical conditions during the pandemic.^{11–19} Hospitals implemented policies to minimise the risk of COVID-19 exposure including restrictions on the number of family members allowed to accompany a sick child during medical visits and hospitalisations.²⁰ The presence of family and friends can provide a key source of support and respite for parents during their child’s hospitalisation.^{6,21} Although COVID-19-related healthcare policy changes were necessary to maintain safety, more information is needed about how these policies, along with state risk reduction mandates introduced impacted the experiences of parents of children with CHD. Understanding the challenges, needs, and concerns of parents navigating the healthcare system for children with CHD during a pandemic is crucial.

In January 2023, a research study⁶ examined self-reported anxiety, depression, stress, support, and resilience in parents of young children with CHD during the COVID pandemic. Using standardised instruments and quantitative data analysis, this research provided evidence of a significant mental health burden in parents of children with CHD. Anxiety, depression, and stress were reported at higher levels than general population norms. This study described a positive association between exposure to certain risk factors (COVID-19 stressors and CHD care-related factors) and anxiety symptoms, depression symptoms, and perceived stress. In contrast, emotional support, informational support, and resilience were found to be protective against these adverse mental health outcomes.

The survey concluded with an open-ended question intended to capture the subjective experience of parents of children with CHD. Specifically, participants were asked “What would

you like healthcare professionals (doctors, nurses) to know about your experience of being a parent with a child with CHD during the COVID-19 pandemic?" The aim of this report is to examine the qualitative data collected from this open-ended question in order to provide a richer understanding of CHD parents' experiences engaging with the healthcare system during the pandemic.

Materials and methods

An online survey was used to collect data on the subjective experiences of parents of young children with CHD. After obtaining study approval from the IRB, participants were recruited using social media platforms of CHD parent support groups. Parents were directed to Research Electronic Data Capture (REDCap); a web-based application developed for clinical research projects to obtain informed consent and participate in the anonymous survey. Data collection was conducted from February 2021 through August 2021, approximately one year into the COVID pandemic. Seventy-one out of the 151 parents in the original study submitted a response to the open-ended question at the end of the survey. The participants in the study represented families from across the United States and Canada. (See Table 1)

A phenomenological approach to the data analysis was utilised to understand the parent experience. This process involved weeks of consensus building and constant comparison of the data among two researchers. First, the narratives were read and reread many times to become familiar with the data and identify meaningful statements or phrases. Second, the meaningful statements or phrases were coded with special attention to *in vivo* (exact quotes), gerund (action phrases), and emotion (expression of feelings) coding. Third, the codes were put into categories that represented groups of similarly coded phrases. In the fourth and final stage of the analysis, themes and subthemes were created from the data. Direct quotes representing each subtheme were identified to ensure the themes were accurately supported by the data. In addition, the number of participants who described experiences in each theme and subtheme was counted to report the frequency and the relative weight of the themes. Bracketing and reflection were key strategies utilised by the researchers throughout the process to minimise bias and ensure trustworthiness.

Results

Two major themes with subthemes and one umbrella theme (see Figure 1) emerged from the parents' responses to the open-ended question "What would you like healthcare professionals (doctors, nurses) to know about your experience of being a parent with a child with CHD during the COVID-19 pandemic?":

- (1) Pandemic Parenting: The Emotional Toll of Hospital Visitation Restrictions, Dealing with Social Distancing, Feeling Isolated, Decision Making in Uncertainty, and Playing it Safe versus Returning to Normal.
- (2) Unmet Expectations of Care: Needing Information, Wanting Empathy, Requesting Respect, Questioning Care Quality.
- (3) Umbrella theme: Our Lives were Turned Upside Down.

Pandemic parenting

More than half of the participants (71.8%, $n = 51$) reported experiencing significant challenges caring for a child with CHD

Table 1. Demographics of participants ($n = 71$)

	n	%
Relationship		
Mother	71	100
Father	0	
Gender		
Female	71	100
Male	0	
CHD child age		
Birth to 12 months	20	30.8
13 months to 24 months	15	23.1
2 years to 5 years	30	46.2
CHD complexity ^a		
Simple	2	2.8
Complex	69	97.2
Marital status		
Married / Partnered	67	94.4
Divorced / Widowed	2	2.8
Single	2	2.8
Education		
High school graduate	4	5.6
Some college	17	23.6
Bachelor's degree	29	40.3
Master's degree	17	23.6
Doctoral degree	5	7
Income		
Less than 50K	15	21.4
50K–150K	39	55.7
More than 150K	15	21.4
Rather not say	1	1.5
Other children		
No other children	21	29.6
1 other child	31	43.7
2 other children	10	14.1
3 or more other children	9	12.7
Race		
American Indian	0	
Asian	4	5.6
White	63	88.7
Black	0	
More than one race	4	5.6
Not sure / Rather not say	1	1.4
Ethnicity		
Hispanic or Latino	7	9.9
Not Hispanic or Latino	63	88.7

(Continued)

Table 1. (Continued)

	n	%
Unknown	1	1.4
State of Residence		
United States ^b	55	79.8
Canada	13	18.8
Australia	1	1.4

n = 69 for state, n = 70 for income, n = 65 for CHD child age.

^aGuidelines from RACHS-1, Aristotle, and STS-EACTS CHD complexity scoring were used to determine complexity categories (Jacobs, *et al.*, 2008).

^bRepresenting the South, Northeast, Midwest, and West regions of the United States

during the pandemic. These narratives informed the creation of the theme “Pandemic Parenting” with five subthemes: (1) The Emotional Toll of Hospital Visitation Restrictions, (2) Dealing with Social Distancing, (3) Feeling Isolated, (4) Decision Making in Uncertainty, and (5) Playing it Safe versus Returning to Normal.

The emotional toll of hospital visitation restrictions

The most frequent feedback from parents contained descriptions of the impact of hospital visitation restrictions. Parents wanted health professionals to know how the visitation restrictions eliminated access to their sources of emotional support and negatively affected their ability to cope.

“Having both parents present during life-threatening open-heart surgery and recovery is *so so so* necessary. *Please please* don’t separate parents or make them choose who gets to see the child, it’s devastating.” (74)

The devastation experienced by these parents was seen clearly and consistently in their responses.

“Inpatient/surgery without allowing the other parent or support person was extremely hard and *felt cruel*. It was an overwhelming experience and to have to do it alone, made it even worse.” (94)

One mother shared her experience of caring for her child alone in the hospital after heart surgery,

“I spent my time trying to take care of him, alone, without my partner, as a first-time parent. His machines left him tethered to his bed, so we had about 9 square feet to interact in. It was incredibly lonely, overwhelming, exhausting, and, at times, cruel. While I understood the need for safety, it has devastating consequences on families.” (19)

Dealing with social distancing

Social distancing presented significant challenges for CHD parents. Parents reported feeling anger, frustration, and guilt from trying to simultaneously protect their CHD child and attend to the needs of their non-CHD children.

“I’m so overwhelmed and cautious I feel like the only way to be assured she won’t catch covid is to keep everyone from not going anywhere or do anything which puts a strain on my other children.” (34)

In an effort to keep their CHD child safe, some parents maintained social distancing even as the states began to lessen the COVID-related mandates.

“CHD parents know how to do hard, but this is a *whole new level of hard*. I’m sure it varies for everyone but the isolation and missed opportunities are overwhelming and depressing. Even if you have supportive people in your life, it is truly hard to find someone that can relate to the level of sacrifice that has occurred in the past year to keep our CHD kiddo safe. It’s taken a toll on everyone in our family. It feels like many families have given

up on any precautions and we don’t have that “luxury” We are constantly weighing the risks and benefits of *every.small.thing*.” (35)

Feeling isolated

Parents reported feeling isolated as a direct effect of the need to protect their CHD child.

“It has been extremely hard to isolate our family during the pandemic to protect our single ventricle child. She had to stop going to preschool and we had to stop social visits with friends and family to protect her from contracting COVID. I know this is hard for everyone, but it’s even more difficult with a CHD child.” (114)

For some, beliefs about how to safeguard their CHD child during the pandemic created conflicts within their relationships and contributed to a sense of isolation.

“I have ended long time friendships over the stupidity of people who refuse to take precautions and were claiming it is all a hoax or plot by a political party. This has added to the stress and sense of isolation while trying to shelter my CHD child.” (77)

Decision making in uncertainty

Parents expressed frustration and fear of the many unknowns related to COVID.

“The unknown about to what could happen if my child contracted the virus is overwhelming and has drastically altered the way we have lived our daily lives this past year.” (58)

They struggled with making decisions in the setting of uncertainty.

“The stress from having to make your own decisions with limited guidance and information about the affect covid19 has on children with CHD has been a big issue.” (103)

Playing it safe versus returning to normal

The pull between two opposing strategies for parenting was described in the responses. CHD parents began to see non-CHD families discontinue COVID risk precautions and yearned to be able to return to normal.

“We have pulled our son from preschool because of his cardiologists recommendation and it’s really hard. There is also fear of being left behind and isolated once most people are vaccinated and “get back to normal.” (106)

However, the view that their CHID child is vulnerable and needs continued protection seemed to take priority.

“I know family and friends sometimes question how cautious we are being and it’s hard to make decisions to not see people or partake in celebrations/gatherings, but every decision made comes after a huge weighing of risks. At the end of the day, she comes first and it’s not always fair, especially to our older son, but it’s just the reality we live in currently. It is what it is.” (147)

“We’ve played it very safe withholding her from daycare, celebrating holidays outdoors and I’m very fatigued by that all, but my mind always runs into “what if?” So, until we move on from this pandemic - we will continue to play it safe.” (174)

Unmet expectations of care

Over a third of the participants (38%, n = 27) conveyed the struggles they experienced navigating the healthcare systems and interacting with members of the healthcare team during the pandemic. These responses informed the creation of the theme “Unmet Expectations of Care” with four subthemes: (1) Needing

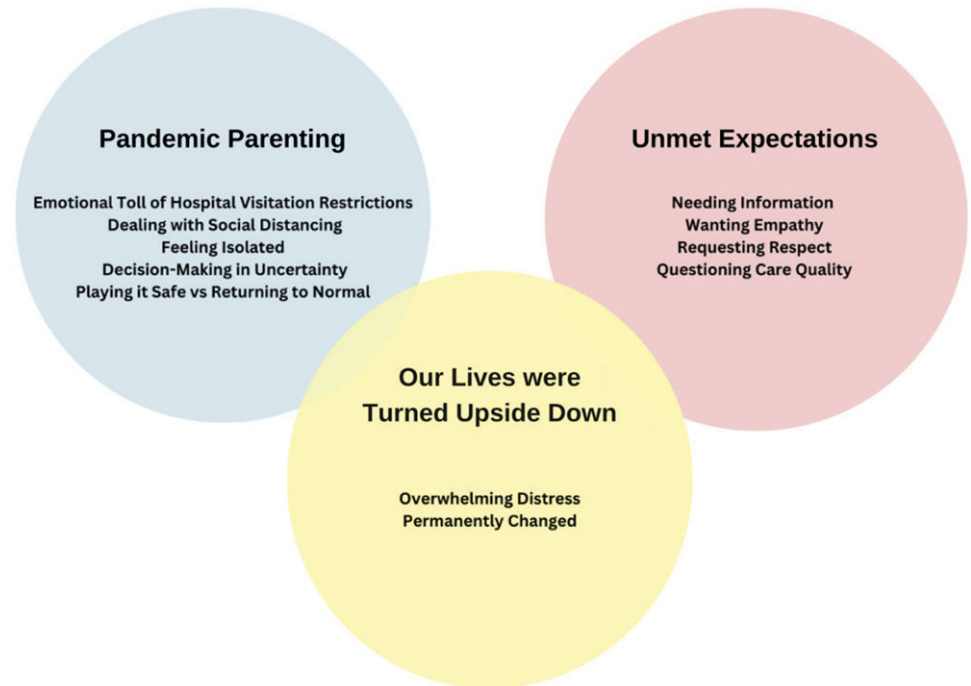


Figure 1. Navigating healthcare during the COVID pandemic: themes and subthemes.

Information, (2) Wanting Empathy, (3) Requesting Respect, and (4) Questioning Care Quality.

Needing information

Parental responses reflected experiences of insufficient information, conflicting information, absence of guidance, and searching for hopeful information. Parents wanted information about the potential impact of COVID on CHD children.

“The scariest thing when my heart warrior contracted COVID-19 was not knowing what the outcome would be. I’m a parent that thrives on any and all information. I want to know even the scary things. It’s my child - so please spare thinking you can terrify me when I’ve already seen her with her chest open.” (3)

At times they received conflicting information.

“We need A LOT more information about what high risk for covid means for our children. Different doctors and nurses tell us different things depending on who we talk with.” (106)

They expressed a desire for more guidance from healthcare professionals.

“I know there is always new research coming out and things are changing, and we just might not know yet, but having some guidance on when it is safe for our CHD child to meet his extended family would be helpful.” (122)

Some parents felt information about good outcomes would help decrease their fear.

“I don’t think we would have had so much fear of literally everything if we had some data showing some kids with CHD have done completely fine after contracting it. We continue to be safe, but I’m hoping there’s more things published regarding happy stories of kids with CHD vs. tragic.” (112)

Wanting empathy

Several responses included requests for healthcare professionals to be more understanding, patient, and supportive of parents struggling to care for their CHD child during the pandemic.

“I have found though that there are some that truly don’t seem to understand or empathize with (in my case at least) being not only a first-time parent, with a child with a CHD but also during a pandemic. It’s hard!” (97)

Parents wanted healthcare professionals to give more attention to the emotional needs of parents and children.

“I would like them to remember that they are not just their medical record, they struggle socially and emotionally. It would be nice to have a Social Worker reach out as well to help our kids and us parents with PTSD, anxiety, depression, etc. during this pandemic.” (160)

“As a healthcare professional, give parents an opportunity to address their concerns both medically AND emotionally so they can feel supported.” (179)

“... for the people who make the “rules.” Masks are BS. My child is already fearful at the hospital, and you take away the ability for her to see a smile and friendly face and it’s awful for her.” (36)

Requesting respect

The subtheme of respect emerged from the data. Parents wanted healthcare professionals to value their knowledge of their child, validate their concerns, listen to their opinions, and to be treated as a team member.

“We know our child. Please have some respect that a mom or dad’s gut instinct is often right! I wish sometimes doctors or nurses would stop holding the “I went to school for this, and you didn’t” over our heads! My son had many great doctors and nurses but there have been some that need that reminder!” (23)

“Many of us are “pros” when it comes to dealing with all things medical (hospital stays, medication, etc.). Our opinions and concerns need to be heard and addressed, even if you think we’re wrong (and sometimes we are). At the end of the day, you have the medical degree, but we have more first-hand knowledge and time with the patient than you do. More than anything, we just want to be a team with you.” (88)

“I have to work which means my CHD kid is in person at school. When I say this please don’t stop and stare at me. It makes me feel terrible.” (119)

“... we are always second guessing ourselves and some decisions cannot be rushed. Also, don't be offended when we ask about something we learned about from an online support group, that we would like to trial/learn more about.” (18)

“Don't be dismissive of concerns.” (71)

Questioning care quality

Quality of care during the pandemic was a concern for several of the participants. A negative effect on outpatient and inpatient healthcare encounters was reported.

“... we were lucky enough to get home from our inpatient stay (including 2 surgeries), in Jan 2020. Thank god we were out of the hospital before Covid shut down the ICUs. Our hospital only allowed 1 parent in the CICU for the first 6 months of covid. Please prioritize the mental health of parents dealing with CHD. We are looking forward to clinic visits without masks so our daughter can make a better connection with our doctors & nurses.”(126)

“It's not easy on parents and the babies. A pediatric cardiologist is often never able to answer questions related to basic pediatric care and vice versa. Because of my babies heart condition, I need to see multiple doctors and multiple therapists. It has not been easy during the pandemic to maintain these appointments or receive proper care.” (85)

“Going to appointments alone with no support, seeing restriction rules not being followed by some, but being strictly enforced for others, not giving the time to explain if Covid truly is a danger to my child (lots of brushing off), or having completely mixed messaging about that topic.” (97)

“The major struggle occurred after our daughter was born, there is very poor care and consideration given to postpartum parents. We were not able to be together, resulting in me not being able to adequately care for my own needs and only care for those of our CHD baby who had surgery at 4days old.” (90)

“Even in healthcare, I often see doctors/nurses with their noses out of masks and things of the like which add to my level of stress. As a parent, I do whatever I can to protect my child... seeing protocols not followed triggers my anxiety.” (163)

Our lives were turned upside down

The additive effect of the COVID pandemic while parenting a child with CHD in terms of magnitude, devastation, and disruption was described in many of the parents' responses (86%, n = 61). This pervasive experience is represented by the umbrella theme titled “Our Lives Were Turned Upside Down”.

“I feel like we are a forgotten group that are very directly affected by the pandemic. Our whole lives were changed drastically again and turned upside down just as we were already grasping reality as a heart family to begin with... It has been a nightmare.” (1)

Reports of overwhelming distress were threaded through the majority of the narratives. Parents used words and phrases such as “terrifying” (84), “one of the biggest/frightening things in my life” (21), “the hardest thing in my life” (136), “insurmountable” stress (40), “devastating” (153), “... constant worry and stress about protecting your child is overwhelming.”(122)

One mother described the effect the pandemic had on her life as a CHD parent.

“Due to our distance from the hospital we moved to the city for the duration of her inpatient, this meant that it was only my husband and myself to support one another, but the hospital rules stated that only one parent could be in the hospital at a time. This resulted us not seeing one another in person for longer than a few minutes as we traded off. We went from 9 months of working from home and only having each other, to living in a

new city and not having access to our only support. We weren't allowed any exceptions; we weren't even allowed to have my husband come and help move us out on discharge day making what should have been a happy day an incredibly stressful experience. I thought having a medically fragile child would be my biggest concern, but really it was the stress of all of the covid restrictions.” (90)

In addition to the significant emotional toll, parents wanted healthcare professionals to understand the lasting effect from the experience.

“Having to learn about CHD on the fly, as well as trying to understand Covid while worrying about my child with virtually no support has been the most overwhelming experience of my life and has permanently changed me. Please understand this and consider it.” (97)

Discussion

This study identifies key themes that emerged from qualitative analysis of the question, “What do parents of children with CHD want healthcare professionals to know about their experiences one year into the COVID pandemic?” Participants described how the challenges of parenting a child with CHD during a pandemic combined with unmet expectations from the healthcare staff led to overwhelming distress. CHD parents explained how hospital policies such as visitation restrictions and social distancing mandates eliminated access to much needed support systems resulting in parental distress and isolation. These results are consistent with earlier observations during the pandemic in which parents of children with chronic health conditions reported that hospital visitation policies contributed to increased stress, decreased support, feelings of isolation, and difficulty coping.^{21–23} These findings offer implications for how hospital policy could be revised in future pandemics. Furthermore, interventions that support respite for parents of hospitalised children are needed.

Parents reported a lack of COVID-specific information and guidance from healthcare providers. As a result, they struggled with decision-making demands during a time of uncertainty and found themselves pulled in opposite directions; between the need to protect their child while also wanting desperately to return to normal. As highlighted by other pandemic researchers,^{21,24–27} CHD parents want consistent and reliable information. Specifically, parents want healthcare professionals to provide clear and proactive communication that is specific to CHD care during a pandemic.²⁷

Distress related to caregiver burden and the need for respite for parents of children with health conditions during the pandemic was seen in these results and has been reported in several other studies.^{18,23,28–29} A request for empathy and respect from healthcare professionals was threaded throughout the parental responses. Similar to the other findings, CHD parents wanted to feel support from the healthcare team and have increased access to mental health services.^{21,23,24,27,30,31} As one mother stated, “I've been incredibly lucky that our doctors/nurses/medical team have been extremely supportive and compassionate/caring. It made the situation at least a LITTLE BIT easier to navigate. It really does make a huge difference.” (153)

Limitations

Although study participants represent parents from across the United States and Canada, the use of convenience sampling resulted in a relatively homogeneous sample. Despite the use of snowball sampling, racially diverse parents, single parents, and

fathers were underrepresented. This selection bias limits the generalisability of the results.

Conclusion

These findings provide important insights into the mental health and caregiver burden experienced by parents of children with CHD during the COVID pandemic. With a greater understanding of the parental experience, healthcare professionals can begin to implement interventions to support the mental health and promote resilience in CHD parents. There is a call to action to revise visitation restrictions, improve communication, support respite, and increase empathy in preparation for future pandemics.

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Ethical standard. The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national guidelines on human experimentation at the University of Washington and with the Helsinki Declaration of 1975, as revised in 2008, and has been approved by the institutional committees at the University of Washington.

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