

COVID-19 impact on adults with congenital heart disease self-perceived vulnerability and coping

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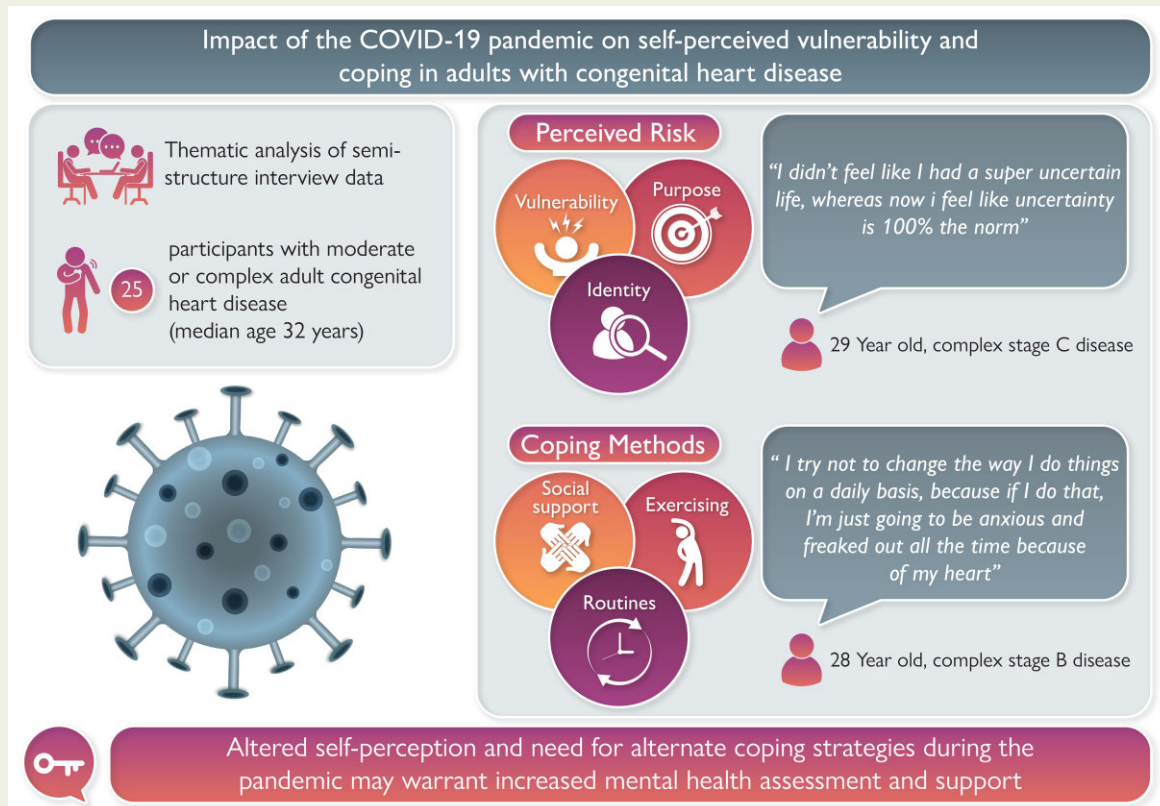
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The COVID-19 pandemic poses risk for worsened quality of life in patients with adult congenital heart disease. In a qualitative thematic analysis of semi-structured interviews conducted July 2020 to August 2021, we examined the pandemic's impact on participants' ($N = 25$) experiences with self-perception and coping. All had moderate or complex disease; median age 32 years. The pandemic altered some participants' self-perception, including increased vulnerability beyond heart-attributed risk. Restrictions frequently prevented participants from using their usual coping strategies, forcing use of alternative methods. For an already at-risk population, these findings suggest the need for increased mental health awareness, assessment, and support.

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Graphical Abstract



Keywords

Adult congenital heart disease • COVID-19 pandemic • Coping • Qualitative research

Novelty

- The COVID-19 pandemic increased feelings of vulnerability beyond that conferred by participants' adult congenital heart disease, affecting self-perception of risk for about one quarter of participants.
- Pandemic restrictions prevented the use of existing coping strategies (84% of participants); therefore, participants were forced to identify and develop new methods of coping during a time of high stress.

Introduction

Patients with adult congenital heart disease (ACHD) live with a chronic, lifelong illness, and many experience significant symptom burden related to physical, cognitive, or emotional challenges. The psychosocial impacts of ACHD are acknowledged barriers to good quality of life in this population,¹ including altered relationships and prognostic uncertainty. The ACHD also affects patients' identities and life choices, and mental health concerns like anxiety and depression are prevalent and often undertreated.² Despite recognition of these difficulties, little is known about patients' strategies for coping with this chronic illness.

The COVID-19 pandemic caused abrupt changes to patients' personal lives and access to medical care. Early COVID-related publications and a statement by the European Society of Cardiology³ appropriately focused on medical-risk assessment and physical health outcomes for patients with ACHD.^{4,5} This population, particularly those with worse disease, is considered 'high risk' for adverse physical outcomes related to COVID infection. Recommendations therefore include strict adherence to pandemic mitigation strategies in an effort to avoid infection. However, the psychosocial impacts of these restrictions on patients with ACHD have not been studied, including patients' experiences with challenges such as disease-related uncertainty and social isolation. We aimed to describe the

psychosocial effects of the COVID-19 pandemic on the experiences of patients with ACHD, focusing on self-perceptions and coping.^{6,7}

Methods

We conducted a qualitative study of patients with moderate or complex ACHD between July 2020 and August 2021, with the primary intention of describing participants' experiences with resilience and strategies for coping with ACHD-related stress. Participants were recruited from an ACHD subspecialty clinic in the northwestern USA, where restrictions included business closures, gathering restrictions, and mandatory masking. Purposive sampling, applied in four recruitment rounds, was used to ensure diversity in age, sex, race, ethnicity, insurance coverage, and ACHD severity; adequate representation was achieved with 25 interviews. Of 75 eligible participants, 10 declined, primarily due to lack of interest or time. Following enrolment, 25 one-on-one, semi-structured interviews were conducted (J.M.S., A.C.B.) by phone ($n = 16$) or video-conference ($n = 9$), per participant preference. Saturation was reached, based on coping and resilience themes in the primary study. When discussing coping, interviewers asked whether the pandemic affected how they handle challenges, manage heart health, or think about their heart. Interviews ranged in length from 34 to 76 min and were voice recorded and professionally transcribed. Demographic information and ACHD diagnosis were obtained from electronic medical records. One interviewer (J.M.S., a cardiologist) had previously encountered some participants in the clinical or research setting; however, no long-term relationships existed.

We used thematic analysis⁸ to analyse interview data. The interviewers (J.M.S., A.C.B.) wrote collaborative memos to organize impressions and generate an initial codebook. All instances addressing the pandemic were identified; the primary analyst (J.M.S.) abstracted these segments, generating a code report of narratives from all participants. Key concepts were distinguished through iterative codebook application to the excerpts and synthesized into themes, which were refined and agreed upon by two additional coders (E.A.B., V.F.). This study was approved by the University of Washington Institutional Review Board and conforms with the principles outlined in the Declaration of Helsinki (*Br Med J* 1964;ii:177). Participants provided informed consent.

Results

Participants' median age was 32 years (range 22–44 years, [Table 1](#)). The ACHD lesion was classified as moderate⁹ (56%) or complex (44%); 76% of participants were functional Class C or D, indicating moderate or worse functional impacts. Around 52% were females, and 28% self-identified as a race or ethnicity other than non-Hispanic white.

The COVID and related pandemic mitigation strategies affected participants' perceived sense of vulnerability ([Table 2](#)): roughly one quarter of participants expressed feeling that the pandemic exacerbated their self-perception of risk for poor health outcomes. Some noted a shift in self-identity, feeling vulnerable, and 'high risk' in a way they had not previously felt despite living with ACHD.

'It makes me feel that I'm a lot more vulnerable than others when it comes to health and I've never really looked at myself that way ... you do feel the vulnerability when there's something threatening the population, because you're not the strongest person when you have congenital heart failure'.—38 years old, moderate Stage C disease

Table 1 Participant demographics

Characteristic	N (%)
Age (years), median (range)	32 (22–44)
ACHD lesion	
Moderate	14 (56)
Severe	11 (44)
ACHD physiology	
B	6 (24)
C	18 (72)
D	1 (4)
Female	13 (52)
Race and ethnicity ^a	
Non-Hispanic white	18 (72)
Black	1 (4)
Hispanic/Latino	4 (16)
American Indian/Alaskan Native	1 (4)
Mixed	1 (4)
Education	
High school or equivalent	6 (24)
Some post-high school	6 (24)
College degree	9 (36)
Graduate degree	4 (16)
Insurance	
Public	9 (36)
Private	14 (56)
None	2 (8)

^aSelf-identified by participant.

Two participants reported gaining new perspectives on their existential life purpose, stepping out of 'autopilot', and wondering if they should be doing something more meaningful with their lives. Conversely, 48% (12/25) did not express a feeling of increased vulnerability. Some noted that this was because they were already accustomed to living with a chronic illness, having previously faced thoughts of their own mortality, or having been isolated for health reasons. Some expressed that they had already decided not to let their ACHD stop them from 'living their lives' as fully and as normally as possible, and for this reason did not feel additionally exposed. For one participant, COVID seemed less threatening than her pre-existing heart health-related anxiety.

The COVID impacted participants' ability to use their typical coping strategies ([Table 2](#)): 84% (21/25) of participants reported that pandemic restrictions altered the way in which they coped with stress. Few participants reported minimal change; these already spent most of their time at home due to illness, unemployment, or previously working from home. Being prohibited from exercising outside the home was the most common lost coping strategy, followed by loss of external social support related to isolation practices.

'You can't see family. I can't travel over to see my family. And that's very hard for me because I go all the time throughout the year. That has caused me more stress on my heart than me actually thinking I'm

Table 2 Key participant quotations**COVID affected participants' sense of vulnerability**

[Previously], when I thought of myself as a vulnerable population, I thought of it more as because I was pregnant not, 'Oh, and you have this heart condition.' Which is strange, ... a double whammy. When I had a heart appointment during my pregnancy, one of the cardiologists said, 'Yeah, it's good that you're being extra cautious because you are a vulnerable population, because of your heart condition.' I was like, 'Oh, yeah.'—32 years old, moderate Stage C disease

Before COVID, I was just like, 'Oh, I have this job, it's just a job to me, but I'm getting by and I'm reasonably happy.' Then COVID happened, and then we all kind of had to ... confront the idea that we could get a terrible disease and die. I think, when I was kid, having to go through sort of a realization that I could die, it had some positive effect. It had some self-actualization in, it granted me some immediacy. I would say that that's what that did for me now, is, I feel like I do actually need to do something.—25 years old, moderate Stage B disease

My family was told to prepare for this, prepare for that. 'He may not make it to this age and that age'. So I've been preparing the whole time through my life because my mother shared this with me. ... And I don't know if that helped or hurt me, but I'm not going to sit here and pass my life in fear. I'm aware of the COVID... but I try not to live my life thinking, 'Oh, well I got to be super cautious in this and that'. So I try to live my life, and go through my daily routine, without thinking of it too much.—44 years old, moderate Stage D disease

I am one of the numbers of person that would totally die if I got it. I respect that deeply. And I've changed my life a little bit for that, but no more than anybody that was already expecting to die tomorrow... I laugh with my friends, like, 'Wouldn't it be weird if I lived all this extra time, and then this stupid thing got me?' It's a waste of a defeat of all these other, bigger diseases in my life I've conquered.—37 years old, complex Stage C disease

It's funny because I never saw my heart condition as ... It never caused that much unsettling uncertainty. There was always uncertainty, but it was enough able to be put in the back of my head. I didn't feel like I had a super uncertain life whereas now I feel like uncertainty is 100% the norm.—29 years old, complex Stage C disease

COVID impacted use of existing coping strategies

Just going to the gym that was such a big stress relief for me and anxiety, and not only that, but it was a healthy thing for me to do, you know? Now, that I don't have that, my anxiety and depression has really gotten worse since then, because I don't have that outlet anymore.—29 years old, complex Stage C disease

Living with this heart condition for as long as I have, it's kind of like I know my limits and I know how to keep myself healthy. ... But I try not to change the way that I do things on a daily basis, because if I do that, I'm just going to be anxious and freaked out all the time because of my heart.—28 years old, complex Stage B disease

I don't know if you've heard of it, but TikTok. It helped me with my loneliness and not being able to go out. I didn't expect to be on TikTok or anything, but I needed something. It was a way to be social with people. We were able to do things socially that we couldn't do outside of our homes with COVID.—39 years old, moderate Stage B disease

It's this constant loop of this in the back of your head you're going to die. Like this, 'Today's the day'. Any little palpitation you feel, any chest pain. Even though you feel it on a daily basis, and you have your whole life. It's still, 'Today's the day you're going to die'. ... Just anything I think that can get our minds off of that loop. And when everything's shut down, it's very difficult.—22 years old, complex Stage C disease

When something happens, I immediately start to brainstorm how am I going to feel better, or how am I going to make sure this isn't happening every day. I think COVID has definitely tested that, just from taking away the gym for me, and pretty much every routine... it's definitely made me have to be resilient in a different way.—24 years old, complex Stage C disease

going to get the virus and die'.—22 years old, complex Stage C disease

The disruption of daily routines was a major stressor. Over a quarter of participants reported feeling a resultant loss of control or purpose, and some reported an increase in stress and health-related anxiety or depression. For newly jobless participants, the loss of routine was more distressing than lack of income.

Only a minority of participants were able to identify ways in which they were better able to cope in response to the pandemic: three described coming to the realization that their jobs were unfulfilling, one felt more comfortable with health-related uncertainty, and another described learning how to feel grateful for even small accomplishments. Some participants also reported using coping mechanisms similar to those they used for managing their ACHD, accepting their physicians' recommendations and feeling this would keep them in good health.

Discussion

This study's most significant finding is that a quarter of participants experienced shifts in self-perception, including feelings of increased vulnerability, during the first year of the COVID-19 pandemic. This shift occurred even though participants had already previously learned to live with a chronic, life-limiting illness. Although not reported by all, these findings are concerning because the ACHD population is already at risk for adverse psychosocial outcomes including poor quality of life. This pandemic-related stressor has been postulated,^{3,10,11} but not previously reported in this population, and may be similarly experienced by other chronic illness populations.

An additional important finding is participants' reports of forced changes to coping with stress, and the associated increase in psychological distress. While these changes are not surprising, the loss of routines, physical exercise, and social support—known important

coping strategies—may have detrimental long-term mental health consequences. This finding aligns with existing studies in this population. Children's decreased physical activity during the pandemic¹² has been postulated to create concern for future quality of life and cardiovascular risk. Additionally, three studies conducted outside the USA^{11,13,14} describe harmful impacts of pandemic isolation on patients' emotional states. In a report from the APPROACH-IS II study, Moons *et al.* describe worry, stress, and fear felt by patients related to the pandemic, though effects on patient-reported outcome scores were minimal. Another study noted persistently elevated psychological distress by December 2020/January 2021 compared with March/April 2020 despite a return to baseline stress.¹⁵ Our study expands these findings with qualitative analysis of such emotions and their associated impacts, including effects further into the pandemic.

A recent scientific statement³ recommends that ACHD clinicians increase efforts to discuss psychological well-being during clinic visits and encourage positive coping strategies. This is echoed by Cousino *et al.*,¹⁰ who reported pandemic-related psychological stress and urged referral to mental health services when appropriate. Our study provides additional evidence that the COVID-19 pandemic has made it harder for patients with ACHD to manage stress and, perhaps more concerning, caused them to question their identity.

These findings emerged as part of a larger study of patients who received care at a single American institution. There were common and unique elements of participants' experiences, stressors evolved rapidly, and we could not account for changes in participants' mental health over time,^{15–17} so findings may not be fully generalizable. Additional research is necessary to fully characterize these effects.

Conclusion

These findings suggest the need for focused action, such as increased assessment and support of patients' mental health, to prevent long-term damage. Awareness of patient perceptions described here is an important foundation for developing strategies to promote adequate coping in this population.

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Data availability

Data are available on request.

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