



# Experiences of fetal care, social support, and emotional functioning during the COVID-19 pandemic in women carrying a fetus with CHD

## Original Article

Priya Nigam<sup>1</sup>, Colette Gramszlo<sup>1</sup> , Shubhika Srivastava<sup>1,2</sup> and Erica Sood<sup>1,2</sup> 

**Cite this article:** Nigam P, Gramszlo C, Srivastava S, and Sood E (2024) Experiences of fetal care, social support, and emotional functioning during the COVID-19 pandemic in women carrying a fetus with CHD. *Cardiology in the Young* **34**: 1045–1051. doi: [10.1017/S104795112300358X](https://doi.org/10.1017/S104795112300358X)

Received: 30 January 2023  
Revised: 6 July 2023  
Accepted: 31 August 2023  
First published online: 7 December 2023

**Keywords:**  
Psychosocial; qualitative; mental health

**Corresponding author:**  
Erica Sood; Email: [Erica.Sood@Nemours.org](mailto:Erica.Sood@Nemours.org)

<sup>1</sup>Nemours Cardiac Center, Nemours Children’s Health, Wilmington, DE, USA and <sup>2</sup>Department of Pediatrics, Sidney Kimmel Medical College of Thomas Jefferson University, Philadelphia, PA, USA

### Abstract

**Objective:** To explore how the COVID-19 pandemic affected fetal care, social support, and emotional functioning for women carrying a fetus with CHD. **Method:** This was a single-centre qualitative study of 31 women who received a prenatal diagnosis of CHD during the pandemic. Patients completed semi-structured interviews about their experiences with fetal care, social support, and perceptions of risk to themselves and their fetus. Consistent themes regarding the impact of the pandemic were identified using an inductive thematic approach. Demographic data were collected via self-report and chart review. **Results:** Women generally reported consistent access to fetal care throughout the pandemic, with frequent use of telemedicine in addition to in-person care, but negative impacts resulting from restrictions on family support at appointments. Limited access to social support overall and a loss of pregnancy traditions were described. Many women reported feeling isolated and experiencing worries and fears about COVID-19 but also noted feeling supported by their healthcare team. Partner/family support during appointments and connection to peer-to-peer support were identified as recommendations to mitigate negative impacts. **Conclusion:** Women carrying a fetus with CHD during the COVID-19 pandemic experienced unique stressors that may affect mental health. However, many also experienced unexpected supports that may mitigate effects of pandemic-related stressors. Results can inform efforts to promote positive family outcomes during and following the COVID-19 pandemic.

### Introduction

The novel coronavirus, or COVID-19, was characterised as a pandemic by the World Health Organization in March 2020.<sup>1</sup> The COVID-19 pandemic has had a wide impact, greatly affecting the healthcare industry as well as mental well-being.<sup>2,3</sup> Changes to healthcare practices were instituted across all fields of medicine during the early phase of the COVID-19 pandemic, including paediatric cardiology and fetal echocardiography. For example, the American Society of Echocardiography recommended performing only urgent and emergent fetal echocardiograms and deferring or rescheduling elective or non-urgent exams.<sup>4</sup>

Studies prior to the COVID-19 pandemic documented heightened anxiety levels among women presenting for fetal echocardiography<sup>5</sup> and found that anxiety further increases when CHD is detected.<sup>6,7</sup> Women carrying a fetus with CHD are known to be at high risk for stress, anxiety, and depression<sup>5–8</sup> and these difficulties often persist or even intensify during the postpartum period. Additionally, studies have suggested that perinatal mental health may impact fetal brain development and child neurodevelopmental outcomes<sup>9–12</sup> which are already negatively affected by a diagnosis of CHD.

The extent to which the COVID-19 pandemic has further affected this already vulnerable population is not known. While the impact of the pandemic on patients with CHD and their families has been investigated,<sup>13</sup> existing research has not focused on the lived experiences of women carrying a fetus with CHD. Often, referrals made for fetal echocardiography due to concern for possible CHD are time sensitive and cannot be postponed, as this impacts counselling for the family and may change pregnancy decisions based on in utero and postnatal outcome predictions. It is likely that this population experienced unique pandemic-related stressors. Thus, we aimed to evaluate the subjective experiences of women who presented for fetal echocardiography and received a diagnosis of fetal CHD during the COVID-19 pandemic.

### Materials and methods

#### Patients

Patients were 31 women who presented for an initial fetal echocardiogram and received a diagnosis of fetal CHD between March 2020 and June 2021 at a paediatric hospital in the

Mid-Atlantic region of the United States of America. Patients were referred for fetal echocardiogram by 12 maternal fetal medicine practices across 3 states. To be eligible for the study, patients had to be 18 years or older, English-speaking, and at least 10 days postpartum at the time of the interview in order to reflect back on the entire pregnancy following the fetal CHD diagnosis. Women who had normal fetal echocardiograms, terminated the pregnancy, or had fetal demise were excluded.

### Procedures

This study was approved by the Nemours Institutional Review Board, and electronic informed consent was obtained prior to study procedures. Patients completed a 30-minute semi-structured individual interview by phone. The interview was structured into three domains. Domain 1 focused on the perceived risk of COVID-19 to the woman and her fetus, domain 2 on the perceived impact of the pandemic on prenatal or fetal care, and domain 3 on the perceived impact of the pandemic on social networks and support. Interviews were audio-recorded and transcribed, and deidentified transcripts were uploaded into Dedoose Version 9.0.46 (SocioCultural Research Consultants, LLC; Los Angeles, California). Patients also completed a demographic questionnaire, and maternal and child clinical characteristics were extracted from the electronic medical record.

### Data analysis

Qualitative data from interviews were analysed using an inductive thematic approach, which focuses on patients' subjective perceptions, feelings, and experiences.<sup>14</sup> The codebook was developed through an iterative process that involved discussions between team members regarding code identification and application. The first several interview transcripts were coded by three team members, after which discrepancies were discussed, code applications were clarified, and the codebook was refined. Another four interview transcripts were then independently coded by the two primary coders (PN, ES) with intercoder reliability of 0.81 (pooled Cohen's kappa coefficient). The remaining transcripts were divided between the two primary coders. Consistent themes and representative quotes were identified from coded data. Thematic saturation was reached by the 9th interview, but all 31 interviews were completed to ensure that the sample was sufficiently diverse on socio-demographic and clinical characteristics.

## Results

### Patient characteristics

Sixty-nine women were eligible for the study. Of these, 32 enrolled and 31 completed the study (45% of eligible women). Twenty-seven women could not be reached by phone, seven expressed interest but could not be reached to complete the consent process, and three indicated that they were not interested in participation. Socio-demographic and clinical characteristics of patients are displayed in Table 1. The study sample was diverse regarding race and ethnicity (42% racial or ethnic minority), socio-economic status, education level, type of fetal CHD, and child clinical characteristics. All interviews, with the exception of one, were conducted after the child with CHD was discharged from the hospital.

**Table 1.** Maternal and child characteristics.

Maternal characteristics (N = 31)	Frequency (%) / Median (1Q–3Q)
<b>Ethnicity</b>	
Non-Hispanic/Latino	28 (90)
Hispanic/Latino	3 (10)
<b>Race</b>	
Caucasian	18 (58)
Black or African American	9 (29)
Asian	1 (3)
Other	3 (10)
<b>Annual household income</b>	
<\$50,000	10 (32)
\$50,000–\$75,000	8 (26)
>\$75,000	9 (29)
Prefer not to answer	4 (13)
<b>Education</b>	
Did not finish high school	1 (3)
High school degree	14 (45)
Associates degree	5 (16)
Bachelor's degree	6 (19)
Graduate degree	4 (13)
Prefer not to answer	1 (3)
Maternal age at first fetal echocardiogram (years)	31 (26–35)
Gestational age at first fetal echocardiogram (weeks)	23 (21–25)
Time from referral to fetal echocardiogram (days)	6 (2.5–8.5)
<b>Child characteristics (N = 31)</b>	
<b>Frequency (%)</b>	
Underwent cardiac surgery or intervention	24 (77)
Cardiac surgery/intervention <1 month of age	17 (55)
<b>Congenital heart disease diagnosis</b>	
Ventricular septal defect	6 (19)
Ebstein's anomaly	2 (6)
Hypoplastic left heart syndrome	2 (6)
Atrioventricular canal defect	3 (10)
Double outlet right ventricle	2 (6)
Pulmonary stenosis	2 (6)
Tetralogy of Fallot with pulmonary atresia	2 (6)
Tetralogy of Fallot with pulmonary stenosis	3 (10)
Tetralogy of Fallot with absent pulmonary valve	1 (3)
Interrupted aortic arch	1 (3)
Left ventricular dysfunction†	1 (3)
D-or-L looped transposition of great arteries	4 (13)
Partial anomalous pulmonary venous return	1 (3)
Coarctation	1 (3)

†Secondary to complete heart block.

### Qualitative themes

Eight themes relating to the impact of the COVID-19 pandemic were identified from qualitative data. Themes were structured by type of impacts including impact on fetal care, impact on access to social networks, and emotional impact. Two additional themes focused on recommendations for clinical teams to mitigate impact. Representative quotes corresponding with each theme and percentages of patients describing each theme are displayed in Table 2. Many themes were described by the vast majority of patients with a range of socio-demographic and clinical characteristics. However, thematic patterns based on socio-demographic characteristics were explored for specific themes in which there were contrasting views (e.g., use of telemedicine) or for which less than two-thirds of patients described the theme (e.g., feeling supported by the healthcare team). Additionally, differences in emotional impact based on CHD severity (i.e., whether or not the child required neonatal cardiac surgery or intervention) were explored.

Psychosocial impacts of fetal CHD diagnosis not directly related to the COVID-19 pandemic were also described during the interviews. Many women reported that the CHD diagnosis was unexpected, highly emotional, heartbreaking, and sometimes hard to believe. Some women reported initially being in denial or grappling with the questions of “why?” and trying to understand what would happen after birth. While important to the experiences of women carrying a fetus with CHD and consistent with prior research,<sup>15,16</sup> psychosocial impacts not directly related to the COVID-19 pandemic were considered outside the scope of the present study and did not contribute to the themes below.

### Impact on fetal care

#### Consistent access to care

Most women perceived minimal to no disruption in their access to obstetric, maternal fetal medicine, and paediatric cardiology care during the pandemic. They noted that healthcare teams appeared to be working hard to find alternatives to continue providing the same level of care. Some women commented that it was actually more convenient to access care and schedule appointments, as routine appointments in the cardiology clinic were cancelled or postponed, and fetal echocardiography appointments for women with low risk were deferred. Others noted that they felt they received more attention from providers and were more of a “priority” than they would have otherwise been prior to the pandemic. However, two women felt that care became more limited or that they received a lack of attentive care with “excuses due to COVID”, and that their prenatal visits felt socially distanced and “closed off”. A few women also commented that at times it was difficult to reach their obstetric clinic as they were short staffed due to the pandemic.

#### Use of telemedicine

Two-thirds of women reported experiencing one or more telemedicine appointments during the pandemic, with contrasting views regarding the use of this platform. Half of women who experienced telemedicine felt that conducting appointments via telemedicine remained personal and direct, and their questions were addressed and answered satisfactorily. They also felt these types of appointments allowed for more flexibility with their work schedules, allowed them the convenience of not having to drive long distances to appointments, and in some instances, made them feel safer not having to leave the house so often for appointments.

Telemedicine appointments also allowed for partners or other family members to participate, which was often prohibited for in-person visits during the pandemic. However, the other half of women who experienced telemedicine noted limitations. Some reported that there was less emphasis on how they were doing emotionally as compared to in-person visits and that the visits felt impersonal. Some also stated that the telemedicine experience felt “different” and that they would have preferred seeing their medical team in-person to feel more connected, especially OB visits to have their blood pressure checked or hear their baby’s heartbeat. Technical challenges were also described related to poor internet service and a tendency for sound to cut out when multiple people spoke simultaneously. Of note, as compared to women who reported predominantly positive experiences with telemedicine, those who reported negative experiences tended to have a lower household income (<\$50,000: 50% vs. 20%) and were more likely to be from a racial or ethnic minority group (60% vs. 20%).

#### Restrictions on support people at appointments

Most women reported that their experiences of fetal care were affected by restrictions on support people accompanying them to appointments. This created additional challenges as women reported having difficulty relaying complex information to their partners or remembering to ask all of their partners’ questions. Many women did note that they were allowed to have their partner present at fetal cardiology appointments, but not obstetric or maternal fetal medicine appointments. For some, it was their first pregnancy and they commented on not being able to have their mothers with them to ask questions that they did not know to ask. For women with older children, many noted that they could not bring their children with them to appointments and had difficulties finding childcare with the social distancing restrictions or felt unsafe leaving their children with other caregivers due to COVID-19. Being alone during prenatal appointments also had a significant emotional impact, as described below.

#### Impact on access to social networks

##### Limited access to social support

Most women described limited access to their support networks due to social distancing restrictions during the pandemic, both during and outside of appointments. Many emphasised that not having the emotional support of family members during their appointments or during the harder times of their pregnancy made the experience more difficult. Even outside of appointments, women were not able to access their social networks as they normally would and felt that they did not have the family support they were used to having. They reported relying on FaceTime and Zoom to connect with their families and friends. A few women commented that their families, who had been planning on coming to help either during their pregnancy or after the baby was born, had to cancel their trips. Some women commented that later in the pandemic, family members started to see each other again, especially during the holidays. This became difficult for women carrying a fetus with CHD who were trying to remain strict with COVID-19 protocols and social distancing recommendations to protect themselves and their fetus.

##### Loss of pregnancy traditions

Several women described feeling the loss of “normal” pregnancy traditions. They were unable to go shopping for baby products in stores, plan baby showers, or celebrate their pregnancy with family

**Table 2.** Qualitative themes and representative quotes.

Theme (% endorsed)	Representative quotes
<b>Impact on fetal care</b>	
Consistent access to care (90%)	<ul style="list-style-type: none"> <li>“... I felt like highly monitored. I felt like more of a priority. Even though... there was limitations.” Study ID 21</li> <li>“... if anything, because they weren't taking regular appointments... it was actually kind of easier to schedule.” Study ID 7</li> </ul>
Use of telemedicine (68%)	<ul style="list-style-type: none"> <li>“... it was actually very convenient and that way it was guaranteed that me and my husband could both be involved, so I kind of liked that... they still made everything very professional, very personal.” Study ID 27</li> <li>“... it's difficult to connect with someone over the phone or not get flustered in a video and not be able to ask all the questions we had planned on asking... when you're in person you can kind of both talk at the same time and still hear what everyone is saying, but telemedicine, you have to... take turns because otherwise you're talking over someone they can't hear you... I don't like them.” Study ID 19</li> </ul>
Restrictions on support people at appointments (94%)	<ul style="list-style-type: none"> <li>“... [my mom] wasn't there, husband wasn't there. And I tried to facetime, but the service [wasn't] great... You're trying to listen to a conversation that you already can't comprehend in person.” Study ID 8</li> <li>“... we had my other son and we... didn't have anybody who could watch him because we were being so strict about COVID-19. So that was that was just kind of rough... not being able to bring my husband or having to stress to find someone to watch my son or coordinate with my husband over... work schedules... that was just kind of stressful, always having to switch my schedule around or try to get my husband to manage our other son while I was off at this test... that part was hard just because your circle [was] so limited.” Study ID 15</li> </ul>
<b>Impact on access to social networks</b>	
Limited access to social support (90%)	<ul style="list-style-type: none"> <li>“... my family... everyone was supposed to be coming out while I was pregnant because I had tried for two years to get pregnant at that point... they all had to cancel their trips.” Study ID 19</li> <li>“... having the emotional support of family members on FaceTime during some of the harder things would have been a little bit better for me, but... I wasn't able to have that...” Study ID 21</li> </ul>
Loss of pregnancy traditions (19%)	<ul style="list-style-type: none"> <li>“... you're not running into the chance of sitting in the waiting room with another pregnant mom, some other woman could have been going... through this the same time as me, but I'll never know it because we were not in there together. We didn't meet in the lobby and become best friends... those experiences are lost because of the pandemic.” Study ID 8</li> <li>“... You can't enjoy it with your family... I couldn't go shop... I [couldn't] look at baby things in the store... no, it was terrible.” Study ID 8</li> <li>“I really relied on... FaceTime and zooming people. That's how we talked to most of our family and friends while the pandemic was happening... So I didn't really even see anyone in person while I was pregnant... it was like I was never even pregnant.” Study ID 9</li> </ul>
<b>Emotional impact</b>	
Feeling isolated (74%)	<ul style="list-style-type: none"> <li>“... because of restrictions with COVID-19, I could not have my husband there. So, finding out by yourself that your child has a heart defect... that was definitely very hard... I finally got back to the car and called my husband that was obviously a very hard, an emotional conversation to have... it felt a lot harder emotionally not having that support person with me because of restrictions of having people at ultrasound with you.” Study ID 5</li> <li>“... it was really scary... it wasn't pleasant at all... that 20 [week] anatomy scan is supposed to be... exciting... where you get to find out the gender and then... something's not right... and you're in a pandemic so you're by yourself... my partner couldn't come into any of the scans with me... I had to call him at work and, you know, I'm crying, he's driving, leaving work and you... don't know what it is...” Study ID 16</li> </ul>
Worries and fears about COVID-19 (84%)	<ul style="list-style-type: none"> <li>“... once he was born, we didn't know how intense the problem was going to be so we weren't sure how the virus – if one of us were to get it and give it to him, or someone else around us were to give him, we didn't know how it could be for him since his heart condition... that was scary.” Study ID 12</li> <li>“I did get the vaccine when I was pregnant. Which I felt... nervous about doing since there wasn't a lot of research on it. But at the same time with [my baby] having the [heart defect], and also with my other daughter here, I felt like it was our best route of action. So I [felt] a little bit better that hopefully she might still have some type of protection from that.” Study ID 26</li> </ul>
Feeling supported by the healthcare team (61%)	<ul style="list-style-type: none"> <li>“... it was nice to go and vent to them and I felt like they were actually listening and could relate and were understanding... they knew that me being in lock down was safest, but they also were recognizing how difficult that was and I never felt pressured to do it a certain way for anyone's benefit... they were very supportive.” Study ID 19</li> <li>“... finding the comfort, finding the... support that we did need definitely did come from the cardiac unit... taking care of me emotionally being a pregnant mother with a child with a heart defect in the middle of a pandemic, I was very much taken care of emotionally and any questions I had... they were ready to answer them.” Study ID 5</li> </ul>
<b>Recommendations to mitigate impact</b>	
Partner and family support during prenatal appointments (29%)	<ul style="list-style-type: none"> <li>“I wish [my husband] would have been allowed in at appointments... when you're going through something like that, you need more support than just a doctor, you need your partner, because you can't bring anyone else obviously. So if you're not seeing anybody and you and your partner are the ones going through it all it would be really nice to be able to have them with you as much as you can because it's a lot of information to take in...” Study ID 19</li> </ul>

(Continued)

Table 2. (Continued)

Theme (% endorsed)	Representative quotes
	<ul style="list-style-type: none"> <li>“... the only thing would have been allowing him to the visits. I mean, that really, really made it tough because it really isolated me because... I wasn't seeing family or friends really and then having to go to all these appointments by myself, you know, and... it's even more [isolating] because... a lot of the appointments, it was just like bad news...” Study ID 16</li> </ul>
Connection to peer-to-peer support (10%)	<ul style="list-style-type: none"> <li>“If they could have any kind of way of... moms who would agree to the next time someone comes in whose going through the same thing to buddy up, or just give them the number to text, talk about it. I think that would be very helpful because it really, really, really helped me not be as scared and concerned.” Study ID 4</li> <li>“... one of her coworkers... went through the same situation as me. And I actually reached out to her and thanks to her she gave me positive words... she... gave me suggestions of how to feel and to not panic and even explained how... my son was gonna look when I went to the hospital with all these wires and she actually explained each wire that the baby will have. I mean, that support that they gave me it was really, really, really helpful.” Study ID 31</li> </ul>

and friends. Some women noted that they were not able to share their pregnancy journeys with their own mothers, like they otherwise would have. One woman stated that it was like she was “never even pregnant”, as she was not able to see friends or family while pregnant and had already delivered her baby by the time she saw friends again. Two women expressed that if they had been able to see their friends and family on a regular basis, they would have been able to share their pregnancies more and receive additional support.

### Emotional impact

#### Feeling isolated

Many women reported feeling isolated and alone during their pregnancies and described the social isolation that resulted from the pandemic as extremely difficult. Many women felt like they went through everything alone when they really needed their support system, especially when receiving a diagnosis of fetal CHD. Women stated it was emotionally difficult to hear that news by themselves and then relay that information again to their partners and families. Several women recalled crying to their partners in the car or over the phone as they tried to explain what they had been told. Some women described feeling anxious leading up to subsequent appointments as they feared that they would hear that something else was wrong with the baby while alone. A couple women also described having to deliver alone due to testing positive for COVID-19, which they described as scary and isolating. Of note, there did not appear to be differences in feelings of isolation based on the severity of the CHD diagnosis.

#### Worries and fears about COVID-19

Most women reported experiencing worries and fears about COVID-19. They worried about contracting COVID-19 during pregnancy as they had more hospital and clinic visits than they otherwise would have with a normal pregnancy. There was worry about what would happen to the fetus with CHD if a woman contracted COVID-19 while pregnant, as well as worry about their child with CHD getting COVID-19. Some women also worried about being separated from their baby after birth if they were to contract COVID-19. For women who were pregnant at the beginning of the pandemic, there were many more unknowns, including when vaccines would become available and whether they would be recommended while pregnant or breastfeeding. Given these fears and unknowns, many women described taking extra precautions to ensure they were not more exposed than necessary, including staying isolated from family and friends.

Of note, there did not appear to be differences in worries and fears about COVID-19 based on the severity of the CHD diagnosis.

Many women did report feeling less anxious with the strict COVID-19 precautions that they saw at the hospital or clinic. Some noted that the COVID-19 pandemic played a large part in their decision-making regarding where to continue their care depending on which doctor's offices or hospitals were following COVID-19 protocols carefully and being cautious. As vaccines became available, a few women recalled feeling hopeful that their babies might have some additional protection, which eased their worries. As more information about COVID-19 became available, women recalled feeling like it was a “little less scary”.

#### Feeling supported by the healthcare team

Many women reported feeling supported by their healthcare team while carrying a fetus with CHD during the COVID-19 pandemic. They felt as if a lot of time and energy was put into caring for them and their baby. Many women appreciated receiving acknowledgement from their providers about how difficult it was to receive a diagnosis of fetal CHD during a pandemic and the challenges of isolating from family and friends. They were also appreciative of having the healthcare team be available to answer questions, especially regarding the unknowns of COVID-19. Most women felt that their healthcare teams took appropriate COVID-19 precautions which they described as supportive and reassuring. A few women noted that their healthcare providers were some of the only people they saw due to social distancing restrictions, further emphasising the importance of the supportive role of the healthcare team. Of note, women who mentioned feeling supported by their healthcare team during the COVID-19 pandemic were less likely to be from a racial or ethnic minority group as compared to those who did not mention this support during their interview (31% vs. 58%). However, there did not appear to be differences in perceived support by the healthcare team based on the severity of the CHD diagnosis.

#### Recommendations to mitigate impact

##### Partner and family support during prenatal appointments

Many women reported wishing they could have had their partner, another family member, or their other children with them during their prenatal appointments. They expressed that having their partner or family member present would have helped them by providing much needed support. For other women, being able to bring their older children to appointments would have made the

process easier overall, as finding childcare was difficult with COVID-19 restrictions.

#### Connection to peer-to-peer support

Several women shared that having other women with whom they could talk about their child's CHD was extremely helpful. A few mothers recalled having co-workers or friends whose children also had CHD; being able to speak with these women helped expectant mothers prepare for their child's surgery, understand how their child might look after surgery, and calm their anxieties and fears. This resource was perceived as so valuable that all women who were able to find support in this way recommended that this resource be available to all women carrying a fetus with CHD.

#### Discussion

Women who receive a diagnosis of fetal CHD are at heightened risk for stress, anxiety, and depression.<sup>5-8</sup> This study highlights additional psychosocial impacts of the COVID-19 pandemic on this vulnerable population. While many aspects of prenatal care were adequately maintained during the pandemic, women described a pervasive feeling of isolation and a severe emotional impact from not being able to readily access support networks, including during fetal care visits.

The impact of the early phase of the COVID-19 pandemic on paediatric and adult patients with CHD and their families has previously been described.<sup>13</sup> Cousino et al found that nearly 40% of patients who were scheduled for cardiac surgery or catheterisation experienced postponement of these procedures during the early phase of the pandemic.<sup>13</sup> Many patients in the study expressed worry about contracting COVID-19 given their underlying heart disease and feared having to come to in-person clinic appointments. Patients desired more information about COVID-19 and risks regarding their healthcare as well as increased access to support groups. Women undergoing prenatal care and fetal echocardiography were not included in this prior study. In the present study, however, most of the women did not note any delays or disruption to their prenatal care. And while some women did note the increased flexibility that telemedicine visits provided, most reported feeling safe coming to clinic as they witnessed the COVID-19 precautions that were being taken. It may be that women perceived the necessity of fetal care as more important than the fear of COVID-19, given that many women were looking for a more definitive fetal CHD diagnosis at the time of their visits. Nonetheless, consistent with Cousino et al., women in the present study expressed a fear of becoming ill with COVID-19 and not knowing how this would affect their health, the health of their fetus, and in some cases their delivery plan. Additionally, there was also a desire for increased access to support groups.

Other studies have demonstrated the impact of the COVID-19 pandemic on children with a variety of health conditions and their families. Kazak et al developed a caregiver-report measure, COVID-19 Exposure and Family Impact Scales, to assess the exposure of children and families to events related to COVID-19, and the impact these events had on families.<sup>17</sup> Utilising this measure, the authors of this study found that one of the biggest negative impacts of the pandemic was on caregiver anxiety and mood. This was consistent with our findings as well, as many women highlighted feeling more anxious, stressed, and fearful of the "unknowns" with COVID-19. Further study of the COVID-19 Exposure and Family Impact Scales revealed that there was an impact on family ability to care for their other children, anxiety,

and access to healthcare.<sup>18</sup> Consistent with this prior research, women in the present study endorsed difficulties in caring for their older children, such as trying to find care for them while the mothers went to prenatal appointments, as well as increased stress and anxiety. Most women, however, did not have difficulty in accessing healthcare or scheduling appointments with their doctors, and in fact, some even mentioned that this became easier. Again, this finding highlights the unique aspects of fetal care. Fetal care is often more time sensitive, aims to predict in utero and postnatal outcomes, and informs perinatal care.<sup>19</sup>

Consistent with prior research, severity of the CHD diagnosis did not appear associated with the emotional impact of carrying a fetus with CHD during the pandemic. While mothers of children with CHD are known to have higher levels of stress, anxiety, and depression than mothers of healthy children, maternal perceptions, coping skills, and social support are stronger predictors of mental health outcomes than objective illness severity.<sup>20</sup> In the present study, women appeared to be similarly affected by feelings of isolation due to COVID-19-related restrictions and fears about the pandemic across the varying degrees of fetal CHD severity. Women going to their prenatal appointments and receiving bad news alone were universally stressful and worrying.

There are opportunities for future research and clinical investigations that may continue to improve support for women undergoing fetal echocardiography and receiving a diagnosis of fetal CHD. Though the pandemic evolved over time, the initial response nationally was to limit exposure and contact with other people, which included limiting familial support at prenatal appointments. While these restrictions may have been necessary to reduce transmission of the coronavirus, it is important to also recognise the emotional vulnerability of this population and the known long-term impacts of perinatal mental health problems. The lasting impact of these experiences is not yet known. Future research should investigate long-term impacts on these families postnatally, especially given the overwhelming majority of these women having to experience their pregnancies and the emotional impact of a fetal CHD diagnosis in isolation. Additionally, supports for using telemedicine should continue to be improved, particularly given that women with low income and from racial and ethnic minority groups tended to report more negative experiences with the use of telemedicine.

Several limitations may affect generalizability of results. While women received obstetric and maternal fetal medicine care throughout the region, fetal cardiology care was conducted at one Mid-Atlantic paediatric hospital. Results may not fully generalise to other institutions or regions. Further, the study sample represented 45% of eligible women and non-English speaking women were excluded. It is possible that additional themes could have been identified from a broader sample. This study explored women's subjective experiences of the pandemic using qualitative methods, and quantitative data regarding access to care and emotional impact were not collected. Further, although thematic patterns based on socio-demographic characteristics were explored, the qualitative nature of this study precluded a more in-depth analysis of socio-demographic differences. As the pandemic and knowledge about coronavirus changed over time, restrictions likely differed in other cities and at other institutions. We did not perform subgroup analyses to look at the impact of the pandemic on psychosocial stressors during different time frames within the pandemic.

In conclusion, this study of women who received a diagnosis of fetal CHD during the pandemic highlighted considerable

psychosocial impacts. There were unexpected benefits for some women, such as more accessible healthcare and more flexibility with scheduling either in-person or telehealth appointments. However, there were also notable concerns around the unknowns of COVID-19 and how this would affect both maternal and fetal health. Perhaps the most challenging experience that nearly all women shared was the loss of their social support system, receiving a diagnosis of fetal CHD alone, and feelings of isolation that followed. Recognising these impacts on maternal health can help inform efforts to promote positive family outcomes moving forward.

**Acknowledgements.** The authors thank the women who shared their experiences as part of this study.

**Financial support.** The senior author received funding from the National Institute of General Medical Sciences of the National Institutes of Health (grant number 1P20GM144270-01).

**Competing interests.** The authors declare none.

**Ethical standards.** The authors assert that all procedures contributing to this work comply with the ethical standards of the Belmont Report and with the Helsinki Declaration of 1975, as revised in 2008, and have been approved by the Nemours Institutional Review Board.

## References

1. WHO Director-General's opening remarks at the media briefing on COVID-19 - 11 March 2020, 2020
2. Dubey S, Biswas P, Ghosh R, et al. Psychosocial impact of COVID-19. *Diabetes Metab Syndr* 2020; 14: 779–788.
3. Blumenthal D, Fowler EJ, Abrams M, Collins SR. Covid-19 - implications for the health care system. *N Engl J Med* 2020; 383: 1483–1488.
4. Kirkpatrick JN, Mitchell C, Taub C, Kort S, Hung J, Swaminathan M. Statement on protection of patients and echocardiography service providers during the 2019 novel coronavirus outbreak: endorsed by the American College of Cardiology. *J Am Soc Echocardiogr* 2020; 33: 648–653.
5. Rosenberg KB, Monk C, Glickstein JS, et al. Referral for fetal echocardiography is associated with increased maternal anxiety. *J Psychosom Obstet Gynaecol* 2010; 31: 60–69.
6. Sklansky M, Tang A, Levy D, et al. Maternal psychological impact of fetal echocardiography. *J Am Soc Echocardiogr* 2002; 15: 159–166.
7. Channing A, Rosenberg K, Monk C, et al. Maternal anxiety associated with fetal echocardiography. *Open J Pediatr* 2012; 02: 143–149.
8. Rychik J, Donaghue DD, Levy S, et al. Maternal psychological stress after prenatal diagnosis of congenital heart disease. *J Pediatr* 2013; 162: 302–7 e1.
9. Brouwers EPM, van Baar AL, Pop VJM. Maternal anxiety during pregnancy and subsequent infant development. *Infant Behav Dev* 2001; 24: 95–106.
10. Qiu A, Rifkin-Graboi A, Chen H, et al. Maternal anxiety and infants' hippocampal development: timing matters. *Transl Psychiatry* 2013; 3: e306–e306.
11. Weinstock M. The potential influence of maternal stress hormones on development and mental health of the offspring. *Brain Behav Immun* 2005; 19: 296–308.
12. Wu Y, Kapse K, Jacobs M, et al. Association of maternal psychological distress with in utero brain development in fetuses with congenital heart disease. *JAMA Pediatr* 2020; 174: e195316.
13. Cousino MK, Pasquali SK, Romano JC, et al. Impact of the COVID-19 pandemic on CHD care and emotional wellbeing. *Cardiol Young* 2021; 31: 822–828.
14. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3: 77–101.
15. Vrijmoet-Wiersma CM, Ottenkamp J, van Roozendaal M, et al. A multicentric study of disease-related stress, and perceived vulnerability, in parents of children with congenital cardiac disease. *Cardiol Young* 2009; 19: 608–614.
16. Tak YR, McCubbin M. Family stress, perceived social support and coping following the diagnosis of a child's congenital heart disease. *J Adv Nurs* 2002; 39: 190–198.
17. Kazak AE, Alderfer M, Enlow PT, et al. COVID-19 exposure and family impact scales: factor structure and initial psychometrics. *J Pediatr Psychol* 2021; 46: 504–513.
18. Enlow PT, Phan TT, Lewis AM, et al. Validation of the COVID-19 Exposure and Family Impact Scales. *J Pediatr Psychol* 2022; 47: 259–269.
19. Pinto NM, Morris SA, Moon-Grady AJ, Donofrio MT. Prenatal cardiac care: goals, priorities & gaps in knowledge in fetal cardiovascular disease: perspectives of the Fetal Heart Society. *Prog Pediatr Cardiol* 2020; 59: 101312.
20. Sood E, Lisanti AJ, Woolf-King SE, et al. Parent mental health and family functioning following diagnosis of CHD: a research agenda and recommendations from the Cardiac Neurodevelopmental Outcome Collaborative. *Cardiol Young* 2021; 31: 900–914.