

Original Article

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“The Mental Health Piece is Huge”: perspectives on developing a prenatal maternal psychological intervention for congenital heart disease

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Abstract

Objectives: Women carrying a fetus diagnosed with congenital heart disease often experience significant distress because of their medical diagnosis. Given the well-documented impact associated with elevated prenatal stress and critical importance of developing targeted interventions, this study aims to examine stressors, coping and resilience resources, and mental health treatment preferences in pregnant women receiving a congenital heart disease diagnosis to inform the development of a psychological intervention to reduce maternal distress prenatally. **Methods:** Three groups of participants were included consisting of two pregnant women carrying a fetus with congenital heart disease, five women of children (4–16 months) with congenital heart disease, and five paediatric cardiology medical providers. Responses were gathered via semi-structured interviews and analysed using qualitative thematic analysis. **Results:** Information regarding four broad areas were analysed of emotional distress during pregnancy; experience of initial diagnosis; coping and resilience; and perspectives on a mental health intervention in pregnancy. Anxiety regarding baby’s future, guilt following diagnosis, and various coping strategies emerged as primary themes among the participant sample. Medical staff corroborated mothers’ heightened anxiety and viewed a psychotherapeutic intervention during the prenatal period as essential and complimentary to standard of care. **Conclusion:** We identified salient themes and preferred components for a future psychological intervention delivered prenatally. **Practice Implications:** Patients’ and providers’ perspectives regarding the nature of maternal distress, resilience and treatment preferences can inform the development of interventions to support the emotional well-being of pregnant women carrying a fetus with congenital heart disease to optimise care and potentially improve outcomes for fetal brain development.

Introduction

Congenital heart disease represents a major global health problem¹ affecting 40,000 births per year in the United States.² It is becoming increasingly evident that congenital heart disease significantly impacts neurodevelopment as early as in utero.³ The impact of congenital heart disease on prenatal brain development reveal some forms of congenital heart disease are associated with gestational age- and weight-adjusted overall brain volumetric growth when compared to normal fetuses.⁴ Further, fetuses with congenital heart disease exhibit disturbances in cortical folding, and biochemistry in utero.^{1,5} It is well-known maternal distress (stress, anxiety, or depression) during pregnancy can also alter brain development of the offspring (e.g. cortical thinning,⁶ altered amygdala⁷ and hippocampal growth⁸ and altered brain microstructure⁹ and functional connectivity¹⁰). Recent data suggest maternal distress is associated with impaired hippocampal and cerebral growth in fetuses with congenital heart disease.¹¹ These disturbances significantly impact development throughout the lifespan.^{12–14}

Although pregnancy is often considered a period of joy and hope for parents, receiving a fetal congenital heart disease diagnosis can alter this sense of parental optimism and instead spark an array of unexpected emotions including grief, fear, confusion, and self-blame.^{15–19} Parents quickly need to make decisions regarding whether they should continue with their pregnancy, discern between treatment options, evaluate short- and long-term risks, understand the risk of complications, conceptualise their baby’s quality of life, and determine whether they are adequately supported to manage through these decisions.^{15,16,20–22} Parents are now faced with much more adversity and stress, as they are needing to make these difficult decisions in the time

of an unprecedented global pandemic.^{23,24} As families brace for the impact of congenital heart disease, both mothers and fathers are psychologically affected at the onset of the fetal diagnosis to post cardiac programmes.^{14,17,18,25} Further, the amount of stress significantly increases with this diagnosis, and parents report greater stress, anxiety, trauma, and depression relative to the general population.^{20,21,26,27}

Research has demonstrated the efficacy of psychological interventions implemented during pregnancy in reducing maternal anxiety, depression, and stress,^{19,28–30} but very few trials have included pregnant women receiving fetal cardiac diagnoses³¹ even though studies assessing prenatal counselling and pre-surgery education have supported a reduction in parental anxiety.³⁰ As greater insights into fetal brain growth and development emerge, the need for surveillance, assessment, and targeted psychological interventions prenatally are warranted,¹¹ to ensure children with congenital heart disease are given the best opportunity to thrive from the outset. To date, there are no standardised evidenced based interventions addressing the mental health needs for pregnant women during this period.^{31,32} To address this gap, the goal of this qualitative study was to identify the emotional experiences, coping and resilience resources, and mental health treatment preferences of pregnant and postpartum mothers receiving a congenital heart disease diagnosis to inform the development of a psychological intervention to reduce maternal distress prenatally.

Materials and Methods

Participants and recruitment

Participants were recruited from Children's National Hospital between May and June, 2020. The duration of recruitment spanned one month and within this limited period only seven participants were enrolled. This study is phase 1 of a larger study analysing the effect of prenatal CBT intervention on maternal stress and fetal brain development. To be eligible, participants were fluent in English, had access to the internet on a computer, tablet, or mobile device, had a confirmed fetal diagnosis of congenital heart disease requiring neonatal open-heart surgery, and were receiving services at this hospital. The research team sent a study announcement via email to current participants enrolled in one of the hospital's larger studies on impaired brain development in fetuses with congenital heart disease to participate in an online 60–90-minute interview on Zoom. Prenatal participants were identified from the hospital's fetal cardiology clinic and who expressed interest in enrolling in the study. Postpartum women were identified as eligible through their prior enrolment in one of our congenital heart disease studies. The study team approached six postpartum research participants whose children were still living. One was lost to follow up due to their child's hospital admission and lack of availability.

The purpose of the study was to identify emotional experiences among pregnant women and postpartum mothers with a congenital heart disease fetal diagnosis, and to understand their preferences with psychological interventions delivered prenatally. After enrolment, a licenced psychologist conducted recorded semi-structured interviews, with each participant individually and accompanied by the clinical research coordinator and two investigators observing. Informed consent was obtained electronically from all participants following a protocol approved by the Institutional Review Board and prior to study procedures. Following completion of the interviews, all participants were mailed monetary compensation in the form of a Health

Insurance Portability and Accountability Act compliant, Institutional Review Board approved debit card.

We approached medical staff ranging from fetal cardiologists to nurse coordinators with clinical experiences ranging up to 25 years who are caring for pregnant women with a fetal congenital heart disease diagnoses to participate in an individual semi-structured interview. Seven providers were approached, five of which agreed to participate, one declined due to lack of availability, and one did not respond. We explained the purpose of the study was to understand the mental health issues pregnant women whose fetuses have been diagnosed with congenital heart disease experience during their services rendered with them. Pregnant and postpartum patients typically seen at this hospital receive care from multiple providers in the Fetal Heart Program, including a fetal cardiologist, licenced social worker, and fetal nurse coordinator. The initial diagnosis is given to families in the presence of these three providers. We aimed to gather information on current resources available for these women and the components of a psychological intervention the medical staff consider would be helpful and/or feasible for this specific population.

Three groups of interviews with research participants were conducted. The *prenatal group* comprised of pregnant women ($n = 2$) with a fetal diagnosis of congenital heart disease and actively receiving services in the fetal cardiology clinic at this hospital. The *postnatal group* was comprised of women ($n = 5$) having already given birth to newborns with congenital heart disease ranging from 4 to 16 months of life and having received fetal cardiology services at this hospital. The *provider group* ($n = 5$) from the fetal cardiology team included four cardiologists, and one nurse coordinator working closely with pregnant women diagnosed with fetal congenital heart disease.

Procedures and measures

All participants completed a demographic questionnaire and a semi-structured interview, with questions stemming from the following domains: challenges faced during pregnancy; methods of coping; changes related to childbirth; available resources; perspectives on mental health and mental health treatment. The interview was conducted by a licenced psychologist with expertise in working with this population and who would be an integral part in the future development of a therapeutic intervention. Questions were developed by core study team with the aim of understanding sources of stress, resilience, and treatment preferences specific to this population; questions were also tailored to each of the three samples. Pregnant women were asked questions regarding the emotions and challenges when faced with receiving a fetal diagnosis of congenital heart disease, how they were managing through hardships, and what resources were available and most helpful for them. Postpartum mothers were asked questions regarding emotions and challenges upon receiving the fetal diagnosis, how these challenges evolved from pregnancy to time of baby's birth, what coping skills were helpful, and what their perspective is on mental health and receiving a therapy treatment prenatally. The medical staff were asked questions about what challenges they perceived pregnant mothers faced with receiving a fetal diagnosis, what resources are offered to these women to cope, and what their thoughts regarding additional helpful programming to manage their patients' distress. Collectively, all participants were asked about what components of an intervention they believe would be the most supportive during the prenatal period.

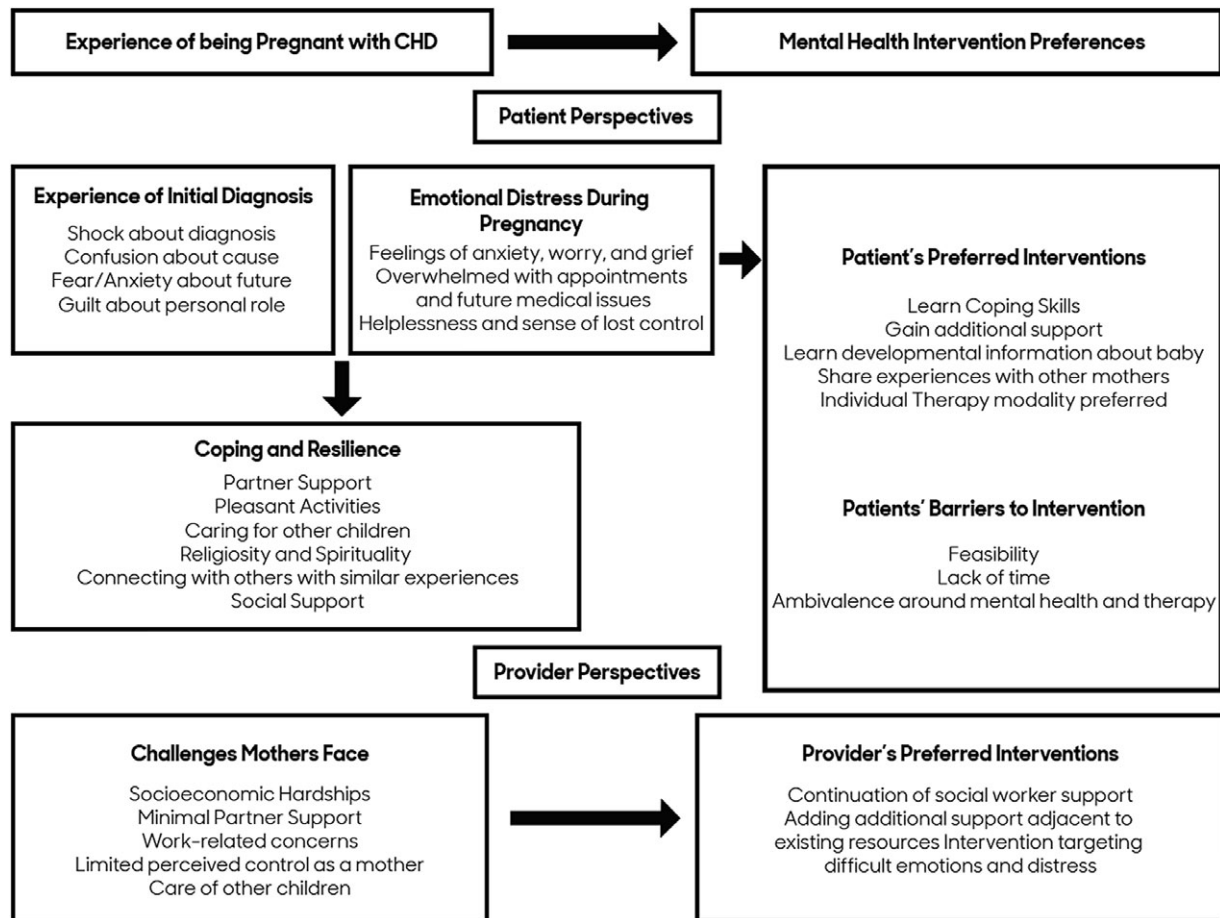


Figure 1. A conceptual summary of themes from patients and providers.

Data analysis

All interviews were recorded and transcribed verbatim. Qualitative data were analysed using thematic analysis. First, the psychologist (K.E) interviewing participants developed a codebook of initial themes, based on the participants' responses regarding experiences of being a mother with a fetus or offspring with congenital heart disease or as a medical provider working closely with this population. Second, two coders (K.E and C.L) participated in identifying the quotes corresponding to these themes. Third, another researcher (M.J) determined the level of agreement between the coders. Finally, all three researchers met with a clinical supervisor (H.L) to discuss areas of disagreement and reached consensus among these areas and subsequent themes. This consensus process took place on several occasions and culminated in a model describing the inter-relationships among these themes by stakeholder (patients and providers) perspectives (Fig 1).

Results

The sample consisted of mothers included five pregnant and two postpartum mothers. Participant mean age was 37.28 (SD = 5.01) and four out of seven participants presented with graduate level education. Mean gestation at time of receiving a congenital heart disease fetal diagnosis was 23 weeks gestation with varying severity of congenital heart disease diagnostic groups. Five women

self-identified as Caucasian, one African American, and one Asian. All women were married. Providers' experience ranged from 2 to 20 years. Data of study participants and providers are summarised in Table 1.

Qualitative themes: pregnant women and postpartum mothers

The responses of most women fell into one of the categories below. Overall, both pregnant women and mothers reported comparable emotions and experiences related to receiving the initial diagnosis and the duration of their pregnancy. Women reported varying coping and resilience resources, including physical exercise, prayer, and spending time with other children, among several others. Generally, they agreed the ideal timing of treatment delivery would be at least two to three weeks after receiving a prenatal fetal diagnosis. Given the endorsement of busy schedules, time-limited and brief interventions appear warranted (e.g. maximum 1 hour, one time per week, etc.). Flexibility in scheduling on weekends and evenings are also preferred options. Using a virtual telehealth platform to deliver the intervention was voiced as most feasible, accessible, and appropriate considering current global events and typical commute times. Desired therapist qualities included approachability and availability, and to be integrated as part of a team alongside cardiologists, nurses, and social work. While women considered the benefits of being part of a group of mothers going through similar challenges, an individual modality was preferred given the gravity and uniqueness

Table 1. Summary of mother participant's sociodemographic information.

Participant ID	Interview 1 - PR	Interview 2 - PR	Interview 3 - PP	Interview 4 - PP	Interview 5 - PP	Interview 6 - PP	Interview 7 - PP
Age	36	44	37	36	41	27	40
Race	White	Asian	White	White	African American	White	White
Ethnicity	Non-Hispanic	Non-Hispanic	Non-Hispanic	Non-Hispanic	Non-Hispanic	Non-Hispanic	Non-Hispanic
Marital status	Married	Married	Married	Married	Married	Married	Married
Education level	Graduate Degree	Graduate Degree	Graduate Degree	Graduate Degree	Undergraduate Degree	Partial College	Undergraduate Degree
Number of children	3	1	2	2	2	1	1
Timing of diagnosis at CNH	31 weeks	25 weeks	19 weeks	21 weeks	21 weeks	24 weeks	20 weeks
CHD diagnosis	Tetralogy of Fallot	Tetralogy of Fallot, right aortic arch	d-TGA	Heterotaxy, Double outlet right ventricle	Tricuspid stenosis, hypoplastic RV	Hypoplastic with mitral stenosis and aortic atresia	Hypoplastic left ventricle, aortic stenosis
Child's age at interview	N/A	N/A	16 months	10 months	16 months	4 months	9 months
GA at birth OR current GA (weeks)	37 4/7	39 4/7	39	39 6/7	38 6/7	38 1/7	39 3/7
Child's sex	Female	Female	Male	Male	Male	Female	Female

PP=postpartum; PR=prenatal.

of each fetal diagnosis and the associated dynamic stressors. However, women who opposed group formats were open to at least one group session focused on information rather than processing personal experiences. Representative quotes from the main themes and intervention preferences are presented in Tables 2 and 3. Figure 1 summarises all themes from both stakeholder perspectives.

Experience of initial diagnosis

Mothers described experiencing several emotions at the time of receiving a fetal diagnosis of congenital heart disease. They noted initially feeling shocked, scared, confused, and then later a sense of guilt and anxiety. They noted an immediate sense of mourning and devastation of the loss of the idealised or "healthy child." There was uniformly a sense of fear regarding the baby's prognosis after birth and what the baby's future would look like regardless of the severity of the fetal diagnosis. Many women described feeling confused as to what caused their baby to have a problem and some wondered whether they could have done something to prevent it or if they did something to cause the diagnosis.

Emotional distress during pregnancy

Mothers reported experiencing a variety of emotions, predominantly negative, during their pregnancy after receiving a fetal diagnosis. Primary emotions were a sense of anxiety, worry, grief, and loss of control. Women described feeling overwhelmed with the amount of varying appointments and future issues they would need to manage during pregnancy and after the baby arrives. Related to this were several feelings of anxiety and concern about something going wrong in the pregnancy (e.g. further complication; fetal demise). Women felt a loss of control in the pregnancy,

feeling as though they were helpless, without an opportunity to do something to make the baby healthier.

Coping and resilience

Despite the range of negative emotional experiences mothers reported, they also identified protective factors and methods of coping with emotional distress during their pregnancies. Some resources included religiosity and spirituality, focusing on increasing pleasant activities, caring for their other children, connecting with others having gone through a similar issue, and relying on others for support. For example, some women noted taking walks or continuing with their exercise regimen were useful. Other women noted that being able to rely on their husbands for support was helpful in their coping with distress.

Perspectives on mental health intervention in pregnancy

Perspectives on mental health and related interventions occurring during the prenatal period varied. Concerns were raised regarding comfort with a mental health professional, feasibility, lack of time in their schedules, or retelling distressing thoughts and emotions related to receiving the congenital heart disease diagnosis. Advantages included gaining additional support, learning about adaptive ways to cope, learning information about the neurodevelopmental future of the baby, and sharing experiences with other mothers.

When considering an intervention, preference for individual versus a group therapy experience were mixed. Mothers preferring individual therapy expressed wanting a sense of confidentiality, tailored treatment, and information related specifically to their baby's CHD diagnosis. Some mothers noted becoming more anxious when exposed to stressful stories from other mothers, while

Table 2. Broad themes and representative quotes of participants: pregnant women and postpartum mothers.

Theme	Representative quotes
Experience of receiving initial diagnosis	It was so scary . . . it was beyond devastating to hear . . . I think every mom wants to have a healthy baby and receiving this news was just upsetting. It was a lot of blame. I blamed myself in some weird way that my baby had to have surgery.
Emotional distress during pregnancy	It was more like the anxiety around what's going to happen. What's in my control? How can I plan for this? Why did this happen to me? It was almost like mourning the pregnancy that I thought we would have . . . mourning the overall health of my baby boy.
Coping and resilience	I was still scared and uncertain of what's going to happen to the baby, but I knew I had support. I knew that he was going to get the best care possible. So, I was hopeful. Having a good family support has been helpful. I'm very emotional in a crisis and my husband's a calm person. That's been helpful.
Perspectives on mental health intervention in pregnancy	I think it [a mental health intervention] would be beneficial because I think everyone going through the same thing and it may be helpful. There's likely so many things to talk about. Time wise and just emotionally. It's like, should I go and seek out therapist? If something was available and if someone was available in house; I would have tapped into that resource immediately.

Table 3. Treatment preferences and representative quotes: pregnant women and postpartum mothers.

Treatment preference	Representative quotes
When treatment should start	Maybe after week one or two of finding out [fetal diagnosis] . . . How I feel those first few days are just processing and it's almost like too soon before that. While she was in this the CICU for those three, four weeks. I think that that would have been phenomenal because there were a couple of times that I even asked for support.
Timing of when sessions should be delivered	Maybe if services were offered on the weekends. For working parents because my doctors were only available Monday to Friday, and I have to work Monday to Friday. If it's not a fixed schedule and mothers can choose their time at their convenience. It will be super helpful if they commit to doing it every week. They can choose a time that's convenient and just go for it.
Method	Time being such a premium . . . virtual therapy is beautiful because you don't factor in getting somewhere. I would be more amenable doing something like a telehealth or zoom type of situation like this current moment..it's that postpartum is a very hard time, I think virtual would be extremely helpful.
Preferred therapist qualities	If I had the therapist's email and cell phone number and that she would be accessible is ideal. Also, I think because at least in my situation, if she is also in the same room with my cardiology team then she's part of the group. I can trust this therapist. I would like a provider who is more experienced and really trained in seeing moms with kids that have chronic illnesses or with mothers who have been through similar situations.
Modality	I think that a one-to-one for 45 minutes to an hour would be most beneficial. I think it would be helpful to do a group session where other women can contribute and share experiences. I think I might be interested in group therapy, but it could go the wrong way . . . there's the potential dynamic of others dominating the conversation . . . I feel like it may compromise my ability to connect with the therapist.
Neurodevelopmental information	Not everyone is comfortable talking to psychologists or social workers. I think talking about neurodevelopment would be a pretty solid way to get a psychologist in, because that would be able to build that trust level with parents.

others believed talking to other women going through a similar experience would be helpful. Women described it would be helpful to talk to someone with prior experience in addition to learning about neurodevelopmental information about the baby as part of the therapy for themselves. Regarding an intervention including their significant partner, mothers noted having at least one session where they could both attend the session.

Perspectives on standard of care

Mothers generally perceived the current standard of care as thorough and supportive, especially with their fetal cardiologists and fetal care team; however, some women noted the amount of information given at the initial diagnosis was overwhelming. Some participants stated that while they had multiple helpful interactions with social work shortly after receiving the diagnosis, they

had difficulty with accessing or being connected to psychological services thereafter (e.g. too much information, did not know who to contact, etc.).

Qualitative themes: healthcare providers

The healthcare provider interviews focused on the challenges their patients face and the need for professional mental health support. Representative quotes are outlined in Table 4.

Challenges mothers face

Providers highlighted several multifaceted factors contributing to stressful challenges for pregnant women at the point in which they receive a fetal congenital heart disease diagnoses (e.g. socio-economic hardship; minimal support; work-related concerns; limited control as a mother).

Table 4. Broad themes and representative quotes: health care providers.

Theme	Representative quotes
Challenges mothers face	I think women who are struggling because of their socio-economic status or who are in an unstable family situation. I think a lot of it depends on who the father of the baby is and what their relationship is like. I think they [mothers] have this vision that their kids [with CHD] will be suffering their whole lives. It's mainly the logistical pieces. I feel for moms, it's about control because they know they cannot control what's going on right now; it's the unknown which is the biggest worry that these moms have.
Perspectives on mental health intervention	I think the mental health piece is huge. And I think it's much needed for our families. I've been a big advocate [for a mental health intervention] from that from day one. I'm happy to hear that there's something trying to take off for it. I think they need more support in that area [mental health], because that's a huge part of this that is preparing them for taking care of their child after they're born, and depression is very common and affects how they take care of their children and the success of their survival.

Need for professional mental health support

Overall, healthcare providers uniformly agreed having a mental health care professional work with women whose fetuses have been diagnosed with congenital heart disease would be useful given the overwhelming emotions accompanying the diagnosis which warrant support. Unanimously, medical providers confirmed the support from their social work team, which is embedded within the cardiology unit, serves to effectively navigate and support the mental well-being of the mother. Providers noted the implementation of an evidenced-based intervention designed to follow patients throughout pregnancy and into the postpartum period may be useful as an adjunct to an already existing relationship with the social worker.

Discussion

The current study examined the subjective experiences of pregnant women, mothers, and medical providers related to carrying a fetus with a congenital heart disease diagnosis that would require open heart surgery, and to understand preferences for a potential psychological intervention. Collectively, all participants, both providers and perinatal women, believe women in the prenatal period receiving a congenital heart disease diagnosis would significantly benefit from a targeted prenatal psychological intervention addressing the specific emotional distress associated with being a parent carrying a fetus with congenital heart disease. To date, there are no standardised and evidence-based interventions addressing the mental health needs for prenatal women carrying a fetus with congenital heart disease.

Implementing an evidence-based psychotherapeutic intervention delivered in the prenatal period would allow providers the opportunity to address mothers' acute psychological needs and strengthen their ability to adaptively cope with the many ongoing stressors they will continue to face throughout their child's development. We found pregnant and postpartum women experience shock, grief, a sense of helplessness and loss of control of the pregnancy when first receiving the fetal diagnosis and long after. Women primarily expressed feelings of anxiety and guilt. Women also revealed several positive resources that allowed them to cope through their pregnancies and in the postpartum period. These findings are consistent with previous studies within this population examining their psychological functioning and perspectives on coping within the context of congenital heart disease.^{20–24,26–29}

Given the distress women endorse and their agreement on the benefit of a prenatal psychotherapeutic intervention, development of an evidence-based targeted intervention is warranted. Pregnant

women and mothers in this study provided important information on the preferred structure and content of potential interventions. Provider feedback demonstrated support for a psychotherapeutic intervention in the prenatal period. Further, provider feedback suggested any new intervention should be complimentary to current social work services. In addition to incorporating information obtained from the current study to tailor a future intervention, incorporation of theoretical frameworks proven efficacious in addressing perinatal depression and anxiety, such as cognitive behavioural and interpersonal psychotherapy,¹⁹ would be most useful.

Our data suggest there exists a certain degree of apprehension around the usefulness of a psychotherapeutic intervention. However, given the high emotional distress these women face, it is critical for care teams and frontline providers to normalise these experiences to increase engagement with mental health intervention.³³ Specifically, to mitigate the development of more clinically relevant symptoms of depression, anxiety, and distress it may be helpful to present the intervention as a preventative measure, rather than treating an existing mental health condition. As such, interventions may then focus on building coping skills and resources for fostering resilience.

Finally, both patients and providers in this study noted the usefulness of a portion of the intervention devoted to learning more about the neurodevelopmental trajectories specific to congenital heart disease. While research informs us children with congenital heart disease are at increased risk of developmental disorder or disabilities or developmental delay,¹⁴ neurodevelopment is multi-factorial and includes child specific risk factors.³⁴ If embedding this information within the intervention is planned, it is paramount the therapist has background knowledge and experience with this population. Research shows neurodevelopmental follow-up and any necessary interventions should begin early in infancy.³⁵ However, future research should consider whether neurodevelopmental information (e.g. ways to support neurodevelopment during infancy; overview of early intervention services, etc.) would be helpful as part of a prenatal psychotherapeutic intervention or would be better suited to another setting.

Limitations

Although the information gained from participants in this study will be essential in developing resources to aid pregnant women with a fetus diagnosed with congenital heart disease, several significant limitations to this study should be noted. First, participant interviews were conducted with a small sample of

predominantly Caucasian, highly educated, and relatively financially comfortable women. Given the extensive evidence of the effects of race, ethnicity, and socio-economic status on disease risk and treatment response,³⁶ future studies must include more participants across racial, ethnic, socio-economic, and cultural groups. Second, our sample only included mothers, not fathers nor same-sex partners, which will be important for future studies to consider as past studies have demonstrated fathers too experience significant distress and emotional strain during this vulnerable time.^{25,37} Third, our sample included more mothers with a child diagnosed with congenital heart disease than pregnant mothers. This is an important factor to consider given information regarding emotions, coping mechanisms, and thoughts at time of pregnancy were provided to us retrospectively. Memories of postpartum mothers may have been influenced by hormonal changes,³⁸ passage of time,³⁹ current emotional state,⁴⁰ or the gravity of recent stressors. Our study used semi-structured interviews and analysed data using qualitative thematic analysis. Future studies should use mental health screening tools, self-administered surveys, and focus groups in addition to individual interviews to elicit more information across different types of modalities. Finally, we were unable to interview any members of the social work team due to their own time constraints. Given provider responses highlighting the importance of social workers during the initial diagnosis, future studies should consider their perspectives on any psychotherapeutic intervention.

Conclusion

This current study was developed with the intent of informing a larger initiative to develop and implement a preventive psychological intervention for pregnant women who receive a fetal diagnosis of congenital heart disease. It is evident that the prenatal maternal experience associated with a fetal diagnosis of congenital heart disease can cause significant distress. A targeted evidence-based intervention supporting mothers, children, and families by strengthening a mother's capacity to cope is clearly warranted. It will be critical to consider to the severity of congenital heart disease diagnosis, culture of the target population, and existing access to resources when developing and implementing future interventions. Mothers are faced with the compounding emotional experience associated with the fetal congenital heart disease diagnosis, and thus evidence-based psychological support has become exceedingly essential.

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Conflicts of interests. The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical standards. The study was approved by the IRB review board at Children's National Hospital in Washington, DC. Written and verbal information about the study was given, emphasising participation was fully voluntary, and informed consent was obtained. Confidentiality was guaranteed.

References

- van der Linde D, Konings EE, Slager MA, et al. Birth prevalence of congenital heart disease worldwide: a systematic review and meta-analysis. *J Am Coll Cardiol* 2011; 58: 2241–2247. DOI [10.1016/j.jacc.2011.08.025](https://doi.org/10.1016/j.jacc.2011.08.025).
- Hoffman JIE, Kaplan S. The incidence of congenital heart disease. *J Am Coll Cardiol* 2002; 39: 1890–1900. DOI [10.1016/s0735-1097\(02\)01886-7](https://doi.org/10.1016/s0735-1097(02)01886-7).
- Donofrio MT, Duplessis AJ, Limperopoulos C. Impact of congenital heart disease on fetal brain development and injury. *Curr Opin Pediatr* 2011; 23: 502–511. DOI [10.1097/MOP.0b013e32834aa583](https://doi.org/10.1097/MOP.0b013e32834aa583).
- Limperopoulos C, Tworetzky W, McElhinney DB, et al. Brain volume and metabolism in fetuses with congenital heart disease: evaluation with quantitative magnetic resonance imaging and spectroscopy. *Circulation* 2010; 121: 26–33. DOI [10.1161/CIRCULATIONAHA.109.865568](https://doi.org/10.1161/CIRCULATIONAHA.109.865568).
- Clouchoux C, du Plessis AJ, Bouyssi-Kobar M, et al. Delayed cortical development in fetuses with complex congenital heart disease. *Cereb Cortex* 2013; 23: 2932–2943. DOI [10.1093/cercor/bhs281](https://doi.org/10.1093/cercor/bhs281).
- Sandman CA, Buss C, Head K, Davis EP. Fetal exposure to maternal depressive symptoms is associated with cortical thickness in late childhood. *Biol Psychiatry* 2015; 77: 324–334. DOI [10.1016/j.biopsych.2014.06.025](https://doi.org/10.1016/j.biopsych.2014.06.025).
- Buss C, Davis EP, Shahbaba B, Pruessner JC, Head K, Sandman CA. Maternal cortisol over the course of pregnancy and subsequent child amygdala and hippocampus volumes and affective problems. *Proc Natl Acad Sci USA* 2012; 109: E1312–E1319. DOI [10.1073/pnas.1201295110](https://doi.org/10.1073/pnas.1201295110).
- Qiu A, Rifkin-Graboi A, Chen H, et al. Maternal anxiety and infants' hippocampal development: timing matters. *Transl Psychiatry* 2013; 3: e306. DOI [10.1038/tp.2013.79](https://doi.org/10.1038/tp.2013.79).
- Rifkin-Graboi A, Meaney MJ, Chen H, et al. Antenatal maternal anxiety predicts variations in neural structures implicated in anxiety disorders in newborns. *J Am Acad Child Adolesc Psychiatry* 2015; 54: 313–321.e2. DOI [10.1016/j.jaac.2015.01.013](https://doi.org/10.1016/j.jaac.2015.01.013).
- Scheinost D, Kwon SH, Lacadie C, et al. Prenatal stress alters amygdala functional connectivity in preterm neonates. *Neuroimage Clin* 2016; 12: 381–388. DOI [10.1016/j.nicl.2016.08.010](https://doi.org/10.1016/j.nicl.2016.08.010).
- 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. DOI [10.1001/jamapediatrics.2019.5316](https://doi.org/10.1001/jamapediatrics.2019.5316).
- Simeone S, Pucciarelli G, Perrone M, et al. Comparative analysis: implementation of a pre-operative educational intervention to decrease anxiety among parents of children with congenital heart disease. *J Pediatr Nurs* 2017; 35: 144–148. DOI [10.1016/j.pedn.2017.01.008](https://doi.org/10.1016/j.pedn.2017.01.008).
- Licht DJ, Shera DM, Clancy RR, et al. Brain maturation is delayed in infants with complex congenital heart defects. *J Thorac Cardiovasc Surg* 2009; 137: 529–537. DOI [10.1016/j.jtcvs.2008.10.025](https://doi.org/10.1016/j.jtcvs.2008.10.025).
- Marino BS, Lipkin PH, Newburger JW, et al. Neurodevelopmental outcomes in children with congenital heart disease: evaluation and management: a scientific statement from the American Heart Association. *Circulation* 2012; 126: 1143–1172. DOI [10.1161/CIR.0b013e318265ee8a](https://doi.org/10.1161/CIR.0b013e318265ee8a).
- Wei H, Roscigno CI, Hanson CC, Swanson KM. Families of children with congenital heart disease: a literature review. *Heart Lung* 2015; 44: 494–511. DOI [10.1016/j.hrtlng.2015.08.005](https://doi.org/10.1016/j.hrtlng.2015.08.005).
- Rychik J, Donaghue DD, Levy S, GS, et al. Maternal psychological stress after prenatal diagnosis of congenital heart disease. *J Pediatr* 2013; 162: 302–307.e1. DOI [10.1016/j.jpeds.2012.07.023](https://doi.org/10.1016/j.jpeds.2012.07.023).
- Woolf-King SE, Anger A, Arnold EA, Weiss SJ, Teitel D. Mental health among parents of children with critical congenital heart defects: a systematic review. *J Am Heart Assoc* 2017; 6: e004862. DOI [10.1161/JAHA.116.004862](https://doi.org/10.1161/JAHA.116.004862).
- Wray J, Cassidy A, Ernst MM, Franklin RC, Brown K, Marino BS. Psychosocial functioning of parents of children with heart disease-describing the landscape. *Eur J Pediatr* 2018; 177: 1811–1821. DOI [10.1007/s00431-018-3250-7](https://doi.org/10.1007/s00431-018-3250-7).
- Sockol LE. A systematic review of the efficacy of cognitive behavioral therapy for treating and preventing perinatal depression. *J Affect Disord* 2015; 177: 7–21. DOI [10.1016/j.jad.2015.01.052](https://doi.org/10.1016/j.jad.2015.01.052).
- Bratt EL, Järholm S, Ekman-Joelsson BM, et al. Parental reactions, distress, and sense of coherence after prenatal versus postnatal diagnosis of complex congenital heart disease. *Cardiol Young* 2019; 29: 1328–1334. DOI [10.1017/S1047951119001781](https://doi.org/10.1017/S1047951119001781).

21. McKechnie AC, Pridham K, Tluczek A. Preparing heart and mind for becoming a parent following a diagnosis of fetal anomaly. *Qual Health Res* 2015; 25: 1182–1198. DOI [10.1177/1049732314553852](https://doi.org/10.1177/1049732314553852).
22. David Vainberg L, Vardi A, Jacoby R. The experiences of parents of children undergoing surgery for congenital heart defects: a holistic model of care. *Front Psychol* 2019; 10: 2666. DOI [10.3389/fpsyg.2019.02666](https://doi.org/10.3389/fpsyg.2019.02666).
23. Almeida M, Shrestha AD, Stojanac D, Miller LJ. The impact of the COVID-19 pandemic on women's mental health. *Arch Womens Ment Health* 2020; 23: 741–748. DOI [10.1007/s00737-020-01092-2](https://doi.org/10.1007/s00737-020-01092-2).
24. Adadms EL, Smith D, Caccavale LJ, Bean MK. Parents are stressed! Patterns of parent stress across COVID-19. *Res Sq* 2020; 2: rs.3.rs-66730. DOI [10.21203/rs.3.rs-66730/v2](https://doi.org/10.21203/rs.3.rs-66730/v2).
25. Hoffman MF, Karpyn A, Christofferson J, et al. Fathers of children with congenital heart disease: sources of stress and opportunities for intervention. *Pediatr Crit Care Med* 2020; 21: e1002–e1009. DOI [10.1097/PCC.0000000000002388](https://doi.org/10.1097/PCC.0000000000002388).
26. Werner O, El Louali F, Fouilloux V, Amedeo P, Ovaert C. Parental anxiety before invasive cardiac procedure in children with congenital heart disease: contributing factors and consequences. *Congenital Heart Dis* 2019; 14: 778–784. DOI [10.1111/chd.12777](https://doi.org/10.1111/chd.12777).
27. Wei H, Roscigno CI, Hanson CC, Swanson KM. Families of children with congenital heart disease: a literature review. *Heart Lung* 2015; 44: 494–511. DOI [10.1016/j.hrtlng.2015.08.005](https://doi.org/10.1016/j.hrtlng.2015.08.005).
28. Bischoff M, Howland V, Klinger-König J, et al. Save the children by treating their mothers (PriVileG-M-study) - study protocol: a sequentially randomized controlled trial of individualized psychotherapy and telemedicine to reduce mental stress in pregnant women and young mothers and to improve child's health. *BMC Psychiatry* 2019; 19: 371. DOI [10.1186/s12888-019-2279-0](https://doi.org/10.1186/s12888-019-2279-0).
29. Isgut M, Smith AK, Reimann ES, Kucuk O, Ryan J. The impact of psychological distress during pregnancy on the developing fetus: biological mechanisms and the potential benefits of mindfulness interventions. *J Perinat Med* 2017; 45: 999–1011. DOI [10.1515/jpm-2016-0189](https://doi.org/10.1515/jpm-2016-0189).
30. Marokakis S, Kasparian NA, Kennedy SE. Prenatal counselling for congenital anomalies: a systematic review. *Prenat Diagn* 2016; 36: 662–671. DOI [10.1002/pd.4836](https://doi.org/10.1002/pd.4836).
31. Kasparian NA, Kan JM, Sood E, Wray J, Pincus HA, Newburger JW. Mental health care for parents of babies with congenital heart disease during intensive care unit admission: systematic review and statement of best practice. *Early Hum Dev* 2019; 139: 104837. DOI [10.1016/j.earlhumdev.2019.104837](https://doi.org/10.1016/j.earlhumdev.2019.104837).
32. Gramszlo C, Karpyn A, Demianczyk AC, et al. Parent perspectives on family-based psychosocial interventions for congenital heart disease. *J Pediatr* 2020; 216: 51–57.e2. DOI [10.1016/j.jpeds.2019.09.059](https://doi.org/10.1016/j.jpeds.2019.09.059).
33. Gramszlo C, Karpyn A, Christofferson J, et al. Supporting parenting during infant hospitalisation for CHD. *Cardiol Young* 2020; 30: 1422–1428. DOI [10.1017/S1047951120002139](https://doi.org/10.1017/S1047951120002139).
34. Peyvandi S, Latal B, Miller SP, McQuillen PS. The neonatal brain in critical congenital heart disease: insights and future directions. *Neuroimage* 2019; 185: 776–782. DOI [10.1016/j.neuroimage.2018.05.045](https://doi.org/10.1016/j.neuroimage.2018.05.045).
35. Butler SC, Sadhwani A, Stopp C, et al. Neurodevelopmental assessment of infants with congenital heart disease in the early postoperative period. *Congenital Heart Dis* 2019; 14: 236–245. DOI [10.1111/chd.12686](https://doi.org/10.1111/chd.12686).
36. Williams DR. Race, socioeconomic status, and health. The added effects of racism and discrimination. *Ann N Y Acad Sci* 1999; 896: 173–188. DOI [10.1111/j.1749-6632.1999.tb08114.x](https://doi.org/10.1111/j.1749-6632.1999.tb08114.x).
37. Sood E, Karpyn A, Demianczyk AC, et al. Mothers and fathers experience stress of congenital heart disease differently: recommendations for pediatric critical care. *Pediatr Crit Care Med* 2018; 19: 626–634. DOI [10.1097/PCC.0000000000001528](https://doi.org/10.1097/PCC.0000000000001528).
38. Shin NY, Bak Y, Nah Y, et al. Author correction: disturbed retrieval network and prospective memory decline in postpartum women. *Sci Rep* 2018; 8: 14437. DOI [10.1038/s41598-018-32260-1](https://doi.org/10.1038/s41598-018-32260-1).
39. Sun Q, Gu S, Yang J. Context and time matter: effects of emotion and motivation on episodic memory overtime. *Neural Plast* 2018; 2018: 7051925. DOI [10.1155/2018/7051925](https://doi.org/10.1155/2018/7051925).
40. Pio de Almeida LS, Jansen K, Köhler CAé, Pinheiro RT, da Silva RA, Bonini JS. Working and short-term memories are impaired in postpartum depression. *J Affect Disord* 2012; 136: 1238–1242. DOI [10.1016/j.jad.2011.09.031](https://doi.org/10.1016/j.jad.2011.09.031).
41. Kasparian NA. Heart care before birth: a psychobiological perspective on fetal cardiac diagnosis. *Prog Pediatr Cardiol* 2019; 54: 101142. DOI [10.1016/j.ppedcard.2019.101142](https://doi.org/10.1016/j.ppedcard.2019.101142).