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Opportunities to enhance parental well-being during prenatal counseling for congenital heart disease

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ABSTRACT

Prenatal diagnosis of congenital heart disease (CHD) can be a life-altering and traumatic event for expectant parents. Parental anxiety, depression, and traumatic stress are common following a prenatal cardiac diagnosis and if untreated, symptoms often persist long-term. During prenatal counseling, parents must try to manage psychological distress, navigate uncertainty, process complex medical information, and make high-stakes medical decisions for their unborn child and their family. Physicians must deliver the diagnosis, describe the expected perinatal management plan, discuss short and long-term prognoses and introduce elements of uncertainty that may exist for the particular diagnosis. Physician training in these important skills is highly variable and many in our field acknowledge the need for improved guidance on best practices for counseling and supporting parents during pregnancy and early parenthood after prenatal diagnosis, while also sustaining physicians' own emotional well-being. We describe these challenges and the opportunities that exist to improve the current state of prenatal counseling in CHD.

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Introduction

As prenatal diagnosis of congenital heart disease (CHD) has become increasingly common, the fetal care community has come to understand the profound and lasting effects such a diagnosis has on the lives and well-being of affected families. Parental anxiety, depression, and traumatic stress are

common following this life-altering experience.^{1,2-4} Understanding this has led to an increased focus on how expectant parents are counseled and a desire to enhance the current state of prenatal counseling for CHD to reduce the potential for trauma and to promote parent, child and family well-being.

Prenatal counseling after a cardiac diagnosis entails detailed conversations between the fetal care team and

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expectant parents about the (often complex) anatomy and expected physiology of the heart condition, management strategies, and overall prognosis.⁵ This counseling influences parent decision-making regarding continuation of the pregnancy, where to seek care, and how to prepare for delivery and cope with the uncertainties ahead.^{5,6} This review aims to describe the current state of prenatal counseling for CHD from both parent and physician perspectives. We will illustrate how various factors influence these perspectives, describe the role of empathy and trauma-informed care, and highlight opportunities to promote parent and physician well-being as a core component of prenatal counseling. Quotes previously obtained through qualitative research with parents^{7,8} and healthcare providers⁹ are included throughout to illustrate the concepts presented.

Parent experiences with prenatal diagnosis and counseling for CHD

“The doctor just kind of blurted out that it was Hypoplastic Right Heart Syndrome. Even though I didn’t know at the time what that meant, my heart sunk and I felt helpless for my baby. He gave me all of the facts and I felt like my baby wasn’t likely to survive long. . . Our lives were flipped upside down and everything was so different. I felt like I fell off the face of the earth and I had no one anymore.”

Across studies, several consistent themes regarding parental experiences with initial prenatal counseling have been described. Parents often report feeling shocked, overwhelmed, and highly distressed when they first receive the fetal cardiac diagnosis and often have difficulty focusing or fully attending to the medical information provided.⁸ When reflecting on the counseling process, some parents report negative experiences, either because the physician used medical terms they did not understand, or because they perceived the physician as pessimistic regarding their baby’s prognosis.¹⁰⁻¹² In highly stressful situations like these, the tone and words used by the the counseling physicians carry importance. In one study, for example, parents interpreted the term “rare” to mean there was little chance their baby would survive.¹² Some parents also felt a sense of pressure from the perinatologist or fetal cardiologist to terminate the pregnancy, and some sought a second opinion due to a perceived lack of empathy or optimism from the counseling physician.¹² Conversely, parents’ experiences of prenatal counseling are improved when physicians provide emotional support and hope, use less medical jargon, and clearly explain anticipated management plans.¹³

Parents often also report wanting more information before making decisions about care. After in-depth counseling with a fetal cardiologist, parents often express a need for written or web-based information about the diagnosis and typical outcomes,¹⁴ as well as guidance on how to access professional or peer support.^{12,15} Parents often look to social media for support from experienced families of children with CHD

and consider this support a useful addition to the information received from the fetal care team.¹⁶

Expectant mothers commonly experience feelings of guilt,⁸ and often ask what they may have done to cause the cardiac malformation and what they can do going forward to mitigate the condition. Even with strong partner or family support, many expectant mothers report feeling alone in their experience and often grieve the loss of the pregnancy they had imagined. Expectant fathers commonly describe feelings of powerlessness resulting from not being able to protect their unborn baby from CHD.⁸ They often focus their efforts on staying strong for their partner and family and may have limited opportunities to express and receive support for their own feelings of fear, sadness, and grief.^{17,18}

Applying Attachment Theory to adult relationships, we know that similar motivations between partners can forge deeper emotional bonds. Conversely, the challenges associated with prenatal cardiac diagnosis can also place strain on the relationship between expectant parents and contribute to or exacerbate relational difficulties. One study found greater partner dissatisfaction among women carrying fetuses with CHD compared with those with uncomplicated pregnancies.¹⁹ Expectant mothers who reported greater acceptance and positive reinterpretation of the diagnosis also reported lower anxiety and greater partner satisfaction.

“Learning everything and staying calm was hard. We didn’t know what would happen in our life at that moment or in the future. We really wanted to know what our life would look like. We had so many questions and were so stressed about the uncertainty.”

Managing uncertainty is another common challenge for expectant parents. In the fetal cardiac context, this uncertainty may be practical, including the need to navigate new consultations and clinic appointments, and meet new providers²⁰, or it may relate to the medical uncertainty often inherent to fetal cardiac diagnosis, including limited information about the future course of the heart condition throughout the pregnancy and after birth.²¹ Parents often understand the reasons for uncertainty about the diagnosis, postnatal management and prognosis, and may wish to hear the range of possibilities from least to most optimistic.²⁰ Common strategies parents use to cope with the anxieties associated with uncertainty include seeking information and social support, expressing their emotions, and maintaining positivity and hope for the future.²⁰ The degree to which parents experience fear and distress related to uncertainty may be influenced by the level of uncertainty inherent to the cardiac diagnosis, parents’ individual capacity to tolerate uncertainty, and the ways in which uncertainty is contained and managed by the fetal care team,²² who may also encounter uncertainty related to the exact diagnosis when there are technical limitations to obtaining clear images on the fetal echocardiogram, or progressive changes throughout pregnancy that might alter predicted surgical repair.

Prevalence of psychological distress among parents

“I live each and every day with the sobering reality that tomorrow is never promised. I can wake up tomorrow and things can be very different than they are today and can deteriorate quickly. I feel like I have lost part of myself, because the effects of the trauma, stress, and anxiety have changed me as a person.”

Threats to the health of the fetus have long been recognized as an important risk factor for maternal and paternal psychological disturbance in the perinatal period.³ Parents' experiences of prenatal diagnosis, including feelings of intense sadness, fear, loneliness, anger, guilt, and grief, are often associated with enduring psychological distress.^{4,23,24} A substantial proportion of parents of children with CHD, especially parents of children requiring heart surgery, report symptoms of anxiety, depression, and traumatic stress indicative of a need for clinical intervention, often beginning during pregnancy after fetal cardiac diagnosis.^{1,3} In some cases, these symptoms are at a frequency and severity consistent with a clinical diagnosis of an anxiety disorder (e.g., Generalized Anxiety Disorder, Panic Disorder) or mood disorder (e.g., Major Depressive Disorder, Persistent Depressive Disorder). In other cases, parents may experience a combination of symptoms that do not meet full diagnostic criteria but lead to significant distress and adverse effects on daily functioning, including sleep disturbance and reduced capacity to concentrate. At various time-points after CHD diagnosis, 25% to 50% of parents of children with CHD requiring surgery in their first year of life report clinically-elevated symptoms of anxiety or depression, and up to 80% reported severe psychological distress at some point in their child's medical trajectory.^{1,4} These rates far exceed national norms for perinatal anxiety and depression in the general population²⁴; yet the severity and consequences of these symptoms are often substantially underestimated by healthcare providers.

“[The care team] didn't focus much on us as parents. However, when I look back, I wish they would because we were experiencing trauma that has led to PTSD [post-traumatic stress disorder]. Honestly, our mental health is so important in this journey for our child, but it is often not talked about.”

Parents with higher distress report poorer physical health,²⁵ greater burden associated with parenting,²⁶ higher health service use,²⁷ more suicidal ideation,²⁸ and poorer quality of life for both themselves and their child with CHD^{29,30} compared with parents of sick children with lower distress. Experiencing anxiety or depression can also interrupt the developing bond between parent and baby,³¹ with potential implications for later child attachment, and emotional, physical, and neurobehavioral development.³²⁻³⁶ Decades of research in the general population has demonstrated an association between parent mental health and child development.³⁷⁻³⁹ Studies of children with CHD and their parents suggest that parent psychological distress following CHD diagnosis is one of the strongest

predictors of child emotional, behavioral, and developmental outcomes and quality of life.^{29,40-42} While the mechanisms underlying these associations are not fully understood, it is likely that the family environment and parent-child interactions play an important role.^{23,43} There is also evidence that high and persistent maternal psychological stress and anxiety during pregnancy can alter fetal brain development in both healthy fetuses and fetuses with CHD.³ The parents' experiences during physician counseling can have long-term consequences for their capacity to cope with caring for a sick child.⁴⁴

Influences on medical decision-making

“When I was first informed about my child's heart condition I think I was in shock. I didn't know what to expect or do. The doctor gave me diagrams of a normal heart versus my baby's heart which was helpful. I was also told to go do my research and told what to search for. I did a lot of research including finding other families of children who had similar defects. At my next fetal echo, I came prepared with a list of questions such as survival rate, limitations, and what to expect.”

A core goal of the counseling process is to inform parents in an unbiased and non-directive manner about the fetal cardiac diagnosis and its potential impacts on health and quality of life, and to partner with parents by introducing choices, describing options, and helping parents explore preferences and make decisions using a shared-care model.⁴⁵

Yet the process rarely is as unencumbered as described above.

In the context of prenatal counseling, the communication and interpretation of information may be influenced by a range of explicit and implicit biases. Physicians, for example, have variable (and perhaps strong) attitudes towards pregnancy termination,^{46,47} and may also have differing opinions on the standard of care for some conditions,⁴⁸⁻⁵⁰ which may be based on institutional practices and outcomes, as well as personal or professional experiences.¹² How physicians present information affects the choices their patients make,⁵¹ and communication regarding risk can be affected by either inaccurate physician statements,⁵² or lack of understanding how the risk is presented (ie probability vs percentage, verbal vs numerical).⁵³⁻⁵⁵

Parents may have their own views and biases which can lead to conflict, misunderstanding and miscommunication between physicians and parents. The definitions and expectations of an optimal “quality of life”, for example, may differ between physicians and families.⁵⁶ Maternal age⁵⁷ ethnicity, religious or cultural beliefs and level of education can influence decision-making during pregnancy after fetal CHD diagnosis.^{58,59}

While engaged in considering options, parents often seek information from parents who have experience with the diagnosed condition, and consider the future impact of the diagnosis and their decision on the fetus' life.⁶⁰ Ultimately, decisions by the parents are influenced by their values, past

What Is Trauma-Informed Care?

- Being aware that many people have a history of trauma
- Recognizing trauma symptoms as well as a person's strengths and resilience
- Responding to distressed or agitated patients in a non-judgmental, supportive way
- Ensuring physical and emotional safety for staff and patients
- Being trustworthy and transparent with patients, family members, and staff
- Promoting recovery and healing for those who have experienced trauma
- Making decisions in partnership with patients and avoiding a power imbalance in interactions
- Empowering patients and giving them choice and control over the care they receive
- Promoting self-care among staff and clinicians
- Promoting well-being at a health service or system level
- Acting proactively to prevent or minimize the effects of trauma through early referral to appropriate mental health services

Fig. 1 – Elements of Trauma-Informed Care

experiences, hope, and their belief in their ability to care for a child with CHD.⁶¹

Physician experiences during prenatal counseling

“I don’t think you ever get used to bad things happening. People say ‘you’ve got to harden up’. That never happened to me.”

Physicians who counsel expectant parents face multiple challenges they must navigate simultaneously. They must make the correct diagnosis, understand its implications and potential for change by term, and explain the diagnosis, prognosis, and treatment options in a way the parents can understand in a relatively short period of time.⁵ Physicians are expected to be empathetic and responsive to parents’ emotional and psychological needs, and tailor their communication styles to meet the needs of parents they are meeting for the first time. These expectations of physicians can engender anxiety, especially in the context of a difficult diagnosis^{62,63} and as a field, fetal physicians can often feel ill-equipped to manage unexpected reactions or extreme parental distress during counseling. Some physicians may approach counseling as if teaching medical trainees, which is often not appropriate given the gravity of the personal information being conveyed and the degree of emotional distress experienced by parents. In many centers, access to expert mental health providers is limited or lacking.

Pediatric cardiologists in training receive variable instruction on the emotional aspects of prenatal counseling after a new CHD diagnosis. Existing guidelines on the practice of fetal cardiology focus primarily on the clinical aspects of care⁵. The absence of formal training for physicians on how to deliver distressing information or ‘bad news’ is typical. Recent reports show that only one-third of physicians have had formal training to help develop this important skill.⁶⁴ Physician training in communication and counseling skills often centers around the SPIKES⁶⁵ or similar protocols,⁶⁶ which provide a framework for effective and empathic parent-physician communication, especially in the context of difficult conversations. The “SPIKES” acronym refers to: Setting (choose a private, comfortable, non-threatening setting),

Perception (Uncover what the family thinks is happening), Invitation (Ask patient what they would like to know), Knowledge (explain disease and care options in plain language), Emotion (respect feelings, respond with empathy), and Summarize (recap discussion and decide what’s next).⁶⁵ This protocol and modifications of it have been proposed for counseling after a prenatal diagnosis.⁶⁷⁻⁷¹

Physicians can also play an important role in supporting parents’ adjustment to their baby’s diagnosis through the use of **trauma-informed care** (Fig. 1). Trauma-informed care is widely used in mental and behavioral health, but it is also increasingly being applied in other settings, including primary care, obstetrics and gynecology, and emergency departments. For people with a history of trauma, clinical settings like a small, enclosed examination room, may trigger trauma-related symptoms. A trauma-informed approach emphasizes parent choice and empowerment, creates a safe environment for discussion of trauma experiences and their role in health behavior, is non-judgmental and supportive, emphasizes strengths and resilience, and is sensitive to triggers that may lead to re-traumatization for parents as well as physicians.⁷²

By practicing trauma-informed care, physicians may significantly reduce parent fear and distress, as well as improve the effectiveness of their counseling and parent cooperation with medical recommendations. There is also evidence that trauma-informed care reduces compassion fatigue, secondary traumatic stress and burnout among physicians and other healthcare professionals.

The role of empathy

“The doctor that told us the news was very kind and compassionate with his delivery. I was upset and couldn’t think of one question in that moment that I should ask. He then took the time to draw a diagram of what my son’s heart looked like in comparison to a normal heart. He gave us some facts about my son’s specific CHD. He was direct and told us about the seriousness and severity of the condition, but was also very positive about the outlook and gave us hope. I am very blessed by the doctor that delivered this news to us.”

Physicians may feel uncomfortable expressing empathy or providing emotional support during a counseling session. We may feel that a focus on emotional support could interfere with our primary role, to provide diagnostic and prognostic information in a manner that allows the family to be accurately informed for decision-making.⁷³ For the physician focused on successful patient education about the fetal diagnosis, it may be useful to reframe the role of empathy and emotional support as essential communication tools needed in improve the effectiveness of the consultation itself.⁷⁴

The emotionally distressed parent will retain approximately 20 to 60% of the information provided.⁷⁵ Addressing parents' emotional distress during counseling and actively using communication to provide empathy, reassurance and support⁷⁶ may lower both emotional and physiological responses to stress and improve information processing and later recall.⁷⁷ For example, parents may be better able to process and retain complex information when the physician first reassures them that 1) they didn't do anything to cause this, and 2) that most children with CHD go on to live long and meaningful lives, before delving into the anatomy, physiology, and surgical approach.

Studies examining physician-patient interactions indicate that directly and sensitively acknowledging patients' emotional responses, encouraging questions and shared decision-making, and demonstrating compassion and dependability are associated with greater patient and family satisfaction and perceived quality of care⁷⁸⁻⁸² and with patients' longer-term psychological adjustment.⁸³ In doing this work, we must also acknowledge the impact that delivering such life-changing news to parents can have on us as providers and the ways in which we can be affected by parents' experiences of grief and distress. Secondary traumatic stress and compassion fatigue are common among clinicians,^{84,85} and models aimed at preventing or mitigating trauma in expectant parents should also focus on physician well-being.⁸⁶

Summary

In summary, a prenatal diagnosis of CHD can often be a life-altering and traumatic event for parents, and can have a profound influence on relationships and the psychological health and well-being of the family. Effective, empathetic and trauma-informed prenatal counseling can mitigate parents' experiences of trauma and facilitate healthy psychological adjustment, shared decision-making, and collaborative care.

Physicians who provide prenatal counseling for CHD and other congenital anomalies are typically not trained in practices to best perform this role in a manner that is informed by emotional skills or psychological expertise. The impact of undertaking this role on physicians has not been adequately explored, and the reflective/personal work needed to learn to express empathy and provide emotional support while remaining resilient is typically not addressed in the procedure-focused fields of perinatology and fetal cardiology. Below are some potential opportunities to improve the initial

prenatal counseling experience for parents and better support parent, family and physician well-being.

Opportunities to enhance prenatal counseling with a new CHD diagnosis

- 1) We as a fetal and neonatal care community should **expand our understanding of both parent and physician experiences of prenatal counseling**, with a focus on parent-physician interactions during the counseling process as well as physicians' experiences of compassion satisfaction, compassion fatigue, secondary traumatic stress, burnout, and other facets of mental health. In doing this we can identify obstacles we face in providing optimal and empathetic counseling.
- 2) We should **develop** best practices guidelines on trauma-informed care for the prenatal counseling setting. By collaborating with parent stakeholders with relevant lived experiences as well as mental health professionals with expertise in trauma-informed care, physicians can learn the best way to deliver difficult news about a fetal anomaly, while also sustaining their own emotional well-being.
- 3) The next step would be to **design a training curriculum for physicians who perform prenatal counseling**. Though no formal curriculum currently exists for fetal counseling for CHD, this will likely take shape in the next few years. Part of this curriculum should include an exploration of the ways in which implicit biases can influence the counseling process, practices to cultivate and communicate empathy and emotional support, and evidence-based practices to support physician wellness. The curriculum should be made available across institutions, with the capacity for tailoring to the specific characteristics of different settings.

In conclusion, by gaining a better understanding of parent and physician experiences with prenatal counseling, developing best practice guidelines for counseling that incorporate trauma-informed care, and designing a training curriculum that includes a focus on communicating empathy while also sustaining physician wellness, the fetal care community can optimally counsel and support parents receiving a prenatal diagnosis of CHD, thereby promoting parent, family, and physician well-being.

Declaration of Competing Interest

The authors report no proprietary or commercial interest in any product mentioned or concept discussed in this article.

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