




Adults with CHD balancing motivations and concerns in pregnancy decision-making

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Original Article

Cite this article: West KM, Bayley E, Pechan J, Engelberg RA, Albright C, Buber J, and Steiner JM (2023) Adults with CHD balancing motivations and concerns in pregnancy decision-making. *Cardiology in the Young* **33**: 2221–2227. doi: [10.1017/S1047951122004139](https://doi.org/10.1017/S1047951122004139)

Received: 4 April 2022

Revised: 4 August 2022

Accepted: 28 November 2022

First published online: 12 January 2023

Keywords:

Adult CHD; pregnancy motivations; risk assessment; patient perspectives; qualitative research

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Tweet: Patients with CHD balance internal and external motivations with health risks when considering pregnancy.

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Abstract

Background: While the incidence of pregnancy has increased among individuals with adult CHD, little has been described about considerations and experiences of patients with adult CHD regarding pregnancy. **Objective:** We aimed to explore patients' motivations, concerns, and decision-making processes regarding pregnancy. **Methods:** In April 2019–January 2020, we conducted in-depth telephone interviews with patients (n = 25) with simple, moderate, or complex adult CHD, who received prenatal care at the University of Washington during 2010–2019 and experienced a live birth. Transcripts were analysed using thematic analysis. **Results:** Participants described motivations for pregnancy as both internal desires (motherhood, marriage fulfillment, biological connection, fetal personhood, self-efficacy) and external drivers (family or community), as well as concerns for the health and survival of themselves and the fetus. Factors that enabled their decision to maintain a pregnancy included having a desire that outweighed their perceived risk, using available data to guide their decision, planning for contingencies and knowing their beliefs about termination, plus having a trusted healthcare team, social support, and resources. Factors that led to insurmountable risk in subsequent pregnancies included desire having been fulfilled by the first pregnancy, compounding risk with age and additional pregnancies, new responsibility to an existing child, and reduced healthcare team and social support. **Conclusions:** Understanding individuals' motivations and concerns, and how they weigh their decisions to become or remain pregnant, can help clinicians better support patients with adult CHD considering pregnancy. Clinician education on patient experiences is warranted.

As treatments for adults with CHD permit better health status into adulthood, pregnancy incidence is increasing,¹ and guidelines for managing pregnancy and adult CHD exist.² With additional data regarding pregnancy outcomes in this population, more clinical evidence is available to support shared decision-making between patients and clinicians regarding planning and carrying out pregnancy.^{3–7} However, clinician support for pregnancy may vary, given different levels of experience and comfort caring for patients with adult CHD throughout pregnancy. Less is known about the considerations involved in patients' decisions to become pregnant.

A concept analysis of risk perception in pregnancy among individuals without medical conditions has been proposed.⁸ Attributes of risk perception include the existence of risks to the patient or fetus, and the patient's knowledge and beliefs about risk severity. Consequences of risk perception include decisions regarding birth site and clinicians, medications, health behaviours, and prenatal screening. Motivations for pregnancy have been described in typical-risk populations^{9,10} in five categories in the Motivation to Have a Child Scale: as intrinsic (enjoyment of having a child), to realize one's own life goals, for feelings of pride and success, to meet expectations of others, and lack of motivation. Details regarding how these concepts are experienced for women with adult CHD have not been described in depth.

In this qualitative study, we explored the perceptions of risks and motivations identified by women with adult CHD in the Pacific Northwest United States as they reflected on factors important to them in making pregnancy-related decisions. Understanding how patients navigate risk may help cardiology and obstetric specialists more effectively support their patients and offer insight for patients considering pregnancy.

Materials and methods

This study's methods are described in detail elsewhere, as this article reports a subset of the data from our interview study.¹¹ Briefly, women with simple, moderate, or complex adult CHD per current guidelines¹² who had received prenatal care during 2010–2019 at the University of

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Washington were identified through medical records query and invited by phone and email to participate in a telephone interview. Semi-structured interviews took place between April 2019 and January 2020, lasted 24–64 minutes, and were audio-recorded and professionally transcribed. Questions covered the effect of the participant's heart condition on their life, their interest in pregnancy, clinician recommendations regarding pregnancy, the circumstances and decisions leading to pregnancy, their experiences of pregnancy, labour, delivery, and recovery, and reflections on their care and advice for other patients with adult CHD. Selected interview questions are listed in Supplemental Figure 1. Demographic data including adult CHD diagnosis were collected from the medical record.

Four analysts (EB, JP, JMS, KMW) independently applied a deductive codebook to transcripts in pairs and reconciled discrepancies through consensus. Two analysts (JMS, KMW) conducted a thematic analysis¹³ of coded data. This manuscript reports on themes derived from a subset of codes including “ACHD impact,” “motivations for pregnancy,” “risk-benefit decisions,” “pregnancy planning,” “emotions,” and “social support.” Participants' views on their pregnancy care are reported in Steiner et al.¹¹

Results

All participants ($n = 25$) had experienced at least one live birth; 21 (84%) had more than one live birth. The sample included 6 participants with simple adult CHD (24%), 11 with moderate (44%), and 8 with complex (32%) (Table 1). We report our results in three domains: motivations for pregnancy, risks and concerns, and decision-making in the context of concerns and motivations. We propose a schema for patient considerations of pregnancy in the context of adult CHD (Fig 1). Additional illustrative quotations are reported in Table 2.

Domain 1: Motivations for pregnancy

Participants' reported motivations for pregnancy fell into three categories: a) internal reasoning regarding identities of motherhood, family or marriage, and biological connections in parenthood; b) external reasoning related to cultural or family expectations; and c) motivations specific to unintended pregnancy.

a. Internal motivations: Most participants described a desire to be a mother or “have a baby” or “have a family.” For many participants, not having children was not an option, based on their own deep desires and views of marriage and womanhood. Whether planned or not, pregnancy held important meaning for their lives.

Motherhood identity: The most cited reason for becoming pregnant or carrying a pregnancy was a desire to be a mother ($n = 22$ of 25). Most described a lifelong personal desire; one developed a strong desire in her twenties, and one was particularly interested in the experience of pregnancy. Generally, this was described as a normal desire to be a parent: “I guess wanting to have a baby . . . What girl doesn't want to be a mom? I mean, I know there are some girls out there that don't, but I always thought one day I will eventually be a mom” [28 years old, complex ACHD].

Family identity: Some participants described their desire for pregnancy in terms of the importance of family and marriage, as a collective desire for a family, or a love for children: “I'm the youngest of six and I have, I think, 11 nieces and nephews and we just have a lot of kids. It's kind of just part of my family, so I really wanted that” [36 years old, moderate]. Some expressed beliefs about having children as central to the meaning of marriage: “I love

Table 1. Participant characteristics.

Characteristic	Mean, Median or Percent (n)
Mean current age	35 years Range 23–46
Median age at pregnancy	30.5 years Range 15–41
Any pregnancy before 25 years old	28% (7)
Median time since delivery	4 years Range 0–9
More than one live birth	84% (21)
Race/Ethnicity	
White	68% (17)
Asian	24% (6)
AIAN*	4% (1)
Hispanic/Latina	4% (1)
Married/partnered	76% (19)
Employed	60% (15)
Insured	92% (23)
CHD** Lesion Severity	
Simple	24% (6)
Moderate	44% (11)
Complex	32% (8)
CHD Lesion***	
Anomalous coronary artery	8% (2)
Aortic coarctation	4% (1)
Atrial septal defect	16% (4)
Congenital aortic stenosis / bicuspid aortic valve	20% (5)
Congenital mitral regurgitation	4% (1)
Double chamber right ventricle	4% (1)
Double inlet left ventricle	8% (2)
Partial anomalous pulmonary venous return	4% (1)
Pulmonary atresia intact ventricular septum	4% (1)
Tetralogy of Fallot	8% (2)
Transposition of the Great Arteries, D-type (atrial switch)	8% (2)
Transposition of the Great Arteries, L-type	8% (2)
Tricuspid atresia	4% (1)
Ventricular septal defect	12% (3)

*American Indian/Alaska Native

**CHD = congenital heart disease.

***Lesions are not exclusive; some participants had multiple lesions.

kids, I feel like marriage is having no meaning without kids. Only if you have kids, it's complete. Like your life would be boring. How long can you keep looking at your husband's face?” [44 years, moderate].

Biological parenthood: Some participants had considered alternative methods of becoming a parent, such as adoption or surrogacy, but were deterred by the expense, potential for emotional

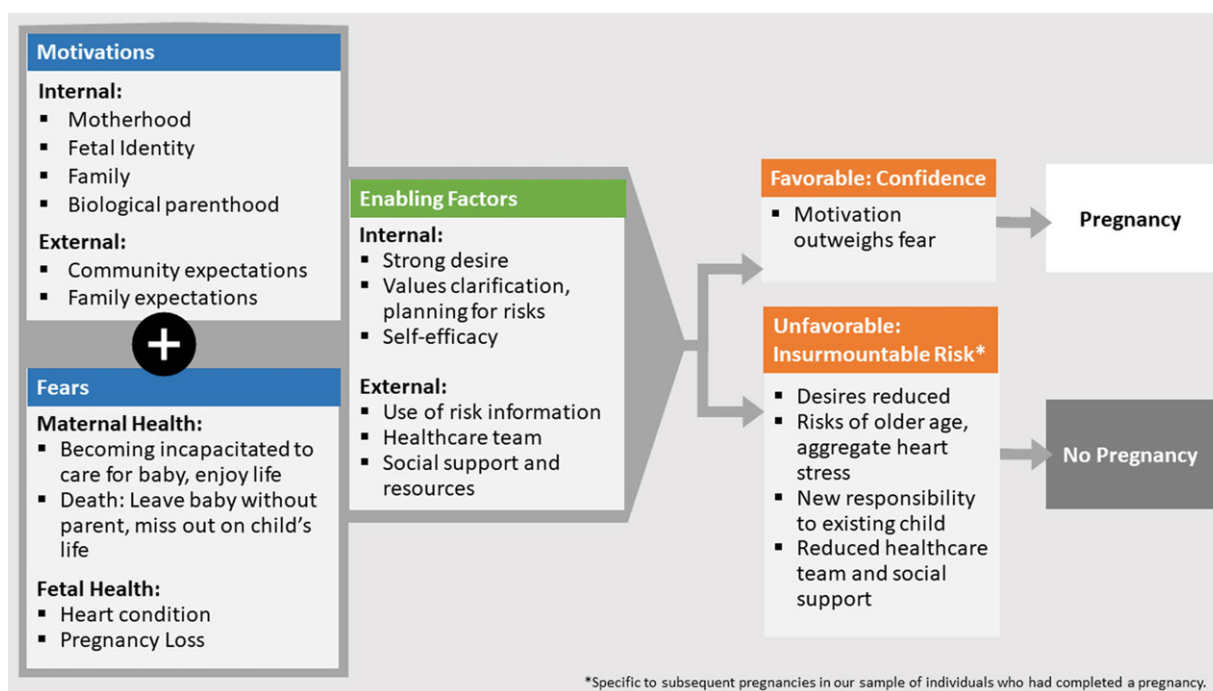


Figure 1. Schema representing factors influencing the decision of individuals with adult CHD who carried out a pregnancy.

distress, or fear of being dismissed because of their heart condition. Several spoke about wanting to bear their own children or to have the biological connection with the child. “I just think, a natural progression of a marriage. Of wanting to have child that’s half you and half your husband, and then generations later passing on those family traditions, and just having that connection with your spouse as well as with your family, past and present, to then be able to for the future” [46 years, moderate].

b. External motivations: Other motivations derived from expectations set by or for others. Approximately a third of participants shared reasons focusing on cultural or community expectations. While external motivations were also internalised by participants, rather than being described in terms of intrinsic value, these reasons were described as motivations enacted through childbearing.

Community expectations: Some participants described socially normalised expectations to have children, regardless of having a heart condition. One explained cultural pressures that she felt prior to marriage that influenced her eventual decision to become pregnant. “It’s kind of part of the culture I grew up in that . . . becoming pregnant is not a choice . . . It’s kind of like your existential reason of living . . . You are considered like this abject failure in the society if you didn’t have a child . . . So, I guess that pressure was always there” [34 years, simple].

Family expectations: In addition to desiring a family, some participants wanted to give their partner a child, their parents a grandchild, or their existing child a sibling. “The situation that really made us say ‘Oh, let’s just do it’ was my husband’s parents both fell ill at the same time. We wanted to be able to share a grandchild with them before they passed” [34 years, simple].

c. Unintended pregnancies: Eight participants (32%) representing all three adult CHD groups reported at least one unintended pregnancy. These were for typical reasons, including lack of access to or failed birth control or having discontinued their birth control method due to unacceptable side effects.

One participant pointed out, “Babies happen, they’re not always planned” [23 years, moderate]. For some, these pregnancies occurred before planned pregnancies, and for others, these occurred after having children, knowing the physical effects of pregnancy. Some reported lacking knowledge about preventing pregnancy or the risks associated with being pregnant with their condition. Nearly all participants had not discussed contraceptives with their adult CHD clinicians.

Most participants who experienced unintended pregnancies desired future pregnancies. Five participants who experienced unintended pregnancies reported that they did not consider terminating their pregnancies because of their beliefs about fetal personhood. One participant reported that she did terminate because of poor health and lacking adequate health insurance to address her symptoms. After she was financially able to obtain an adult CHD diagnosis and treatment, she safely fulfilled her wish to carry a pregnancy. Another participant reported no preexisting motivation to become a parent, however she described both of her unintended pregnancies positively: “It was another adventure . . . The question is why not? . . . I have been diagnosed with a life-threatening illness, but at the same time I don’t know. I just chose to go through with it” [37 years, moderate].

Domain 2: Risks and concerns

Like people without heart conditions, motivations for pregnancy in our population were tempered by concerns. The primary concerns reported focussed on risks to the fetus and risks to participants’ own health and life, in the context of adult CHD.

a. Risks to the fetus: Concerns about the fetus centered on perceived increased risk of adverse health conditions and miscarriage, particularly later in the pregnancy. Half of participants (52%) reported at least one pregnancy loss. Many reflected on the grief associated with that loss and compounded worry during subsequent pregnancies. Some worried about genetically passing on

Table 2. Selected illustrative quotations supporting core themes.

Domain 1: Motivations for pregnancy
<i>Internal motivations:</i> motherhood identity, family identity, biological parenthood
“Prior to becoming pregnant, I think that that’s just something that I really wanted to experience. I feel like as a woman—not everyone chooses to make that decision, but I think it’s something that, it’s such a special experience and such an incredible bond that you can’t describe to anyone unless you had a child.” [36 years old, moderate CHD*]
One participant had always expected that her heart condition would prohibit pregnancy and that she would adopt. When she learned that she could carry a pregnancy, a biological child became the simpler option. “The transition was just like oh okay, this is a possibility Because I guess I had just shut it out, so for me, it wasn’t necessarily a super hard transition . . . I want to adopt, but my end goal is to have a kid.” [34 years old, complex CHD]
<i>External motivations:</i> community, family
“I was in a really good relationship, a committed relationship. That individual didn’t have a child, and so it was really being able to give someone that. I wanted my son to grow up with a sibling.” [26 years old, moderate CHD]
<i>Context of unintended pregnancies:</i> fetal personhood
“Every woman has their right, I completely respect that . . . For me, it’s my body, and I don’t believe that’s an option for me. Yes, I probably sound dumb because I have this heart issue and my life can depend on it, but it’s just not an option for me . . .” [26 years old, moderate CHD]
Domain 2: Risks and concerns
<i>Risks to the fetus</i>
She reflected on her thoughts early in pregnancy, “Is my body going to be able to support [the baby] and him be healthy? And then obviously genetically, it’s, what, 50% that he would have a bicuspid valve, so, is he going to have any anomaly?” [46 years old, moderate CHD]
<i>Risks to self</i>
“I was mostly just worried about going into heart failure and then how that would impact my life afterwards, like would I be able to take care of my baby? How would I work? How would I support myself and my, now, child, or am I going to die?” [27 years old, complex CHD]
Domain 3. Decision-making in the context of risks and benefits
<i>Internal enabling factors:</i> desire over fear, values clarification and planning for risks, self-efficacy
“If I didn’t have this condition, we probably would’ve had kids a few years later . . . I always felt like there was a time clock ticking. It’s not like the normal woman clock. It’s like, I’m on the edge of needing another surgery . . . Can I have kids after the second surgery? . . . And so we made the decision to do it when we did it because of fear of not being able to do it later.” [36 years old, moderate CHD]
<i>External enabling factors:</i> information, trust in their healthcare team, social support
“I kind of trusted the doctors after that point. I put all my trust into them and then myself on being able to carry it and take care of it and stuff.” [28 years old, complex CHD]
<i>Insurmountable subsequent risk</i>
“I don’t think I want to be pregnant again. It was a lot of mental, financial, physical stress. And I have a child now, and she just turned five. So being away from her for six months, being in-patient, would be difficult . . . I know that she would be taken care of and everything, but there’s just so much else going on. And I know a lot more about my heart now, and that makes me way more scared now to be pregnant than when I was young and didn’t really look into my heart condition so much, because you’re invincible.” [34 years old, complex CHD]

*CHD = congenital heart disease.

their heart condition. One accepted high perceived risk and relied on fetal imaging for reassurance.

b. Risks to self: Prominent fears for participants’ health included death, serious illness, or permanent health decline. These fears tended to arise upon further questioning, rather than top-of-mind. Several participants reported that, even if informed about these risks, risk was not truly understood until after pregnancy, which was both disconcerting and a relief to those who preferred to avoid worry during pregnancy.

During subsequent pregnancies, worries for participants’ own health were described in terms of their existing child(ren). Several reported fearing that ill health would prevent them from taking care of their children during pregnancy, or require hospital stays far from their children, or losing the ability to provide or care for their children afterward. Some worried that they would not see their children grow up.

Domain 3: Decision-making in the context of motivation and concern

Participants reported a mix of excitement and fear when balancing motivations and risks of pregnancy. Although some described willingness to assume any risks to carry a pregnancy, many used available evidence and other factors such as a trusted healthcare team, social support, and self-efficacy to inform their decisions.

a. Internal enabling factors: Participants discussed their own feelings which, when present or strong enough, contributed to their confidence in carrying a pregnancy.

Desire over fear: For many considering their first pregnancy, desire outweighed fears of genetic transmission, pregnancy loss, and risks to self. “I wouldn’t do it now, but I probably still would have if I didn’t have a kid. That plays in a lot to my decision, I think . . . Are you willing to risk your life for this? This could be

the outcome” [34 years, complex]. For several, the looming potential for declining health motivated an earlier timing of pregnancy.

Values clarification and planning for risks: Some participants dealt with risks by predetermining their views on various situations, including pregnancy termination. “We were both confident in the fact that we may terminate it prematurely, in the event that my health was being put in jeopardy . . . the biggest thing for my husband and I, is that we wanted Mom . . . to be as active and introduce our child to all the things that brought us together. If I wasn’t able to do that then what’s the benefit?” [36 years, moderate]. In contrast, another participant reported she would not terminate under any condition. “[My doctor] had advised me if I was okay with adopting or foster care because she knew because of my beliefs that I would never terminate a pregnancy regardless of how it affected my health” [37 years, complex].

While some chose not to share their pregnancy news until later in pregnancy, one participant described celebrating with family early because of anticipated pregnancy loss. “The thrill of finally being pregnant . . . then early on we brought our family in . . . just so they would have some time to be able to celebrate us, to celebrate the pregnancy so that if something did happen” [46 years, moderate].

Self-efficacy: For some, confidence was based on a feeling, a sense that the pregnancy was “meant to be,” or trusting their own bodies to carry the pregnancy. “It’s kind of a weird thing. I’m not really religious, but for some reason . . . I had this overwhelming feeling it would be okay. That’s really the only way I can describe it, is I just thought it would be fine” [35 years, complex]. One participant reported confidence from having outlived other health expectations: “Hell, if I made it four weeks old when I was supposed to be dead . . . I figured obviously I’m here for a reason, so why not take the chance on getting pregnant? . . . I just defied all odds, from what I was told” [23 years, moderate].

b. External enabling factors: Participants also described external factors that contributed to pregnancy decision-making.

Information: Several sought information about their individual conditions to inform their decisions. Some pursued pre-pregnancy testing to ensure that their hearts were likely to withstand hemodynamic demands of pregnancy, and those without such care expressed regret over missing that opportunity for information. Pre-pregnancy testing was seen as a kind of certification or sign-off to become pregnant. “I mean I can’t look at my own heart . . . So once we had that objective data, I think we felt very confident” [36 years, moderate].

Trust in their healthcare team: Participants shared a range of experiences with clinician recommendations regarding pregnancy, comparing recent care with prior, sometimes negative experiences with other clinicians. Some reported that regular monitoring by their adult CHD clinician helped them to avoid stress. Having confidence in their care team, especially physicians who were experienced with adult CHD and pregnancy, inspired confidence in their own ability to carry the pregnancy. This concept is further described in Steiner et al.¹¹

Social support: Some patients relied on both practical resources and moral support from their families, parents, siblings, friends, and partners to lend confidence in their decision to proceed with pregnancy. “The support of my husband, honestly . . . He’s like, ‘You’ve got to get those fears and worries out of your head.’ I had his full support, and that was about the only thing really that was why” [23 years, moderate].

c. Insurmountable subsequent risk: Many factors contributed to individuals’ decisions to avoid subsequent pregnancy. These

included shifts in desire, having core motivations satisfied by prior pregnancies; increasing risk corresponding with age and accumulated physical stress; and prioritising their existing children. Participants who described lack of support from their family, social network, or healthcare teams, cited this reason not to pursue an otherwise wanted pregnancy. “My entire support team thought it was a bad idea . . . I did end up terminating that pregnancy at the discussion of [doctors] . . . They didn’t have that confidence that they had with the first two [pregnancies] and I reacted to that” [36 years, moderate].

Some participants described sadness over their decision that additional risks to their health were not acceptable. One opted for sterilisation after two children, not wanting to risk an unintended pregnancy. “It still kind of hurts now, just because I know that I can’t have any more kids, because it could end up costing me my chance with the kids I have . . . At the same time, it was like ‘okay, well, this is how it is’” [29 years, moderate].

Discussion

This study offers one of the first detailed descriptions of the decision-making considerations for women with adult CHD who pursued pregnancy, including demonstration of the motivation-risk analysis that brought participants to their decisions. Significant motivators that participants identified included internal drivers, such as the desire to be a mother, to experience pregnancy, to have a family or fulfill their marriage, to have the biological connection a child provides, and to align with their beliefs about a fetus’s personhood. External drivers included expectations from one’s community or family, and to give to others another relation, such as a biological child or sibling. Concerns focussed on the fetus’s and their own health and survival. Decision-making depended on favourable enabling factors such as strong desire to carry a pregnancy, supporting data, confidence in the healthcare team, social support, and self-efficacy. Our study adds detail and depth to concepts described in previous studies,^{14–18} specific to a large United States healthcare setting and diverse adult CHD complexity. We also suggest a schema of decision-making factors to help clinicians better support their patients in pregnancy-related considerations (Fig 1).

Reasons for choosing pregnancy among our sample of patients with adult CHD aligned with all five categories previously described in the general population⁹ suggesting this population does not differ substantially in motivations. In contrast, while some themes in our schema reflect the concept analysis for risk prediction proposed for patients without medical conditions,⁸ our population had more complexity to consider, and perhaps constrained choices regarding medications, birth sites, and clinicians.¹¹ Our findings are more similar to, although with nuanced distinctions, a study characterizing risk perception among patients with high-risk pregnancies in Iran, which identified the perception of controlling risk through resources or faith as enabling patients’ to choose pregnancy, and that priorities of motherhood and fulfilling ideas of marriage outweighed perceived risks.¹⁹ Our study population tended to overestimate their risks of genetic transmission and pregnancy loss, compared with clinical perspectives on these risks. Understanding the source of this overestimation and how to mitigate these fears is a topic for further research.

Our findings are also consistent with a phenomenological study of a small, homogeneous sample of Italian women with adult CHD (n = 12) focused on participants’ feelings about pregnancy and being a mother with adult CHD.¹⁵ They reported that participants’

Key Points for Clinicians

- Adult patients with CHD describe similar internal and external motivations for pregnancy as patients without heart disease, which are tempered by perceived risks associated with pregnancy.
- Shared decision-making regarding pregnancy is desired by adult patients with CHD. Using data to guide decisions, planning for adverse outcomes, and having a trusted healthcare team and social supports are key.
- Pre-conception counseling and contraceptive counseling and access are needed as regular aspects of CHD care for all patients of reproductive age.

Figure 2. Summary of key points for clinicians.

decisions were influenced by desire to be mothers, fears about uncertainties and increased risk to mother and baby, and the importance of social support from both their community and their healthcare team. A qualitative study of Australian women with (n = 20) and without (n = 20) adult CHD, all who had never been advised against pregnancy, reported largely similar motivations and concerns in both groups. However, the study represented milder disease and lacked a rich description of patients' perspectives.¹⁴ Future research is needed to determine whether our schema, based on a more diverse, US-based sample, would apply more broadly to women with high-risk pregnancies.

Nearly half of pregnancies in the United States of America are unintended,²⁰ a trend which holds in the adult CHD population.²¹ While one-third of our participants experienced at least one unintended pregnancy and some were advised against pregnancy, those who reported discussing contraception with adult CHD clinicians typically did so only after becoming pregnant, with the intention of spacing or avoiding future pregnancies. In a multi-center study (n = 505 with moderate to complex adult CHD), 25% reported an unintended pregnancy, and 43% reported having discussed contraception with their adult CHD clinicians.²² Similar to another study,²¹ at least two of our participants became pregnant while using contraception. This highlights the impracticality of simply recommending against becoming pregnant, particularly without providing reliable, long-term means of prevention. Our data demonstrate the necessity of raising conversations about contraception proactively in cardiology care, ensuring that adolescents and older adults alike receive relevant information and access to contraceptives with low failure rates to reduce the rate of unintended pregnancies and allow for recommended¹ pre-pregnancy cardiology care. The need for contraception and pre-conception counseling to become a regular part of cardiology care may become even more urgent with the recent US Supreme Court ruling²³ overturning *Roe v. Wade*, as termination will become increasingly difficult to access in much of the United States.

Our sample was limited to a single centre that specialises in adult CHD care, and so does not represent views of all patients. However, our multidisciplinary programme is long-standing and supports a five-state region, and those who had been pregnant under the care of other clinicians shared views based on their experiences at all sites. Additionally, despite purposive sampling efforts, response bias is likely; the women who agreed to participate all had positive feelings about their care at our programme. While we attempted to reach a demographically representative cohort, and we did reach patients with a range of religious and cultural views, our final sample does not represent the full diversity of the adult CHD population. Our sample size is small, though typical of qualitative studies. Finally, we only included individuals who had at least one live birth. If we had included individuals who had

considered and opted against pregnancy due to their CHD, we likely would have seen a different decision-making balance among participants. This topic, including interviewees who opted for pregnancy termination before giving birth, should be explored in future research.

Individuals may be likely to carry pregnancies even when medically contraindicated, and they may hold different risk assessments than those of their clinicians. We agree with Cauldwell et al. that additional clinician training is warranted.²⁴ To provide patient-centered care, clinicians must understand patients' motivations and how they choose to assume risks of pregnancy, in addition to pregnancy outcomes data, to present confidently and engender trust among patients (Fig 2). Future studies might consider clinicians' experiences of managing pregnancy in patients with adult CHD and their knowledge of patients' motivations and risk considerations, the correlation between adult CHD patient trust in their clinician and pregnancy outcomes, and ways to ensure that clinicians and patients share an understanding about what is important to the patient and what level of risk patients are willing to take to fulfill their pregnancy goals.

Supplementary material. To view supplementary material for this article, please visit <https://doi.org/10.1017/S1047951122004139>

Acknowledgements. None.

Financial support. Funding was provided by a grant from the Alpha Phi Foundation.

Conflicts of interest. None.

Ethical standards. None.

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