Sexual and Reproductive Health Care Experiences and Perceptions of Women with Congenital Heart Disease

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Abstract

Due to medical advances, women with congenital heart disease (CHD) are living longer, healthier lives and many are considering pregnancy. The hemodynamic changes of pregnancy present high risks of morbidity and mortality for many women with CHD. As little is known about these women's reproductive health experiences, this study explores their perceptions of pregnancy and family planning care as related to CHD. Women ages 18–45 years with a diagnosis of CHD associated with a World Health Organization (WHO) classification II-IV for pregnancy morbidity and mortality participated in individual, semi-structured interviews exploring their experiences, attitudes, and preferences toward parenthood, pregnancy, contraception and family planning care provision. Interviews were audio-recorded, transcribed verbatim. Two independent coders performed analysis using deductive and inductive coding approaches. Twenty women with CHD participated in interviews (average age 30.1 years, SD 5.85). Nine women had a prior pregnancy and 14 considered becoming a parent in the future. We identified 5 key themes among the women: (1) CHD impacted their reproductive health goals and decisions; (2) Women with CHD perceived a lack of safe contraceptive methods for their condition; (3) Women desired tailored, disease-specific sexual and reproductive health (SRH) information; (4) Women viewed their cardiologist as the primary source for SRH information and prefer provider-initiated discussions starting in adolescence; and (5) Women desire coordinated pre-pregnancy and intrapartum care between their cardiologists and women's health providers. These results provide a foundation for interventions to improve patient-centered interdisciplinary reproductive healthcare for this population.

1. Background

Due to advances in surgical and medical management, women with congenital heart disease (CHD) are reaching reproductive age in increasing numbers. In 2010 an estimated 500,000 women with CHD were of childbearing age in the United States [1]. Women with CHD are 22 times more likely to experience maternal mortality compared to the general population [2]. That said, the heterogeneity of patient's CHD manifests the importance of individual family planning counseling to optimize health [3].

The changes to cardiovascular physiology during pregnancy are profound, and include increased plasma volume, decreased systemic and pulmonary vascular resistance, and increase in cardiac output [4]. The risk of maternal morbidity and mortality is specific to the patient's heart condition. Several tools have been designed to assist in triaging pregnancy risk for women with CHD; the modified World Health Organization (WHO) pregnancy risk classification ranges from Class I, with no increased risk of maternal mortality or morbidity, to Class IV, wherein the risk is so high that pregnancy is thought to be contraindicated [5]. While some women with CHD can tolerate the hemodynamic changes of pregnancy, others may be at risk for both short- and long-term morbidity and mortality.

Given these concerns, early, multidisciplinary reproductive health counseling is recommended for this population [5-8]. The American College of Obstetricians and Gynecologists (ACOG) and The American Heart Association (AHA) have recommended individualized pre-pregnancy counseling by

multidisciplinary physician teams including Adult Congenital Heart Disease (ACHD) and Maternal Fetal Medicine (MFM) providers [8]. However, despite these care recommendations, women with CHD have poor knowledge regarding their cardiovascular pregnancy risk and the safety of various forms of contraception, and many hold misconceptions about CHD and sexual and reproductive health (SRH) [9-14].

Limited attention has been given to the SRH experiences of women with CHD, and the SRH care provision and preferences of women in this population have not been examined. The expectation that most patients with CHD will live long and full lives has prompted promotion of formal transition programs for adolescent patients to transition from pediatric to adult providers. SRH counseling is highlighted as a key feature of this transition process [15]. The ACHD clinical community has increased efforts to optimize SRH counseling and management for patients with CHD, underscoring the importance of clarifying patients' needs, priorities, and feedback. This study explores the perceptions, knowledge, and care experiences regarding SRH of adult women with CHD. Results can help improve patient-centered models of care for women with CHD as they face their reproductive futures.

2. Methods

2.1 Study participants

We recruited a convenience sample of women ages 18-45 years with diagnosis of CHD associated with modified WHO class II-IV for pregnancy morbidity and mortality (increased risk). Participants were recruited through the outpatient clinic at a single large, accredited university-affiliated CHD center in Pittsburgh, Pennsylvania between July 2019 and January 2020. The recruitment site was based out of a pediatric hospital. Providers at the recruitment center were both pediatric-trained cardiologists and adult-trained cardiologists with additional sub-specialty training in ACHD. Participants were screened by a research coordinator (OMS). Participant WHO class was confirmed with the cardiology provider. Additional clinical information was obtained via patient report and limited to diagnosis, date of diagnosis and medication use.

2.2 Interviews and data collection

Participants completed semi-structured, individual telephone interviews investigating topics related to CHD-specific SRH. Interviews were conducted by a single female, cis-gender Master's level research coordinator (OMS) with significant experience conducting sensitive qualitative interviews in women with chronic disease. The interviewer was not directly involved in the participants' clinical care.

We structured interviews with key questions and probes intended to guide conversation. We derived our interview guide from prior research conducted by the research team with reproductive-age women with cystic fibrosis [16]. We asked participants to reflect on their experiences with SRH care and counseling and how it interacted with their CHD. The interviews explored past reproductive SRH experiences,

reproductive goals, experiences obtaining and using contraception, and the role of their cardiology provider in their SRH care.

We audio-recorded, de-identified, and transcribed all interviews verbatim. Interviews lasted between 31 and 58 minutes. We reached thematic saturation after the 15th interview, suggesting that this sample was adequate for capturing the range of responses [17]. We conducted an additional five interviews to ensure no new themes arose. The University of Pittsburgh Institutional Review Board approved this study [IRB#19040336].

2.3 Data analysis

A transcription firm contracted by the University of Pittsburgh transcribed the interviews. We analyzed interview transcripts through an iterative process of coding to identify themes [18]. After reviewing the codebook of prior research among women with other chronic conditions [16-19], two coders with formal training in qualitative research (NS and OMS) independently reviewed 5 transcripts and developed an initial set of codes. NS is a cis-gender female cardiologist. The coders discussed and used these transcripts to create an initial codebook. Using a consensus coding approach, each transcript was independently coded, and then the study team met to review coding, discuss any discrepancies, and define new codes. This process was iteratively repeated after every 5 transcripts. A senior investigator (TMK) reviewed the codebook as a means of investigator triangulation and provided feedback as needed to reach consensus about any differences. TMK is a cisgender female pulmonologist and health services researcher. The final coding scheme was applied to all transcripts and central themes were identified. We selected representative quotations from the transcripts to illustrate themes. We used Dedoose software to facilitate data management and coding.

3. Results

3.1 Study participants

The final sample included 20 participants with an average age 30.1-41.8+/- 5.85 [21-43] years. The research team confirmed participants all were modified WHO class II-IV for pregnancy morbidity and mortality with their cardiologist. Specific diagnoses as identified by the participants are included in **Table 1**. Nine of the participants reported complex CHD, and 10 reported CHD of moderate severity as per the American College of Cardiology/AHA anatomic classifications for CHD. Given the anonymous nature of the interviews, we are unable to comment on the physiologic grade of participants' CHD [9]. One participant did not know her diagnosis. Nine participants had previously been pregnant, and 18 were sexually active. **Table 2** summarizes the demographic information of the participants.

3.2 Themes

Several central themes regarding SRH and CHD emerged in the interviews. These are discussed below and highlighted by participant quotes**.**

3.2.1. Theme 1: Women saw CHD as impacting their reproductive health goals and decisions.

The majority of participants expressed a belief that having CHD has impacted their reproductive health goals and decisions. They viewed CHD as a major factor in considering whether and how to have children. This applied both to participants who had engaged in pre-pregnancy counseling with their cardiology provider and to those who had not. One 23-year-old participant with tetralogy of Fallot noted, “Well, see, I’ve also always grown up knowing that there was potential that I couldn’t [safely get pregnant], I guess. I don’t even know if I should’ve assumed that.”

Many participants considered themselves to be at higher risk for complications with pregnancy and delivery. Most of the participants had considered adoption, fostering, or use of a surrogate. “I still would like kids in some way,” stated a 34-year-old woman with pulmonary atresia, ventricular septal defect and dextrocardia, “Even though I can’t necessarily have them on my own, there’s other options out there, which is good.”

Several participants shared concerns that their children would be at increased risk of inheriting CHD. A 35-year-old woman with coarctation of the aorta stated, "I don’t know what or if I would pass anything on to them and I wouldn’t wanna put them in a position where they would maybe have a life-threatening illness.”

Additionally, participants were concerned about their ability to parent well. One 34-year-old participant with pulmonary atresia and atrial septal defect stated: "I do have concerns...in the future am I gonna be able to keep up with [my kids]... Am I gonna be able to support them with anything with school or help with field trips and stuff...Normally, you put your kids first." About half of the participants expressed concern that they would not be able to do important things with their children; further, several stated they feared being a burden to their children. One 33-year-old participant with aortic stenosis expressed, “It scares me because I don’t want any child I would have to worry about me…I don’t want them to have to worry about the health issue[s] of their mother.”

3.2.2. Theme 2: Women with CHD perceived a lack of safe contraceptive methods for their condition.

While several patients had a good understanding of which contraception methods were safe and available to them, a large proportion of this high-risk population did not, and incorrectly believed they had limited or no options for birth control. Half of all participants stated that they believed there were limitations on safe contraceptive methods for their specific CHD condition. For this reason, four women who were sexually active did not use contraception or used only barrier methods. A 33-year-old woman with valvular disease noted, “[My gynecologist] said, ‘Oh wait—you’re a heart patient. You probably shouldn’t be taking [the pill].’ I relied on condoms from that point on, because I didn’t feel that that was safe for me.” A 22-year-old woman with hypoplastic left heart now post-heart transplant reported, "I'm not sure if I'm allowed to take birth control because of my heart condition. Yeah, it's complicated.”

Six of the twenty participants reported using long-acting reversible contraception methods (LARCs), and one had a salpingectomy.

3.3.3. Theme 3: Women with CHD desire tailored, disease-specific SRH information.

As participants' reproductive health concerns were impacted significantly by the presence of CHD, most participants expressed a desire for SRH information that was specific to them. While some participants had good experiences with pre-pregnancy from their cardiologists, others reported inadequate discussion and education. "Going into [pregnancy] I wanted to know my cardiac risks...I wanted to know what effect pregnancy was gonna have on my heart, what effect my pregnancy was going to have on my repair...what the effect to my heart was going to be during delivery. Those were things that really weren't ever discussed," reported a 35-year-old woman with a bicuspid aortic valve and coarctation of the aorta.

Several participants reported that they were not given SRH information until they became pregnant. "It was uncertainty and then just feeling passed off, I guess," stated one participant, "because the next answer was, 'Oh, we'll refer you to a high-risk pregnancy specialist.' Well, before I get pregnant, I want to know how I'm going to be affected and where I'm at with my heart health and all of that."

A minority of participants searched online for CHD-specific SRH information as a first step, noting that it is difficult to know what information obtained on the internet is directly applicable to them. One 35-year-old woman with coarctation of the aorta noted, "I don't know how much I found specific to me, specific to my [cardiac] repair." Several participants reported being influenced by misinformation they found online. One 23-year-old woman with a ventricular septal defect and mitral valve insufficiency stated, "I one time saw [on the internet] that each baby you have is doubly at risk to develop your specific condition… I was really afraid for years to ever have another baby, but then I talked to my doctor about this… and she said not to her knowledge. The baby is at an increased risk, about three times more likely than the average baby. Even so, that's no so great a risk that it should scare me that badly."

3.3.4. Theme 4: Women with CHD viewed their cardiologist as the primary source for SRH information and prefer provider-initiated reproductive health discussions starting in adolescence.

Almost all participants reported having a primary care provider and most had an obstetrics and gynecology provider. Despite this, almost all participants expressed a preference for their cardiologist to provide SRH information. Participants highlighted that their cardiology provider is the most familiar with their overall health and risks and often knows them best and for the longest duration. "I've always included my cardiologist in almost everything I do just because I know that the circulatory system…is so interconnected," noted a 34-year-old woman with pulmonary atresia and atrial septal defect. Participants also stated that they frequently end up being referred back to their cardiologist by other health care providers for disease-specific information. "See, a lot of doctors always refer me to my cardiologist," stated a 23-year-old female with Tetralogy of Fallot, "I don't think I've ever had a doctor that has not told me to refer to my cardiologist, because they don't know.".

Most participants preferred cardiology providers to initiate discussions about SRH. "Looking back, I wish that he [my cardiologist] had brought up…that I don't have any implications for my heart in terms of family planning. It's something I thought about, and would be nice to know," stated one 34-year-old participant with bicuspid aortic valve and coarctation of the aorta.

The majority of participants felt that these discussions should start in early adolescence, and many felt that their providers had not started SRH discussions early enough. "Even when we were younger…I'd wonder if I could have kids. I was only...11, 12 years old, but I was thinking that could be a big question in my future," noted one 34-year-old participant with pulmonary atresia and an atrial septal defect. To this point, one 34-year-old participant with pulmonary atresia, VSD and dextrocardia recommended, “just keeping the lines of conversation open with the cardiologist even when they’re in pediatric cardiology… just to make sure they know because they really should be responsible about it for their own health, and so they know there’s a good way to go through it.”

A few participants expressed concern that the presence of parents in the room for outpatient visits may deter providers from initiating conversations about SRH. One 21-year-old woman with ventricular noncompaction stated, “[The conversation] was more like a one-way because I didn’t really know what to say because my mother was also right outside of the door. I’m sure she heard the conversation, so I just felt awkward.”

3.3.5. Theme 5: Women with CHD desire coordinated pre-pregnancy and intrapartum care between their cardiologists and women’s health providers, and those who engaged with integrated care had positive experiences.

Among those who had been pregnant, participants had a variety of experiences, both positive and negative, with care during pregnancy and delivery. They unanimously expressed a desire for robust communication and coordination of care between women’s health providers and cardiologists. There was a distinct difference between the participants who received care in a multi-disciplinary center involving coordinated care between women’s health and cardiology providers, and those who had not. One 34-year-old participant with bicuspid aortic valve and coarctation of the aorta stated, "In general it's good to have a whole team to communicate amongst each other when someone who has a heart condition is pregnant. At least when I was pregnant it seemed like there was a communication gap.” The participants acknowledged that providers in each specialty were limited in what they could provide, further necessitating coordinated communication and care. "We always end up getting shoved back to our cardiologist. The cardiologist doesn't understand a lot of the reproduction stuff…Somebody's got to be there for us," expressed another 36-year-old participant with Tetralogy of Fallot.

Women who reported a positive experience with their prenatal and peripartum care emphasized the value of interdisciplinary communication. “Everyone did a really great job with staying on the same page,” stated one 32-year-old participant with Tetralogy of Fallot “[My different health care providers] worked in tandem to make sure that I had the safest delivery possible and I of course was high risk, so all of my information was communicated back and forth, and...I never felt like I fell through the cracks or that any

of the information was disoriented." Additionally, participants who had received pre-pregnancy counseling by a multidisciplinary team that included genetic counseling were thankful for this interaction.

4. Discussion

This study explored patient experiences, attitudes, and preferences related to reproductive health in CHD care. We found that women with CHD face a variety of disease specific SRH concerns and desire coordinated reproductive healthcare from their cardiologists and women's health providers.

These results build on the limited previous work evaluating the SRH experiences of women with CHD. One cross-sectional analysis found that 50% of women with CHD report moderate to significant concerns regarding pregnancy and their reproductive futures [12]. A prior qualitative analysis found that women with CHD have similar motivations to conceive regardless of the severity of risk associated with CHD, and pursue pregnancy at similar rates [20]. We found that women with CHD frame their reproductive goals around the presence of CHD, and harbor fears about their own risks during pregnancy and delivery, as well as heritability and their ability to parent well. Early and individualized counseling has the potential to provide insight and allay fears.

Prior studies also show that many women with CHD carry misconceptions about CHD and SRH. In one cross-sectional analysis, only 51% of women with CHD accurately assessed their cardiovascular pregnancy risk classification, while approximately 22% underestimated, and 27% overestimated their risk [11]. Most women with CHD do not have an absolute contraindication to pregnancy; however, many require medication adjustments or pre-pregnancy medical and surgical optimization to encourage safe pregnancy and delivery [8,21]. One study found that 18 of 98 women for whom pregnancy is *not* contraindicated reported having been counseled to avoid pregnancy by a doctor or nurse [10]. While our analysis did not assess individual clinical severity of disease in relation to understanding of risk, we identified the lack of clarity many of the participants had with respect to their risk and the desire for specific tailored SRH information.

Prior investigations found that one- to two-thirds of women with CHD reported never discussing the risks of pregnancy or the safety of contraception related to their heart condition with a physician [9-11, 13-14]. Most of the participants in our study report having had a conversation about SRH with a provider at some point; however, many still had misconceptions about their risks and options for care. This is perhaps reflective of the timing of counseling. Similar to prior work [9-10], most participants in our study did not have SRH discussions with a provider until they were either trying to conceive or had already conceived.-This is too late to provide optimal care. In prior studies, 80-90% of adult women with CHD reported being sexually active [10-11]. One analysis found that age of sexual debut for women with CHD was later when compared with peers, and fewer adolescents with CHD were sexually active when compared with age-matched peers [22]. Similar studies of women with other pediatric-onset chronic disease, however, demonstrate sexual behaviors in line with the general United States population [23]. Participants in our study expressed a clear desire for early discussions regarding SRH.

Women with CHD will ideally transition from a pediatric cardiology provider to an adult congenital heart disease (ACHD) specialist in adolescence [7]. Despite this, a 2018 systematic review of qualitative studies found that approximately half of young adults with CHD were not transferred to an ACHD center. [24]. SRH and pregnancy management are a substantive part of ACHD providers' care for patients, and emphasized as essential elements of care for transition clinic providers [7]. Initiation of transition to an ACHD program may potentially engage patients in SRH counselling earlier, but even when executed appropriately this may be too late to start counselling. The AHA's best practices recommendation for age-appropriate reproductive health information on sexual health, contraception, and pregnancy is to begin at age 12 years (Class I) [15], meaning that pediatric cardiologists are responsible for early conversation initiation. There is limited data on how comfortable pediatric-trained cardiologists are with SRH conversations. Our sample was recruited from both pediatric and adult congenital clinics at a children's hospital site; thus, we are unable to speak to differences between providers in accordance of their training.

Additionally, women with CHD have reported receiving incorrect recommendations regarding contraceptive safety [10-11]. Only about half of women with CHD in prior studies reported receiving information on birth control options and risks from a provider [9-11,13-14]. As demonstrated in our study, women frequently expressed concern about a lack of safe contraception options due to CHD. Estrogen-containing birth control options are not recommended for patients with certain conditions, including cyanosis, prosthetic heart valves, history of blood clots, and hypertension [25]. Long-acting reversible contraceptives (LARCs), including intrauterine devices and subdermal implants, are safe for most women with CHD [4, 26]. Six of the 20 participants in our study reported using LARCs, and although a minority, this is a higher proportion than prior studies on contraceptive use in women with CHD [9]. In one cross-sectional analysis, 40% of sexually active adult women with CHD reported using either no contraception or exclusively methods with high failure rates (as deemed by the Centers for Disease Control and Prevention as Tier III, or a 18-28% failure rate per year) [10, 27]. The consequences of inadequate patient understanding of contraceptive options are significant. Lindely et al found that 33 of 100 women with CHD ages 18-45 years reported at least one unplanned pregnancy [10]. Contraception is critical for women with CHD to prevent or time pregnancies for optimal health.

While some women avoid using effective contraception for fear it is unsafe, others are prescribed contraception without knowledge of the potential risks. In one study of 31 women for whom the use of combined oral contraceptives was felt to be contraindicated, 14 had previously been on this method of birth control [10]. This manifests the importance of individualized SRH counseling; moreover, it draws attention to the key role of cardiologists in providing this counseling. Given the heterogeneity of disease within the CHD population, most participants believed that their cardiologist is uniquely capable of providing personalized information related to SRH. ACOG and AHA developed enhanced guidelines reflecting the importance of SRH counseling by CHD providers [6-8]. Given only about half of women in prior studies report getting SRH counseling from their cardiologist, it is clear that many cardiologists have not fully embraced this role [9-11, 13-14].

The collaboration between cardiology and women's health providers is key to filling gaps in SRH care provision that patients are experiencing. There is evidence that multidisciplinary SRH counseling and care is effective for women with CHD. With a combined family planning and CHD clinic, more than half of the women with CHD who participated switched to more effective methods of contraception, suggesting that women who wanted to avoid pregnancy were able to access more effective methods [28]. In our sample, women who received prenatal and peripartum care in a multidisciplinary model had good experiences and felt well cared for. The success of integrated models of care for SRH management should be built on going forward.

Our findings are similar to other pediatric-onset chronic disease populations, including cystic fibrosis, epilepsy, and inflammatory bowel disease [15, 29-30]. For patients with each of these childhood-diagnosed chronic diseases, women had disease-specific SRH concerns, and their illness played into their SRH decisions and goals [15, 18, 29-30]. Additionally, the need for sub-specialist SRH education and counseling was identified among these populations. Women with such conditions often believe that their subspecialist functions as a de facto primary care provider and thus assumes a role in SRH care provision and counseling [15, 18, 29-30]. As noted, despite most of our participants having PCPs, most desired SRH information specifically from their cardiologist.

By examining the concerns, knowledge, and care experiences of women with CHD we gain insight into a key stakeholder perspective of what is being done well, and what needs to be improved. This study is the first to explore the attitudes of patients with CHD as they relate to SRH education and delivery. Importantly, this work highlights the specific components of SRH counseling that are valued by this population and will inform efforts to integrate SRH care into practice, in line with existing guidelines. Future investigation is needed to understand provider knowledge about, comfort with, and training in SRH counseling.

This study has several limitations. First, qualitative research is used to explore participant perspectives in great depth; thus, generalizability may be limited due to small sample size and self-selection bias of participants interested in the topic area. Likewise, these interviews were conducted at a single center and thus may not be generalizable to a broader population. Interviews were conducted by one interviewer, and data analysis was performed by the collaboration of 3 members of the study team. As is true of qualitative research, the positionality of the study team influenced the interview interactions. Through debriefings after interviews and regular team meetings during our analysis, we attempted to understand these influences and enhance the credibility of the study. Third, health information, including disease severity and patient experience, is subject to recall bias. Finally, the participants had providers from different training backgrounds (pediatric cardiologist vs ACHD specialist); thus, it is possible that the perspectives and training experiences of different providers impacted their approach to SRH counselling and the experiences of the participants.

In conclusion, women with CHD frequently receive inadequate SRH counseling, and hold misconceptions regarding their reproductive health risks and options. Cardiologists play an essential role in early SRH

counseling, pre-pregnancy counseling, and peripartum management. Counseling should start early in teen age years (pediatric cardiologist) and continued through and after transition to ACHD care. Strong provider-facilitated interdisciplinary communication is paramount in successful patient care experiences.

Declarations

Statements and Declarations:

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References

1. Gilboa SM, Devine OJ, Kucik JE, Oster ME, Riehle-Colarusso T, et al. (2016). Congenital heart defects in the United States: Estimating the magnitude of the affected population in 2010. *Circulation; 134(2):*101-9.
2. Thompson JL, Kuklina EV, Bateman BT. (2015). Medical and obstetric outcomes among pregnant women with congenital heart disease. *Obstetrics and Gynecology, 126(2):*346-54. https://doi.org/10.1161/circulationaha.115.019307.
3. Thorne S, MacGregor A, Nelson-Piercy C. (2006). Risks of contraception and pregnancy in heart disease. *Heart, 92*:1520 –5. https://doi.org/10.1136/hrt.2006.095240.
4. Mahendru AA, Everett TR, Wilkinson IB, et al. A longitudinal study of maternal cardiovascular function from preconception to the postpartum period. J Hypertens 2014; 32:849. https://doi.org/10.1097/hjh.0000000000000090.
5. Regitz-Zagrosek V,Roos-Hesselink JW, Bauersachs J, Blomstrom-Lundqvist C, Cifkova R, et al. (2018). 2018 ESC guidelines on the management of cardiovascular diseases during pregnancy. *European Heart Journal*. 39(34):3165-3241. https://doi.org/10.5603/kp.2019.0049.
6. Presidential Task Force on Pregnancy and Heart Disease (2019). ACOG Practice Bulletin No. 212: Pregnancy and Heart Disease. *Obstetrics & Gynecology, 133(5):* e320-e356. https://doi.org/10.1097/aog.0000000000003243.

7. Warnes CA, Williams RG, Bashore TM, Child JS, Connolly HM, et al. (2008). ACC/AHA 2008 Guidelines for the Management of Adults with Congenital Heart Disease: Executive Summary: a report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines (writing committee to develop guidelines for the management of adults with congenital heart disease). *Circulation, 118*:2395–451. https://doi.org/10.1161/circulationaha.108.190811.
8. Stout KK, Daniels CJ, Aboulhosn JA, Bozkurt B, Broberg CS, et al. (2019). 2018 AHA/ACC Guideline for the Management of Adults With Congenital Heart Disease: Executive Summary: A Report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines. *Journal of the American College of Cardiology, 73*:1494. https://doi.org/10.1016/j.jacc.2018.08.1028.
9. Kovacs AH, Harrison JL, Colman JM, Sermer M, Siu SC, et al. (2008). Pregnancy and contraception in congenital heart disease: what women are not told. *Journal of the American College of Cardiology, 52:*577. https://doi.org/10.1177/1753495x14568055.
10. Hinze A, Kutty S, Sayles H, Sandene EK, Meza J, et al. (2013). Reproductive and contraceptive counseling received by adult women with congenital heart disease: a risk-based analysis. *Congenital Heart Disease, 8:*20–31. https://doi.org/10.1111/j.1747-0803.2012.00677.x.
11. Lindley KJ, Madden T, Cahill AG, Ludbrook PA, Billadello JJ. (2015). Contraceptive Use and Unintended Pregnancy in Women With Congenital Heart Disease. *Obstetrics & Gynecology, 126*(2):363-369. https://doi.org/10.1097/aog.0000000000000911.
12. Harrison JL, Silversides CK, Oechslin EN, Kovacs AH. (2011). Healthcare needs of adults with congenital heart disease: study of the patient perspective. *Journal of Cardiovascular Nursing, 26:*497–503. https://doi.org/10.1097/jcn.0b013e31820984c9.
13. Lyon, S., Katz, A., Farrell, A., Shew, M. (2021). Reproductive health conversations in adolescents with congenital heart disease. *Cardiology in the Young*; 1-6. https://doi.org/10.1017/s1047951121000019.
14. Kaemmerer M, Vigl M, Seifert-Klauss V, Nagdyman N, Bauer U, et al. Counseling reproductive health issues in women with congenital heart disease. Clin Res Cardiol. 2012 Nov;101(11):901-7. https://doi.org/10.1007/s00392-012-0474-9.
15. Sable C, Foster E, Uzark K, Bjornsen K, Canobbio MM, et al. (2011). Best practices in managing transition to adulthood for adolescents with congenital heart disease: the transition process and medical and psychosocial issues: a scientific statement from the American Heart Association. *Circulation, 123*:1454-1485. https://doi.org/10.1161/cir.0b013e3182107c56.
16. Leech MM, Stransky OM, Talabi MB, Borrero S, Roe AH, et al. (2021). Exploring the reproductive decision support needs and preferences of women with cystic fibrosis. *Contraception, 103(1):*32-7. https://doi.org/10.1016/j.contraception.2020.10.004.
17. Crabtree BF, Miller ML, editors. Doing qualitative research. London: Sage; 1999.
18. Saldana J. The coding manual for qualitative researchers. 2nd ed. London: Sage; 2016.

19. Wolgemuth T, Stransky OM, Chodoff A, Kazmerski TM, Clowse ME, et al. (2021). Exploring the preferences of women regarding sexual and reproductive health care in the rheumatology context: a qualitative study. *Arthritis care & research,* 73(8):1194-1200. https://doi.org/10.1002/acr.24249.
20. Ngu, K., Hay, M., & Menahem, S. (2014, Sep). Case studies of the perceptions of women with high-risk congenital heart disease successfully completing a pregnancy. Heart Lung Circ, 23(9), 811-817. https://doi.org/10.1016/j.hlc.2014.03.019.
21. Task Force on the Management of Cardiovascular Diseases During Pregnancy of the European Society of Cardiology. (2003). Expert consensus document on management of cardiovascular diseases during pregnancy. *European Heart Journal,* 24:761-81. https://doi.org/10.1093/eurheartj/ehr218.
22. Reid GJ, Siu SC, McCrindle BW, Irvine MJ, Webb GD. (2008). Sexual behavior and reproductive concerns among adolescents and young adults with congenital heart disease. *International Journal of Cardiology, 125*:332–338. https://doi.org/10.1016/j.ijcard.2007.02.040.
23. Britto MT, Garrertt JM, Dugliss MA, Johnson CA, Majur JM, et al. (1999). Preventive services received by adolescents with cystic fibrosis and sickle cell disease. *Archives of Pediatric and Adolescent Medicine, 153(1):*27-32. https://doi.org/10.1001/archpedi.153.1.27.
24. Chong LSH, Fitzgerald DA, Craig JC, et al.(2018). Children's experiences of congenital heart disease: a systematic review of qualitative studies. *European Journal of Pediatrics, 177*:319-36. https://doi.org/10.1007/s00431-017-3081-y.
25. Silversides C, Sermer M, Siu S. (2009). Choosing the Best Contraceptive Method for the Adult with Congenital Heart Disease. *Current Cardiology Reports, 11*:2. https://doi.org/10.1007/s11886-009-0043-7.
26. Vigl M, Kaemmerer M, Seifert-Klauss V, Niggemeyer E, Nagdyman N, et al. (2010). Contraception in women with congenital heart disease. *American Journal of Cardiology, 106*:1317–21. https://doi.org/10.1016/j.amjcard.2010.06.060.
27. Division of Reproductive Health, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention (CDC). (2013). U.S. Selected Practice Recommendations for Contraceptive Use, 2013: adapted from the World Health Organization selected practice recommendations for contraceptive use, 2nd edition. *Morbidity and Mortality Weekly Report Recommended Report, 62*:1-60.
28. Rogers P, Mansour D, Mattinson A, O'Sullivan JJ. (2007). A collaborative clinic between contraception and sexual health services and an adult congenital heart disease clinic*. Journal of Family Planning and Reproductive Health Care, 33*:17–21. https://doi.org/10.1783/147118907779399648.
29. Kazmerski TM, Sawicki GS, Miller E, Jones KA, Abebe KZ, et al. (2018). Sexual and reproductive health behaviors and experiences reported by young women with cystic fibrosis. *Journal of Cystic Fibrosis, 17(1):*57-63. https://doi.org/10.1016/j.jcf.2017.07.017.
30. Manski R, Dennis A. (2014). A mixed-methods exploration of the contraceptive experiences of female teens with epilepsy. *Seizure, 23(8*):629-35. https://doi.org/10.1016/j.seizure.2014.04.014.

Tables

Table 1: Primary diagnoses as identified by participants with associated WHO pregnancy risk class

No. Participants	Primary CHD lesion[a]	WHO pregnancy class
3	Pulmonary atresia	III
5	Tetralogy of Fallot	II
1	Transposition of the great vessels	III
1	Ebstein's anomaly	III
1	Single ventricle	II
4	Coarctation of the aorta	II
1	Noncompaction cardiomyopathy	II-III
1	Aortic stenosis	II
2	Primary valve disease, unspecified[b]	II-IV
1	Primary arrhythmia[c]	Unknown

Note: [a]Primary lesion as identified by patient

[b]Participant did not provide additional specific details

[c]Participants identified "Wolff Parkinson White syndrome" as primary lesion, although this would have not have qualified for study participation on initial screening and is thus unlikely to be the primary lesion

Table 2: Participant demographics

Characteristics		*n (%)* *n=20*
Age, mean (SD)		30.05 (5.9)
Race	White	17(85%)
	Black	3 (15%)
Age at CHD diagnosis	Birth	13 (65%)
	<1 year	3 (15%)
	>1 to <3 years	2 (10%)
	>3 years	1 (5%)
	Unknown	1 (5%)
Pregnancy history	Ever Pregnant	9 (45%)
	Never Pregnant	11 (55%)
Contraception, current	LARC	6 (30%)
	Surgical sterilization	3 (15%)
	OCP	3 (15%)
	Depo Provera	2 (10%)
	Barrier methods	2 (10%)
	None	2 (10%)
	Active pregnancy	2 (10%)
Has PCP	Yes	19 (95%)
	No	1 (5%)
Has OB/Gyn	Yes	19 (95%)
	No	1 (5%)

Note: surgical sterilization includes salpingectomy and vasectomy; Barrier methods include condoms and spermicide. *Abbreviations:* LARC (Long acting reversible contraceptives); OCP (oral contraceptive pill)