



Published in final edited form as:

Womens Health Issues. 2025 ; 35(2): 65–73. doi:10.1016/j.whi.2025.01.005.

Reproductive Health Counseling and Outcomes Among Women With Congenital Heart Defects: Results From the Congenital Heart Survey to Recognize Outcomes, Needs, and Well-Being, 2016–2019

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Supplementary Data

Supplementary data to this article can be found at <https://doi.org/10.1016/j.whi.2025.01.005>.

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention. We did not collect data on the sex or gender of the birthing person. For clarity in terminology, “maternal” is used to identify the person who is pregnant or postpartum throughout this manuscript; the authors are aware that pregnancy is not equated with the decision to parent nor do all parents who give birth identify as mothers. The following text makes use of concepts or descriptions that align with the traditional gender definitions by using concepts such as “maternal”; however, the concepts described are translatable to all people who experience a pregnancy, regardless of their gender identity.

Abstract

Background: Guidelines recommend tailored reproductive health counseling for women with congenital heart defects (CHDs) beginning in adolescence, yet provider adherence to recommendations remains understudied, particularly outside specialized cardiac care settings.

Study Design: We conducted a cross-sectional cohort study among women aged 19 to 38 with CHDs, identified from active population-based birth defects registries in three states. Participants completed surveys from 2016 to 2019, including questions about contraception, pregnancy counseling, concerns, and experiences. Multivariable Poisson regression, adjusted for sociodemographic and health characteristics, assessed associations between CHD severity, counseling, and reproductive health outcomes.

Results: Of 765 women, those with severe CHDs, compared with non-severe, were more likely to report receiving clinician counseling about safe contraceptive methods (44.0% and 13.7%; adjusted prevalence ratio [aPR] = 3.0; 95% confidence interval [95% CI] [2.2, 4.0]), pregnancy, (63.3% and 16.5%; aPR = 3.6; 95% CI [2.7, 4.6]), and pregnancy avoidance (32.0% and 6.4%; aPR = 4.3; 95% CI [2.9, 6.6]); be concerned about ability to have children (40.9% and 31.2%; aPR = 1.4; 95% CI [1.1, 1.8]), and delay/avoid pregnancy (26.6% and 10.7%; aPR = 2.2; 95% CI [1.5, 3.2]). No disparity was found in ever being pregnant (30.0% vs. 37.2%; aPR = 1.0; 95% CI [0.7, 1.2]). One-third of the respondents with any CHD reported concerns about their ability to have children (33.6%).

Conclusion: We found that only a minority of women with CHDs reported receiving counseling on safe contraception and pregnancy, and about a third reported concerns about their ability to have children. These findings highlight a gap between guideline recommendations and clinical practice, underscoring the need for improved reproductive health discussions for women with CHDs.

Congenital heart defects (CHDs) are the most common structural birth defects, affecting approximately 1% of all births (Hoffman & Kaplan, 2002; Reller et al., 2008). With advances in medical management and improved surgical techniques, most people with CHDs now survive to adulthood (Oster et al., 2013). There are an estimated 1.4 million adults living with CHDs in the United States (Gilboa et al., 2016). In 2017, defect-specific expert recommendations were established for the care of adults with CHDs, including pregnancy and pre-pregnancy planning (Canobbio et al., 2017). Individuals assigned female at birth, hereafter referred to as women, with CHDs have higher risk of pregnancy-related morbidity and mortality (Downing et al., 2020; Hardee et al., 2021; Roos-Hesselink et al., 2019), but even with preexisting cardiovascular and hemodynamic dysfunction, most women with CHDs have healthy pregnancies (Downing et al., 2020; Hardee et al., 2021).

National guidelines recommend that health care providers counsel all women with CHDs about their reproductive health beginning in adolescence (Stout et al., 2019). A small study of women with CHDs receiving cardiology care found that 51% recalled ever receiving counseling about contraception, and only 37% were informed about the elevated risk of pregnancy-related complications (Kovacs et al., 2008). However, studies conducted among adults currently receiving congenital cardiac care may be biased toward those with greater access to health care or with more severe CHDs, reducing generalizability to most

individuals with CHDs who are lost to cardiac follow-up care (Andrews et al., 2023; Apers et al., 2015; Khairy et al., 2008; Mackie et al., 2009; Spector et al., 2018).

Using a population-based cohort of women with CHDs, including those who have not had recent cardiology care, we assessed clinician counseling about reproductive health and reproductive outcomes and examined whether these differed by sociodemographic and clinical characteristics, including CHD severity.

Materials and Methods

The Centers for Disease Control and Prevention (CDC) funded two sites, Arizona and Arkansas, to use their population-based birth defects registries with active case-finding methods to identify individuals born with CHDs between 1980 and 1997 and recruit these individuals to participate in the Congenital Heart Survey To Recognize Outcomes, Needs, and well-being (CH STRONG). The CDC selected sites based on number and diversity of cases, and geographic diversity of the sites. Additionally, the CDC used the Metropolitan Atlanta Congenital Defects Program (MACDP) data for the third site. Surveys were distributed between 2016 and 2019; therefore, respondents were 19 to 38 years old at time of survey (Farr, Galindo, et al., 2020).

Sites identified 11,695 individuals born between 1980 and 1997 with a six-digit CDC-modified version of the British Paediatric Association (CDC/BPA) codes for CHDs (745.0–746.860, 746.880–746.9, 747.1–747.4, 747.9) in the birth defects registries. CHD diagnoses were recorded at or around the time of birth and confirmed by clinical review. After excluding individuals deceased or incarcerated at the time of survey, 9,312 remained eligible. Sites found current contact information for 74.6% ($n = 6,943$), all of whom were mailed survey materials. Surveys comprising 81 questions on health care, comorbidities, quality of life, education, and work history were completed by 1,656 (23.9%) individuals; women answered additional reproductive health questions. Survey data were linked to census data, birth defects registry information, and vital records. Using an established algorithm, CHD CDC/BPA codes were classified into five categories: severe, shunt + valve, shunt, valve, and other (Webb & Williams, 2001). Severe CHDs consisted of defects that typically require intervention in the first year of life. The remaining four categories were combined into a non-severe category for this analysis.

We only used data on female respondents ($n = 894$) as determined by sex from the birth certificate, in this study referred to as women. CH STRONG was approved by the CDC Institutional Review Board (Protocol #6768).

Survey Question Design

Among the 81 questions on the entire CH STRONG survey, survey developers included 39 questions from U.S. national and state-based surveys, including the National Health Interview Survey, National Health and Nutrition Examination Surveys, Behavioral Risk Factor Surveillance System, and American Community Survey. Among the included reproductive health survey questions, one (“Have you ever been pregnant?”) was sourced from National Health Interview Survey. However, CH STRONG was one of the first projects

to survey women with CHDs on their sexual and reproductive health within the context of their heart condition, so there were no existing national surveys available from which to draw the remaining CHD-specific questions to assess reproductive health. For these and any other questions unique to CH STRONG, survey developers ensured use of plain language to improve readability.

Reproductive Health Counseling, Concerns, and Outcomes

Three CH STRONG questions inquired about receipt of reproductive health counseling by a clinician: 1) “Has a doctor, nurse, or other health care worker ever talked with you about the safest type of birth control or contraception to use because of your heart problem?”; 2) “Has a doctor, nurse, or other health care worker ever talked with you about special concerns about becoming pregnant because of your heart problem?”; and 3) “Has a doctor, nurse, or other health care worker ever advised you to avoid pregnancy because of your heart problem?”

We also examined three questions on reproductive health concerns and outcomes: 1) “How concerned are you about your ability to have children?”; 2) “Have you ever delayed or avoided getting pregnant because of concerns about your heart problem?”; and 3) “Have you ever been pregnant?”

Sociodemographic and Health Characteristics

Sociodemographic characteristics for this analysis included state of birth (Arkansas, Arizona, or Georgia), self-reported race/ethnicity (Hispanic, non-Hispanic Black, non-Hispanic white, or none of the above), insurance status (private, public, other, or none), education level (less than high school, high school graduate, or some college or above), marital status (has ever been married or never married), and, based on census tract-level data for the respondent’s current address, residential rurality (>50% urban vs. ≤50% urban) and percentage of families in census tract with household income below the federal poverty level (<10% of families, 10%–40% of families, or >40% of families). CH STRONG also included a question asking whether the survey was completed by proxy (e.g., by a parent).

We categorized race/ethnicity based on two survey questions: 1) “Do you consider yourself to be Hispanic or Latino?”, with available responses “Yes” or “No”; and 2) “What race or races do you consider yourself to be? One or more categories may be selected” with options “American Indian or Alaskan Native,” “Asian,” “Black or African American,” “Native Hawaiian or Pacific Islander,” and “White.” Eight respondents did not report race or ethnicity. So as not to exclude these cases, we used the maternal race/ethnicity reported on the birth certificate. All those indicating Hispanic ethnicity are categorized as “Hispanic,” regardless of their reported race. To protect the identity of respondents, race/ethnicity categories were aggregated for those containing fewer than 10 respondents. The “None of the Above” race/ethnicity category includes respondents from the Non-Hispanic American Indian or Alaskan Native, Non-Hispanic Asian, Non-Hispanic Native Hawaiian or Pacific Islander, and Non-Hispanic Multiple Races groups.

Health characteristics included presence of cardiac and non-cardiac comorbidities, based on survey report, and documentation of a comorbid chromosomal abnormality (e.g., Down

syndrome), derived from data from the birth defects registries. Cardiac comorbidities were identified by survey response to “Have you ever been told by a doctor or other health professional that you had any of the following conditions?: congestive heart failure; cardiac dysrhythmias or irregular heartbeat; a heart attack (also called myocardial infarction); stroke; hypertension, also called high blood pressure.” Non-cardiac comorbidities were identified by survey response to the question: “Have you ever been told by a doctor or other health professional that you had any of the following conditions?: diabetes or sugar diabetes; obstructive sleep apnea; cancer or a malignancy of any kind; a mood disorder or depression; asthma; ulcer (stomach, duodenal, or peptic ulcer); arthritis, gout, lupus, or fibromyalgia.”

Statistics

Initially, we examined the prevalence of sociodemographic characteristics by CHD severity using χ^2 tests. In a previous analysis, CH STRONG respondents largely reflected the eligible population. However, respondents were slightly more commonly non-Hispanic white and had severe CHDs compared with non-respondents (Glidewell et al., 2018). To minimize response bias and improve generalizability, we standardized prevalence estimates of respondents to the entire population of eligible women ($n = 4,515$) by maternal race/ethnicity and CHD severity, as well as birth year and site. Maternal race/ethnicity reported on the birth certificate was used for standardization, as this was available for all eligible participants, versus reported race/ethnicity, which was only available for respondents. Standardized prevalence estimates and 95% confidence intervals (CIs) were calculated by CHD severity for all reproductive health counseling and outcomes. Mean proportions of those with severe CHDs and those with non-severe CHDs were compared using z-scores and corresponding p -values. Additionally, the percentage of women in CH STRONG reporting ever being pregnant was compared with the general population of women ages 19 to 38 years who reported ever being pregnant using data from the 2017 National Health Interview Survey (NHIS) (National Center for Health Statistics, 2017). To account for complex sampling, NHIS-specified weighting was used to generate a population-based estimate and 95% CI.

Adjusted prevalence ratios (aPRs) and 95% CIs for reproductive health counseling and outcomes were calculated using multivariable Poisson regression. Models for reproductive health counseling and outcomes included all considered variables, except no women with chromosomal abnormalities reported ever being pregnant, so this variable was removed from the model. Two sensitivity analyses were conducted: 1) excluding all individuals with proxy-reported survey responses, and 2) excluding those with known chromosomal abnormalities. All analyses were performed in R version 4.2.1 (R Core Team, 2021).

Results

Population Description

Of the 894 female respondents, 14.4% ($n = 129$) were excluded from analysis due to missing data. The 765 women included in the analysis differed from those excluded with respect to pregnancy history, state of birth, insurance status, education, and proxy report (Supplemental Table 1). Of the analytic sample, 28.5% ($n = 218$) had severe CHDs, but

proportions differed across sites (Table 1). A larger percentage of women with severe CHDs had chromosomal abnormalities and proxy-reported surveys. No other characteristics differed by CHD severity.

Prevalence of Reproductive Health Counseling, Concerns, and Outcomes

After standardization, 21.3% of the sample reported receiving counseling on safe contraceptive methods. Compared with women with non-severe CHDs, more women with severe CHDs reported receiving safe contraceptive counseling (44.0% vs. 13.7%), clinician counseling on pregnancy (63.3% vs. 16.5%), and clinician advice to avoid pregnancy (32.0% vs. 6.4%; all $p < .01$; Figure 1; Supplemental Table 2). Overall, 33.6% of women with CHDs were concerned about their ability to have children, and concerns were more prevalent among women with severe CHDs than those with non-severe CHDs (40.9% vs. 31.2%, $p = .01$). Accordingly, more women with severe CHDs reported avoiding or delaying pregnancy than did those with non-severe CHDs (26.6% and 10.7%, $p \leq .001$). Although a history of pregnancy was lower among the women with severe CHDs (30.0% vs. 37.2%, $p = .07$), this did not meet statistical significance. Additionally, a lower percentage of women in CH STRONG (35.4%, 95% CI [32.2, 38.7%]) reported ever being pregnant compared with similarly aged women in the general population (54.1%; 95% CI [51.8, 56.4%]; $p < .001$).

Factors Associated With Reproductive Health Counseling

After adjustment for potential confounders, CHD severity was still associated with reporting clinician counseling about safe contraceptive methods (aPR = 3.0; 95% CI [2.2, 4.0]), clinician counseling on pregnancy (aPR = 3.6; 95% CI [2.7, 4.6]), and advice to avoid pregnancy (aPR = 4.3; 95% CI [2.9, 6.6]; Table 2). Prevalences of clinician counseling about safe contraceptive methods (aPR = 1.5; 95% CI [1.0, 2.0]), clinician counseling on pregnancy (aPR = 1.2; 95% CI [0.9, 1.6]), and advice to avoid pregnancy (aPR = 1.4; 95% CI [0.9, 2.1]) were higher among women with at least one cardiac comorbidity, although the differences were not statistically significant as all three CIs included 1.0. Women living in the highest-poverty census tracts were more likely to report receiving pregnancy counseling about their heart condition (aPR = 1.7; 95% CI [1.0, 2.9]). More women who had ever been married reported receiving contraceptive counseling (aPR = 1.7; 95% CI [1.2, 2.5]), pregnancy counseling (aPR = 1.6; 95% CI [1.1, 2.2]), and clinician advice to avoid pregnancy (aPR = 1.4; 95% CI [0.9, 2.4]), although the 95% CI included 1.0 for the last of these. Women with proxy report were less likely than self-respondents to report receiving clinician counseling on pregnancy (aPR = 0.5; 95% CI [0.3, 0.9]). Women who were identified in MACDP were more likely to report receiving clinician counseling about safe contraceptive methods compared with women identified from the Arkansas birth defect registry (aPR = 1.6; 95% CI [1.1, 2.4]). No other characteristics were associated with reproductive health counseling or advice.

Factors Associated With Reproductive Health Concerns and Outcomes

More women with severe CHDs were concerned about their ability to have children (aPR = 1.4; 95% CI [1.1, 1.8]) and delayed or avoided pregnancy due to concerns about heart health (aPR = 2.2; 95% CI [1.5, 3.2]; Table 3). Having at least one non-cardiac comorbidity was associated with concern about ability to have children (aPR = 1.5; 95% CI [1.1, 1.9]), but

it was not associated with ever being pregnant (aPR = 1.0; 95% CI [0.7, 1.2]). Women with CHDs were more likely to report pregnancy if they had no insurance (aPR = 1.6; 95% CI [1.1, 2.4]). Those who had ever been married were more likely to have ever been pregnant than their counterparts (aPR = 2.9; 95% CI [2.1, 3.8]). Women with proxy report were less likely than self-respondents to have ever been pregnant (aPR = 0.2; 95% CI [0.1, 0.4]).

Associations did not substantially differ in sensitivity analyses excluding 71 women with chromosomal abnormalities or separately excluding 119 women with proxy-reported survey responses (Supplemental Tables 3 and 4).

Discussion

Principal Findings

This population-based survey highlights gaps in reproductive health counseling. Fewer than 30% of women with CHDs reported that they received guidance from health care providers in this area. Fewer than half of those with severe CHDs, who face elevated risks with hormonal contraceptives, reported receiving clinician counseling about safe contraceptive methods. Yet, one-third of these women reported advice by a health care provider to avoid pregnancy.

Furthermore, more than a third of women with CHDs were concerned about their ability to have children, but less than a third reported receiving clinician counseling on pregnancy related to their heart condition. Women with severe CHDs were more likely to report receiving advice by a health care provider to avoid pregnancy, have concerns about having children, and to delay or avoid pregnancy. Significantly fewer women with CHDs reported at least one pregnancy compared with similarly aged women in the general population.

Results in the Context of What Is Known

More than half of women with CHDs surveyed in previous studies conducted at congenital cardiology clinics reported receiving counseling about contraception, but those studies were performed in clinic populations that accessed specialized health care (Andrews et al., 2023; Kovacs et al., 2008; Miner et al., 2017). Consequently, the results of those studies are generalizable to less than half of the CHD population. Additionally, a recent study analyzing perceptions of sexual and reproductive health care among women with CHDs utilized in-depth interviews to identify key themes. Women with CHDs expressed concerns for safe contraceptive options tailored to their CHD and a desire for reproductive health counseling specific to their condition (Stokes et al., 2023). Our study also suggests that health care providers providing care for women with CHDs may not routinely discuss these reproductive health topics with women with CHDs, even though guidelines advise that they do so (ACOG Practice Bulletin No. 212: Pregnancy and Heart Disease, 2019; Canobbio et al., 2017).

Implications for Practice and/or Policy

The American Heart Association/American College of Cardiology, as well as the American College of Obstetricians and Gynecologists, recommend multidisciplinary reproductive

health counseling of women with CHDs by both cardiologists and obstetrician-gynecologists (ACOG Practice Bulletin No. 212: Pregnancy and Heart Disease, 2019; Canobbio et al., 2017). Women with CHDs have also expressed appreciation for multidisciplinary care that included collaboration between their cardiologist and women's health providers before, during, and after pregnancy (Stokes et al., 2023). Preconception counseling should include an individualized pregnancy plan with consideration of social factors like insurance and distance from specialty care (Canobbio et al., 2017; Miner et al., 2017). Provider-facilitated discussions about safe contraception should account for special considerations for different CHD types (Canobbio et al., 2017). For example, increased thrombotic risk must be considered when prescribing estrogen-based oral contraceptives for women with Fontan palliation, a surgical repair for hypoplastic left heart, a severe CHD (Miner et al., 2017; Pundi et al., 2016; Thorne et al., 2006).

Women with CHDs have higher risk of adverse pregnancy-related outcomes compared with those without CHDs, especially those with cardiac comorbidities; however, published obstetric care recommendations tailored to specific CHD types and status, per World Health Organization (WHO) pregnancy risk category, improve the likelihood of a healthy pregnancy (Canobbio et al., 2017; Downing et al., 2020, 2023; Farr, Downing, et al., 2023; Hardee et al., 2021; Kops et al., 2021; Roos-Hesselink et al., 2019). Pregnancy is contraindicated only for a minority of women with WHO pregnancy category IV status. This cardiac status, which includes severe mitral stenosis, severe aortic stenosis, unrepaired severe coarctation, severe aortic dilation, and previous pregnancy-related cardiomyopathy, is rare and comprises a very small proportion of women with CHDs (Canobbio et al., 2017). Still, one-third of women with severe CHDs in CH STRONG were advised by a health care provider to avoid pregnancy, and just over a quarter of women with severe CHDs chose to delay or avoid pregnancy due to their cardiac diagnosis. Provider preconceptions of women with CHDs may be a reason for the disproportionate percentage of women in CH STRONG reporting provider advice to avoid pregnancy, a phenomenon that has been documented in women with disabilities (Farr, Galindo, et al., 2023; Horner-Johnson et al., 2019).

Shared decision-making between women with CHDs and health care providers plays an important role in advancing reproductive health care. By acknowledging potential biases and prioritizing patients' preferences, providers can cultivate a more collaborative and patient-centered approach. Evidence-based continuing medical education for clinicians (including cardiologists, primary care providers, and obstetricians/gynecologists) can further enhance access to comprehensive reproductive health services for the growing population of women with CHDs. A valuable resource in this effort is the American Academy of Pediatrics and CDC's Congenital Heart Defects Toolkit (Congenital Heart Defects Toolkit, 2024).

Strengths and Limitations

In CH STRONG, efforts were made to include individuals reflective of the population with CHDs, not just those receiving care; however, the low response rate makes response bias a concern. To minimize this, estimates were weighted according to characteristics of the entire population of recruited women. We excluded 14.4% of respondents missing data on variables of interest. Women with more than a high school education, with insurance

coverage, and who self-reported survey answers were more likely included in the analytic sample. Also, counseling could have been conducted but not recalled. However, counseling not recalled by a patient is likely ineffective. Additionally, all women included in this study were of childbearing age, and counseling is recommended throughout a woman's reproductive life. Site of birth may not reflect current residence. Nevertheless, findings, especially regarding clinical practices, may be limited to Arizona, Arkansas, and Georgia and the surrounding geographic areas and influenced by local policies and practices.

A limited number of reproductive health matters were assessed to keep the survey length manageable. Questions about timing of counseling and reproductive health experiences, aside from pregnancy, were not included, diminishing the ability to analyze outcomes relative to events. Further assessment of age at counseling and detailed pregnancy and birth outcomes in a larger cohort would increase understanding.

Conclusions

Women with CHDs have similar desires to start a family as women without CHDs (Reid et al., 2008). Childbearing is a feasible option for most women with CHDs (ACOG Practice Bulletin No. 212: Pregnancy and Heart Disease, 2019; Canobbio et al., 2017); however, this study suggests about 15% of women with CHDs delay or avoid pregnancy, and compared with the general population, a lower percentage of women with CHDs report ever being pregnant. Furthermore, fewer than 30% of women with CHDs reported receiving counseling on safe contraception and pregnancy, and about a third reported concerns about their ability to have children.

Here, we present self-reported outcomes from the perspective of women with CHDs about their own reproductive health concerns and experiences. Almost half of individuals in CH STRONG had not received care from an adult congenital cardiologist within the past 5 years, and this did not differ by sex (Andrews et al., 2023). For women with CHDs, obstetrics and gynecology visits may be the only opportunity to address their unique reproductive health needs, as well as obtain referrals to appropriate cardiology care. Our results suggest most women with CHDs are not routinely receiving this care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

This analysis has been independently replicated by Amanda Dorsey, intern at the Centers for Disease Control and Prevention.

The work reported in this manuscript was funded by the Centers for Disease Control and Prevention (grant number: 1U38OT00199). The authors report no conflict of interest.

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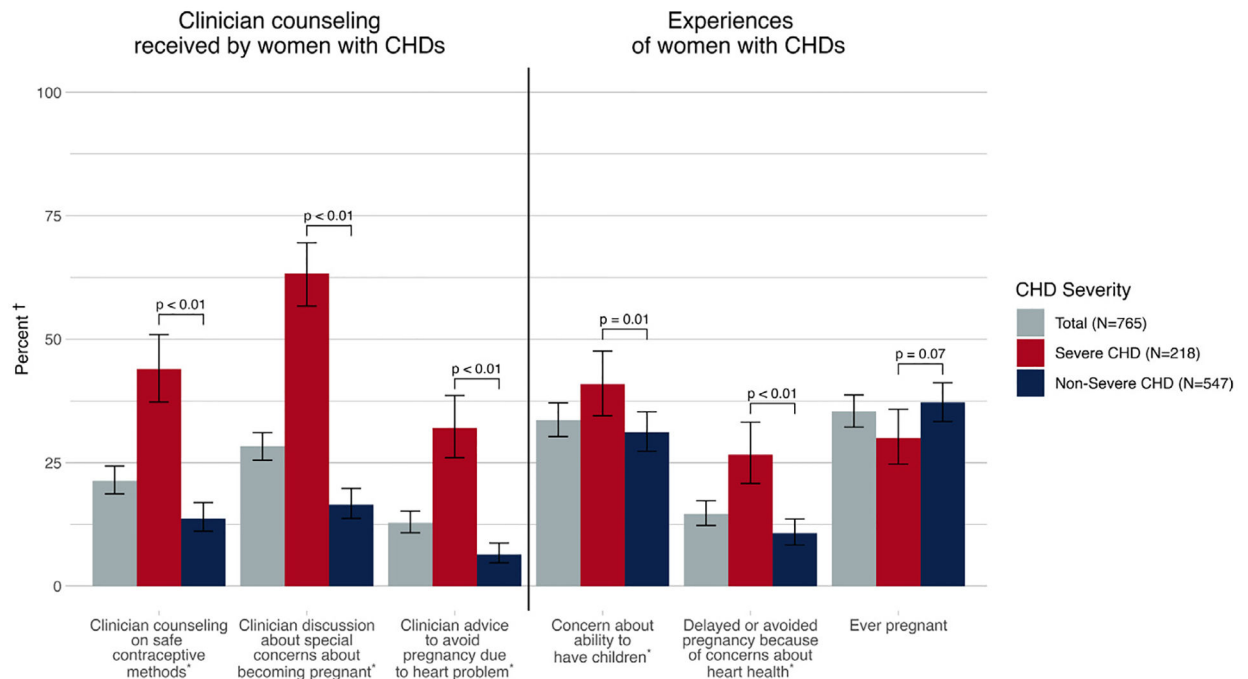


Figure 1.

Reported clinician counseling about reproductive health and reproductive health experiences among women with CHDs, by defect severity, CH STRONG, 2016, 2019. Standardized prevalence estimates and 95% confidence intervals (CIs) were calculated for all reproductive health outcomes. * $p \leq .01$ comparing severe and non-severe CHDs. †Standardized to the birth year, maternal race/ethnicity, site, and CHD severity of the CH STRONG-eligible female population. CHDs, congenital heart defects; CH STRONG, Congenital Heart Survey To Recognize Outcomes, Needs, and well-being.

Table 1
Demographic and Health Characteristics of Women With CHDs, by Severity, CH STRONG, 2016–2019

Characteristic	Total (N = 765)	Non-severe CHDs (N = 547)	Severe CHDs (N = 218)	p Value
	N (Standardized % [#])	N (Standardized % [#])	N (Standardized % [#])	
Place of birth				<.01
Arizona	319 (48.5)	254 (52.4)	65 (36.8)	
Arkansas	190 (22.9)	120 (19.1)	70 (34.1)	
Georgia	256 (28.6)	173 (28.4)	83 (29.1)	
Race/Ethnicity [*]				.61
Hispanic	72 (10.9)	50 (10.3)	22 (12.8)	
Non-Hispanic Black	138 (22.6)	104 (23.7)	34 (19.5)	
Non-Hispanic white	510 (60.1)	359 (59.6)	151 (61.7)	
None of the above [†]	45 (6.4)	34 (6.5)	11 (6.0)	
Age at survey completion, y				.58
19–24	311 (43.5)	216 (44.9)	95 (39.4)	
25–30	317 (39.7)	231 (40.0)	86 (38.9)	
31–38	137 (16.8)	100 (15.1)	37 (21.7)	
Cardiac comorbidities [‡]				.25
0 comorbidities	583 (76.0)	423 (76.9)	160 (73.4)	
1 or more comorbidities	182 (24.0)	124 (23.1)	58 (26.6)	
Non-cardiac comorbidities [§]				.76
0 comorbidities	340 (46.2)	245 (46.9)	95 (43.8)	
1 or more comorbidities	425 (53.8)	302 (53.1)	123 (56.2)	
Insurance status				.66
Private	429 (54.2)	310 (54.5)	119 (53.2)	
Public	227 (31.1)	156 (29.6)	71 (35.4)	
Other insurance	43 (5.8)	31 (5.9)	12 (5.6)	
No insurance	66 (8.9)	50 (10.0)	16 (5.8)	
Education				.37
Some college or above	518 (66.5)	377 (68.3)	141 (61.1)	
High school graduate	197 (26.5)	138 (25.7)	59 (28.6)	

Characteristic	Total (N = 765)	Non-severe CHDs (N = 547)		Severe CHDs (N = 218)		p Value
	N (Standardized % [#])	N (Standardized % [#])		N (Standardized % [#])		
Less than high school	50 (7.1)	32 (6.0)		18 (10.2)		
Census rurality designation ^{//}						.66
Mostly urban (>50%)	592 (76.4)	421 (75.9)		171 (77.9)		
Mostly rural (≤50%)	173 (23.6)	126 (24.1)		47 (22.1)		
Families in census tract with income below poverty [¶]						.06
<10%	269 (31.4)	178 (29.5)		91 (37.1)		
10%–40%	432 (59.0)	321 (60.8)		111 (53.8)		
>40%	64 (9.6)	48 (9.8)		16 (9.0)		
Down syndrome or other known chromosomal condition						.02
No	694 (90.9)	505 (92.4)		189 (86.3)		
Yes	71 (9.1)	42 (7.6)		29 (13.7)		
Marital status						.15
Never married	551 (72.7)	386 (72.7)		165 (72.7)		
Married at least once	214 (27.3)	161 (27.3)		53 (27.3)		
Survey completed by proxy						.01
No	646 (84.2)	473 (86.3)		173 (77.9)		
Yes	119 (15.8)	74 (13.7)		45 (22.1)		

Abbreviations: CHDs, congenital heart defects; CH STRONG, Congenital Heart Survey To Recognize Outcomes, Needs, and well-being.

Note: p-values in bold are <.05.

* Race and ethnicity determined by self-reported race. In the cases of missing race, maternal race/ethnicity from birth certificate was used (n = 8).

[†] None of the above races include non-Hispanic Asian or Pacific Islander, non-Hispanic American Indian or Alaska Native, non-Hispanic other, and unknown.

[‡] Cardiac comorbidities identified by “Have you ever been told by a doctor or other health professional that you had any of the following conditions?: congestive heart failure; cardiac dysrhythmias or irregular heartbeat; a heart attack (also called myocardial infarction); stroke; hypertension, also called high blood pressure.”

[§] Comorbidities identified by “Have you ever been told by a doctor or other health professional that you had any of the following conditions?: diabetes or sugar diabetes; obstructive sleep apnea; cancer or a malignancy of any kind; a mood disorder or depression; asthma; ulcer (stomach, duodenal or peptic ulcer); arthritis, gout, lupus, fibromyalgia; other.”

^{//} Proxy variable determined by census: % of individuals who live in rural areas in census tract at survey completion.

[¶] Proxy variable determined by census: % of families with children younger than 18 that live in poverty in county at survey completion.

[#] Standardized to the birth year, maternal race/ethnicity, site, and CHD severity of the CH STRONG-eligible female population.

Table 2
Associations Between Demographic and Health Characteristics and Reporting Reproductive Health Counseling Among Women With CHDs, CH STRONG, 2016–2019

Characteristic	Clinician Counseling on Safe Contraceptive Methods*		Clinician Counseling on Special Concerns About Becoming Pregnant*		Clinician Advice to Avoid Pregnancy Due to Heart Problem*	
	%	aPR	95% CI	%	aPR	95% CI
CHD severity						
Non-severe	14.3	Ref		17.7	Ref	
Severe	44.5	2.95	[2.17, 4.01]	61.0	3.52	[2.69, 4.62]
Place of birth						
Arizona	15.7	Ref		23.2	Ref	
Arkansas	24.7	1.54	[.96, 2.47]	34.2	1.33	[.90, 1.99]
Georgia	3.5	1.59	[1.06, 2.39]	35.5	1.26	[.89, 1.78]
Race/ethnicity						
Non-Hispanic white	22.4	Ref		3.2	Ref	
Hispanic	29.0	.95	[.53, 1.70]	31.9	.89	[.54, 1.47]
Non-Hispanic Black	13.3	1.30	[.84, 2.00]	26.7	.99	[.67, 1.46]
Other	2.8	.61	[.26, 1.44]	27.8	.87	[.47, 1.63]
Age at survey completion, y						
19–24	2.9	Ref		28.9	Ref	
25–30	21.5	.94	[.64, 1.36]	28.4	.80	[.58, 1.11]
31–38	3.7	1.18	[.74, 1.87]	36.5	.95	[.63, 1.42]
Cardiac comorbidities						
0	2.1	Ref		27.4	Ref	
≥1	31.9	1.46	[1.05, 2.03]	38.5	1.21	[.91, 1.62]
Non-cardiac comorbidities						
0	23.8	Ref		32.6	Ref	
≥1	22.1	.98	[.72, 1.34]	28.0	.93	[.71, 1.22]
Insurance status						
Private	22.4	Ref		33.6	Ref	
Public	22.9	1.20	[.79, 1.82]	24.2	.98	[.67, 1.42]
Other	2.9	1.07	[.53, 2.15]	27.9	.91	[.50, 1.66]

Characteristic	Clinician Counseling on Safe Contraceptive Methods*			Clinician Counseling on Special Concerns About Becoming Pregnant*			Clinician Advice to Avoid Pregnancy Due to Heart Problem*		
	%	aPR	95% CI	%	aPR	95% CI	%	aPR	95% CI
None	27.3	1.20	[.70, 2.05]	28.8	.83	[.50, 1.37]	12.1	.91	[.42, 1.98]
Education									
> High school	22.4	Ref		32.8	Ref		12.9	Ref	
High school graduate	24.9	1.25	[.84, 1.87]	23.9	.96	[.66, 1.39]	14.2	.97	[.57, 1.67]
< High school	2.0	.95	[.47, 1.92]	26.0	1.00	[.54, 1.86]	18.0	.94	[.42, 2.11]
% Rurality									
Mostly urban >50%	24.3	Ref		31.6	Ref		14.4	Ref	
Mostly rural ≤50%	17.9	.90	[.58, 1.40]	24.9	.84	[.58, 1.22]	11.0	.75	[.43, 1.30]
% Family poverty									
<10%	26.8	Ref		29.7	Ref		13.0	Ref	
10%–40%	2.4	.83	[.60, 1.17]	28.9	1.17	[.87, 1.58]	13.0	1.12	[.71, 1.76]
>40%	23.4	.90	[.49, 1.66]	39.1	1.72	[1.04, 2.86]	2.3	1.67	[.80, 3.47]
Chromosomal abnormality									
No	23.8	Ref		31.6	Ref		13.8	Ref	
Yes	14.1	.57	[.27, 1.21]	15.5	.80	[.40, 1.63]	11.3	.61	[.26, 1.45]
Ever married									
No	2.3	Ref		26.5	Ref		13.1	Ref	
Yes	29.4	1.71	[1.16, 2.50]	39.3	1.57	[1.13, 2.19]	15.0	1.44	[.86, 2.41]
Survey completed by proxy									
No	23.7	Ref		33.1	Ref		13.3	Ref	
Yes	18.5	.98	[.55, 1.74]	13.4	.46	[.25, .85]	15.1	1.18	[.60, 2.33]
N		765			765			765	
Pseudo R ²		.17			.21			.17	

Abbreviations: aPR, adjusted prevalence ratio; CHDs, congenital heart defects; CH STRONG, Congenital Heart Survey To Recognize Outcomes, Needs, and well-being; aPR, adjusted prevalence ratio; CI, confidence interval; Ref, reference group.

Note: Bolded values have *p* value < .05.

* Multivariable models included all factors in complete table.

Associations Between Demographic and Health Characteristics and Reported Reproductive Health Experiences Among Women With CHDs, CH STRONG, 2016, 2019

Table 3

Characteristic	Concern About Ability to Have Children*			Delayed or Avoided Pregnancy due to Concerns About Heart Health*			Ever Pregnant†		
	%	aPR	95% CI	%	aPR	95% CI	%	aPR	95% CI
CHD severity									
Non-severe	31.1%	Ref		11.3%	Ref		37.5%	Ref	
Severe	42.7	1.42	[1.09, 1.84]	25.7	2.22	[1.53, 3.22]	26.1	.83	[.61, 1.13]
Place of birth									
Arizona	31.0	Ref		12.2	Ref		41.4	Ref	
Arkansas	39.5	.87	[.61, 1.25]	16.3	1.51	[.85, 2.67]	25.8	.94	[.64, 1.39]
Georgia	34.8	.86	[.62, 1.19]	18.8	1.61	[.99, 2.64]	31.6	.79	[.57, 1.08]
Race/ethnicity									
Non-Hispanic white	32.2	Ref		13.3	Ref		31.6	Ref	
Hispanic	34.8	1.11	[.73, 1.70]	21.0	1.19	[.59, 2.39]	47.1	1.36	[.83, 2.25]
Non-Hispanic Black	44.4	.97	[.68, 1.40]	22.2	1.39	[.83, 2.35]	35.6	1.70	[1.21, 2.38]
Other	43.1	1.42	[.88, 2.31]	15.3	1.34	[.65, 2.74]	27.8	1.07	[.63, 1.83]
Age at survey completion, y									
19–24	38.6	Ref		12.5	Ref		14.8	Ref	
25–30	36.3	.95	[.72, 1.25]	16.4	1.12	[.71, 1.76]	42.0	2.04	[1.43, 2.92]
31–38	2.4	.58	[.37, .90]	19.7	1.31	[.75, 2.28]	6.6	2.36	[1.59, 3.52]
Cardiac comorbidities									
0	33.1	Ref		14.6	Ref		32.6	Ref	
≥1	38.5	1.18	[.89, 1.57]	18.1	1.06	[.70, 1.62]	39.6	1.13	[.85, 1.49]
Non-cardiac comorbidities									
0	29.1	Ref		13.2	Ref		35.0	Ref	
≥1	38.6	1.46	[1.12, 1.89]	17.2	1.25	[.85, 1.84]	33.6	.96	[.74, 1.23]
Insurance status									
Private	35.4	Ref		13.3	Ref		32.4	Ref	
Public	29.1	.80	[.57, 1.13]	19.4	1.54	[.95, 2.52]	32.6	1.62	[1.16, 2.26]
Other	37.2	1.02	[.60, 1.72]	9.3	.66	[.23, 1.87]	34.9	1.25	[.73, 2.15]
None	43.9	1.21	[.80, 1.84]	19.7	1.29	[.68, 2.44]	51.5	1.62	[1.08, 2.41]

Characteristic	Concern About Ability to Have Children*			Delayed or Avoided Pregnancy due to Concerns About Heart Health*			Ever Pregnant†		
	%	aPR	95% CI	%	aPR	95% CI	%	aPR	95% CI
Education									
>High school	35.7	Ref		15.8	Ref		36.1	Ref	
High school graduate	33.5	1.03	[.74, 1.43]	13.2	.70	[.41, 1.19]	28.9	1.24	[.90, 1.72]
<High school	24.0	.70	[.37, 1.30]	2.0	.81	[.38, 1.69]	36.0	1.00	[.60, 1.67]
% Rurality									
Mostly urban >50%	37.2	Ref		14.9	Ref		31.6	Ref	
Mostly rural ≤50%	24.9	.71	[.50, 1.02]	17.3	1.41	[.87, 2.28]	43.4	1.16	[.86, 1.57]
% Family poverty									
<10%	34.6	Ref		12.6	Ref		25.7	Ref	
10%–40%	31.9	.95	[.72, 1.27]	15.3	1.24	[.79, 1.93]	38.9	1.21	[.90, 1.64]
>40%	5.0	1.36	[.87, 2.12]	28.1	2.15	[1.12, 4.11]	39.1	1.21	[.74, 1.97]
Chromosomal abnormality									
No	35.4	Ref		15.6	Ref		37.8		
Yes	23.9	.87	[.48, 1.57]	14.1	.87	[.39, 1.92]	.0		
Ever married									
No	37.7	Ref		14.5	Ref		19.8	Ref	
Yes	25.7	.75	[.53, 1.04]	17.8	1.43	[.89, 2.28]	71.5	2.85	[2.12, 3.83]
Survey completed by proxy									
No	36.4	Ref		15.5	Ref		39.6	Ref	
Yes	23.5	.68	[.42, 1.12]	15.1	1.17	[.59, 2.32]	5.0	.17	[.07, .39]
N		765			765			765	
Pseudo R ²		.08			.10			.30	

Abbreviations: aPR, adjusted prevalence ratio; CHDs, congenital heart defects; CH STRONG, Congenital Heart Survey To Recognize Outcomes, Needs, and well-being; aPR, adjusted prevalence ratio; CI, confidence interval; Ref, reference group.

Note: Bolded values have *p* value < .05.

* Multivariable models included all factors in complete table.

† No women with chromosomal anomalies reported ever being pregnant, so this factor was removed from the model. All other factors included in model.