Reproductive health outcomes of congenital heart disease survivors: A report from the congenital heart disease project to understand lifelong survivor experience (CHD PULSE study)

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Abstract

Background Improved survival of individuals with congenital heart disease (CHD) into adulthood has made reproductive health a crucial aspect of CHD care. Despite existing guidelines on heritability, contraception, pregnancy, and postpartum care, little is known about CHD survivors' experiences and attitudes toward reproductive health. This study aimed to examine reproductive health outcomes and experiences among adults with CHD, with a focus on female survivors.

Methods Data were drawn from the CHD PULSE (Project to Understand Lifelong Survivor Experience) study, a cross-sectional survey conducted from September 2021 to April 2023. Participants were adults (≥18 years) with at least 1 CHD intervention at 1 of 11 U.S. Pediatric Cardiac Care Consortium centers. CHD severity was categorized based on initial diagnosis and intervention. Categorical and continuous variables were analyzed using Chi-square and Kruskal-Wallis tests, respectively.

Results Among 3,073 respondents (1,704 females, 1,369 males), 48% of female participants reported receiving no reproductive counseling. Factors significantly associated with receiving counseling included older age, later age at last surgery, marital history, severe CHD, higher income, government insurance, and more comorbidities ($P < .001$). Women were significantly more likely to have biological children than men (40.4% vs 37.5%, $P < .0001$).

Conclusion Reproductive counseling is infrequent among women with CHD, especially among younger, unmarried, low-income individuals with less severe CHD and fewer comorbidities. Significant gender disparities in reproductive outcomes emphasize the need for tailored, gender-specific reproductive health counseling for CHD survivors. (Am Heart J 2026;294:107338.)

Background

Advancements in diagnosis, medical management, and surgical treatments for congenital heart disease (CHD) have significantly improved survival rates, with 97% of children diagnosed currently reaching adulthood.[1] Consequently, addressing reproductive health has become increasingly important in the care of CHD.[2] Most individuals with CHD are sexually active,[3,4] and women with CHD share similar motivations to conceive regardless of the severity of their condition.[5] The modified World

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Health Organization (WHO) classification assigns pregnancy risk for women with CHD to 4 classes, from minimal risk (Class I) to extremely high risk (Class IV).[6] Class IV patients, facing severe mortality or morbidity risks, are advised against pregnancy, with termination recommended if pregnancy occurs.

The American Heart Association (AHA) recommends prepregnancy counseling for all women with CHD, involving an adult CHD cardiologist to assess maternal cardiac, obstetrical risks, and fetal risks, as well as potential long-term risks to the mother.[7] Comprehensive reproductive counseling is also essential for both men and women with CHD to discuss heritability concerns.[8] It should occur at or soon after reaching sexual maturity, covering the effective and safe contraceptive options, particularly for women with CHD. However, studies indicate that healthcare providers infrequently discuss pregnancy-related risks to maternal and fetal health or the safety of contraception methods related to their heart condition.[9,10] Reported unintended pregnancy rates among adult women with CHD range from 32% in 1 study[11] to 54% in another.[10]

Despite established guidelines on heritability, contraception, pregnancy, and postpartum care for CHD survivors, little is known about how individuals with CHD experience reproductive healthcare or their understanding and attitudes toward the care they receive. This study seeks to bridge this gap by examining reproductive health outcomes, counseling experiences, and knowledge in both women and men with CHD, with a particular focus on factors influencing reproductive health in female CHD survivors. Using data from a large, multicenter cross-sectional survey, this study evaluates the prevalence of reproductive counseling and explores sociodemographic and clinical factors associated with counseling disparities.

Methods

Study design

Data for this study was obtained from the Congenital Heart Disease Project to Understand Lifelong Survivor Experience (CHD PULSE) study.[12] CHD PULSE is a cross-sectional survey conducted between September 2021 and April 2023. It surveyed adult CHD survivors identified by the Pediatric Cardiac Care Consortium (PCCC), a 47-center North American registry of cardiac catheterizations, surgical operations, and autopsies performed for infants, children, and adults with CHD since 1982. The study was approved by the Western Institutional Review Board and each participating center's local institutional review board, per that institution's policy.

Study participants

Participants were living adults over 18 years old who had undergone at least 1 intervention for CHD at one of the 11 U.S. centers in the PCCC included in CHD PULSE. Each participant was assigned to a CHD severity group based on his/her initial diagnosis and the type of intervention documented in PCCC data. CHD severity was categorized as mild, moderate, severe 2-ventricle, or single ventricle using an adapted classification scheme initially introduced in the Canadian Conference on the Care of Adults with CHD.[13]

Survey

Surveys were mailed to those eligible to be completed by themselves or a proxy. The survey questions spanned multiple domains, including demographics, surgical history, health insurance, healthcare utilization, visits to heart specialists, general health and disability, anthropometrics, education and work history, and COVID-19 (Oster et al.[12]). The survey questions were worded similarly to those used by the U.S. Centers for Disease Control and Prevention in the Congenital Heart Survey to Recognize Outcomes, Needs, and Well-being initiative for comparability.[14]

Outcomes of interest

This analysis focuses on several reproductive health questions asked to both male and female participants about family planning. Additionally, it includes questions specific to female participants regarding contraception, pregnancy risks, and pregnancy outcomes. These questions encompass the participants' recall of advice received from healthcare providers about pregnancy. Female participants who answered the question on pregnancy counseling were divided into 3 groups based on whether they were (1) told to avoid pregnancy because of their heart problem, (2) were not told to avoid pregnancy, but were told about special concerns about being pregnant because of their heart problem, or (3) not told about any pregnancy concerns by any healthcare provider.

Statistical analysis

Categorical variables were presented as frequencies and percentages and were compared using chi-square tests. Continuous data was displayed as medians with interquartile ranges (IQR) and compared using Kruskal-Wallis tests. Characteristics and reproductive outcomes were compared between males and females and between reported counseling groups. Results were stratified by sex and CHD severity.

Log binomial regression models estimated the univariable likelihood of being told to avoid pregnancy or told of pregnancy concerns among female participants with CHD. The main outcome was recategorized into a binary variable for whether female participants were told to avoid pregnancy or informed of risks versus not told at all. Results were given as prevalence ratios with 95% confidence intervals and p-values. Prevalence ratios are

less likely to overestimate the strength of an association for nonrare outcomes (prevalence >10%) compared to odds ratios.[15] We examined the association of different factors related to being informed about pregnancy concerns by a healthcare provider: last visit to cardiology care, being told of the necessity of lifelong care, ever delaying or avoiding getting pregnant due to heart health, being advised about the safest birth control due to a heart problem, intentions for pregnancy, the number of times ever pregnant, and the number of times ever given birth. We also analyzed several covariates: age at survey, age at last surgery, CHD severity, race/ethnicity, pregnancy-associated comorbidities, mental health, insurance status, education history, income levels, marital history, and proxy response. A secondary analysis focused on pregnancy-associated comorbidities.

In a multivariable analysis, we individually modeled the family planning-related factors for their association with the type of pregnancy counseling received, adjusted by the above covariates. Since the log binomial model failed to converge, a Poisson regression with log link and robust sandwich estimator was used instead.[16] All models met assumptions and converged. There was a moderate ($r > 0.4$) association found between some covariates: age at survey and marital status ($r = 0.52$), age at survey and age at last surgery ($r = 0.47$), and marital status and income level ($r = 0.46$) (all $P < .0001$). Since the correlation was not strong, these covariates were kept in the model. Backward selection was utilized to iteratively remove covariates with a p-value>0.20 to ensure the most parsimonious model.

Statistical significance of variables was assessed at an alpha = 0.05 level. Unknown and missing responses were not included in statistical calculations for significance or modelling. All statistical analyses were performed using SAS version 9.4 (Cary, NC).

Results: male and female reproductive health analysis

Demographics

Of the 14,322 eligible subjects, 3,133 (1,727 female and 1,406 male) responded to the CHD PULSE survey, representing a 21.9% response rate. After excluding those who did not answer reproductive health questions (23 females and 37 males), 1,704 female and 1,369 male respondents were included. The median age of female respondents at the time of response was 32.5 years, with an interquartile range (IQR) of 27.2 to 39.5 years, while the median age of males was 33.2 years (IQR 27.2-40.2 years). Among all respondents, 86.6% of females and 89.2% of males were non-Hispanic white; the most common CHD severity was moderate. The male demographics are outlined in Supplementary Table 1. The female overall demographics are outlined in Table 1, with additional medical characteristics in Table 2, stratified by the type of reproductive counseling they received.

Parenthood outcomes for males and females combined

Overall, male and female respondents with mild and unclassified CHD had the highest rates of reporting having children (42.3% and 49.4%, respectively), compared to 19.6% of those with single ventricle (SV) CHD ($P < .001$). Of all participants who did not have children, 32.2% planned to have children and 20.8% reported no interest in having children. A small percentage of overall participants (2.7%) reported unsuccessfully trying to have children, including 4.5% of those with SV CHD. Of all participants, 4.9% reported being advised against having children, compared to 24.1% of SV CHD respondents.

Table 3 summarizes responses to the survey question, "Do you have biological children?" stratified by CHD severity and sex. Females were significantly more likely than males to have biological children (40.4% vs 33.8%, $P < .0001$), with this trend observed across all CHD severity groups, except for the SV group. A lack of interest in having children was more prevalent among males than females (25.4% vs 17.0%), except in the single 2-ventricle (S2V) disease group. Females were more likely than males to report being unable to have children despite wanting them (3.4% vs 1.8%) across all severity groups, with the highest prevalence among females with SV CHD (6.4%). More females reported not having children due to advice from their physician about concerns related to their heart condition compared to males (8.3% vs 0.7%, respectively). Of these females, 44% had SV disease severity. Males had low rates of being advised against having children due to their heart condition across all CHD severity groups. Supplementary Figure 1 describes reproductive intentions in females by CHD severity. Women with SV CHD had the high rates of being advised to avoid pregnancy.

Female-only reproductive health analysis

Figure 1 presents the reported successful birth rates among women with varying CHD severity who have been pregnant, excluding those who were experiencing their first pregnancy at the time of the survey. Women with SV disease had a lower likelihood of reporting successful childbirth compared to mild CHD (65.2% vs 91.5%, $P < .01$). There were no significant differences in successful childbirth rates for women with moderate or S2V CHD when compared to mild CHD.

Reproductive counseling

Of all female respondents, 22% reported they were advised to avoid pregnancy, 30% reported they were informed about pregnancy-related risks, and 48% reported

Table 1. Comparison of female respondent demographics by type of reproductive counseling received

Variable		Overall $N = 1,704$	Avoid $N = 373$ N (%)	Concern $N = 508$ N (%)	Not told $N = 823$ N (%)	*P*-value
Age	Median (IQR)	32.5 (27.2, 39.5)	35.8 (31.1, 42.9)	32.7 (27.9, 38.5)	30.8 (26.2, 37.7)	< **.001**
Age group	<25	258	35 (13.6%)	69 (26.7%)	154 (59.7%)	< **.001**
	25-29	383	49 (12.8%)	113 (29.5%)	221 (57.7%)	
	30-34	394	88 (22.3%)	128 (32.5%)	178 (45.2%)	
	35-39	276	73 (26.4%)	93 (33.7%)	110 (39.9%)	
	40+	393	128 (32.6%)	105 (26.7%)	160 (40.7%)	
Race	NH White	1,466	316 (21.6%)	448 (30.6%)	702 (47.9%)	.409
	NH Black	82	18 (22.0%)	19 (23.2%)	45 (54.9%)	
	Hispanic	76	19 (25.0%)	24 (31.6%)	33 (43.4%)	
	NH Other	69	17 (24.6%)	14 (20.3%)	38 (55.1%)	
	Unknown	11	3 (27.3%)	3 (27.3%)	5 (45.4%)	
Highest education	No HS degree	54	21 (38.9%)	8 (14.8%)	25 (46.3%)	< **.001**
	HS degree	585	133 (22.7%)	128 (21.9%)	324 (55.4%)	
	Associate or bachelor's degree	726	150 (20.7%)	243 (33.5%)	333 (45.9%)	
	Graduate or professional degree	335	69 (20.6%)	129 (38.5%)	137 (40.9%)	
	Unknown	4	0 (0.0%)	0 (0.0%)	4 (100.0%)	
Income	< $24,999	298	77 (25.8%)	61 (20.5%)	160 (53.7%)	< **.001**
	$25,000-$49,999	295	66 (22.4%)	76 (25.8%)	153 (51.9%)	
	$50,000-$74,999	244	58 (23.8%)	73 (29.9%)	113 (46.3%)	
	> $75,000	565	112 (19.8%)	215 (38.1%)	238 (42.1%)	
	Unknown	302	60 (19.9%)	83 (27.5%)	159 (52.6%)	
Perception of finances	Excellent	353	70 (19.8%)	122 (34.6%)	161 (45.6%)	**.002**
	Good	936	191 (20.4%)	290 (31.0%)	455 (48.6%)	
	Only fair	306	84 (27.5%)	79 (25.8%)	143 (46.7%)	
	Poor	97	28 (28.9%)	15 (15.5%)	54 (55.7%)	
	Unknown	12	0 (0.0%)	2 (16.7%)	10 (83.3%)	
Insurance status	Uninsured	67	14 (20.9%)	15 (22.4%)	38 (56.7%)	.297
	Insured	1,625	358 (22.0%)	491 (30.2%)	776 (47.8%)	
	Unknown	12	1 (8.3%)	2 (16.7%)	9 (75.0%)	
Insurance plan	Private or military	1,018	204 (20.0%)	350 (34.4%)	464 (45.6%)	< **.001**
	Government	318	99 (31.1%)	61 (19.2%)	158 (49.7%)	
	More than 1	92	12 (13.0%)	15 (16.3%)	65 (70.7%)	
	None or unknown	276	58 (21.0%)	82 (29.7%)	136 (49.3%)	
Marital status	Ever married	886	215 (24.3%)	328 (37.0%)	343 (38.7%)	< **.001**
	Never married	805	154 (19.1%)	177 (22.0%)	474 (58.9%)	
	Unknown	13	4 (30.8%)	3 (23.1%)	6 (46.2%)	
Survey Response	Self-Response	1,566	52 (22.5%)	496 (31.7%)	718 (45.8%)	< **.001**
	By Proxy (total)	119	16 (13.5%)	8 (6.7%)	95 (79.8%)	
	Parent	105	13 (12.4 %)	6 (5.7%)	86 (81.9%)	
	Sibling/other family	8	2 (25%)	1 (12.5%)	5 (62.5 %)	
	Partner/spouse/caregiver (other)	6	1 (16.7%)	1(16.7%)	4 (66.7%)	
	Unknown	19	5 (26.3%)	4 (21.1%)	10 (52.6%)	

P-values were calculated by chi-square and Kruskal-Wallis tests without unknown values. Bold p-values are significant.
Abbreviations: 2V, two ventricles; HS, high school; IQR, interquartile range; NH, non-Hispanic.

receiving no reproductive counseling by any healthcare provider. Women with SV disease were more likely to be advised against pregnancy (73.8%, $P < .001$). A substantial portion of women with mild (76.8%) and moderate (46.0%) CHD reported receiving no reproductive counseling (Figure 2).

Of female respondents, 52% had undergone surgery before age 5. There was a significant association between the age at the last surgery and the type of pregnancy counseling received. Of women who had surgery in their first year of life, 58% reported receiving no pregnancy counseling, while only 24% of those who had surgery af-

Figure 1. Success of childbirth in women with congenital heart disease by disease severity. Figure 1 presents the reported successful birth rates among women with varying CHD severity who have been pregnant, excluding those who were experiencing their first pregnancy at the time of the survey. *statistically significant ($P < .01$) difference when compared to mild CHD (reference). Abbreviations: 2V, two ventricles.

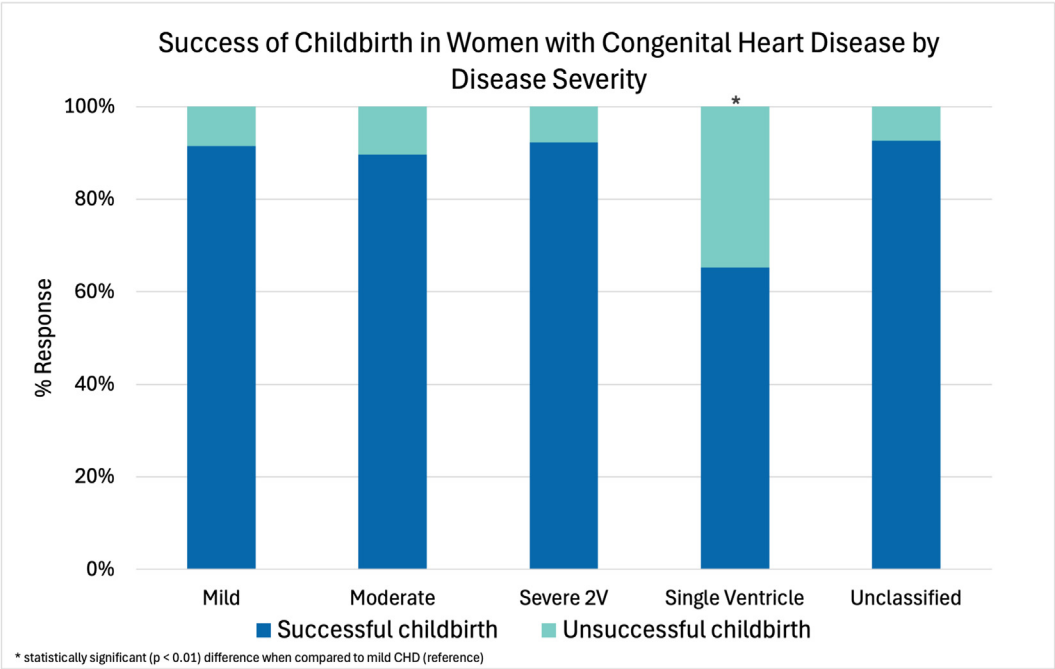


Figure 2. Distribution of reproductive counseling responses in females stratified by congenital heart disease severity. Figure 2 demonstrates the female survey responses stratified by congenital heart disease severity. Survey responses included advice to avoid pregnancy (red), pregnancy concerns discussed (orange), and no counseling provided (beige). Single-ventricle patients show the highest proportion of being advised to avoid pregnancy, while a notable lack of counseling is observed in mild CHD cases. Abbreviations: 2V, two ventricles.

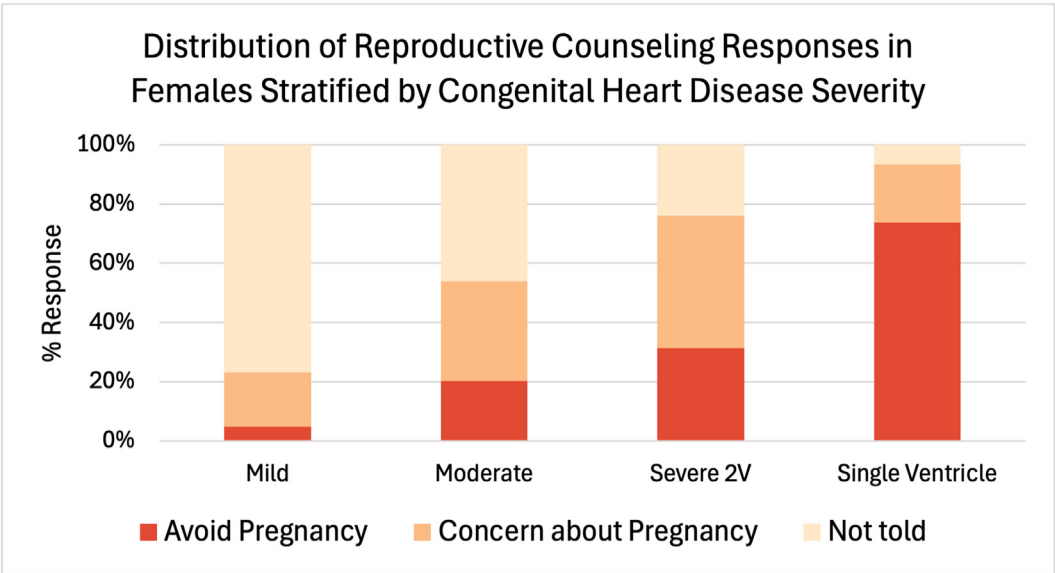


Table 2. Comparison of female respondent cardiac and medical characteristics by type of reproductive counseling received

Variable		Overall $N = 1,704$	Avoid $N = 373$ N (%)	Concern $N = 508$ N (%)	Not told $N = 823$ N (%)	*P*-value
CHD severity	Mild	568	28 (4.9%)	104 (18.3%)	436 (76.8%)	< **.001**
	Moderate	643	131 (20.4%)	216 (33.6%)	296 (46.0%)	
	Severe 2V	233	73 (31.3%)	104 (44.6%)	56 (24.0%)	
	Single ventricle	122	90 (73.8%)	24 (19.7%)	8 (6.6%)	
	Unclassified	138	51 (37.0%)	60 (43.5%)	27 (19.6%)	
Age at last surgery (y)	<1	377	45 (11.9%)	114 (30.2%)	218 (57.8%)	< **.001**
	1 to 5	524	89 (17.0%)	135 (25.8%)	300 (57.3%)	
	6 to 17	362	77 (21.3%)	118 (32.6%)	167 (46.1%)	
	Over 17	363	151 (41.6%)	125 (34.4%)	87 (24.0%)	
	Unknown	78	11 (14.1%)	16 (20.5%)	51 (65.4%)	
Last visit with cardiologist	0-2 years ago	1,051	333 (31.7%)	385 (36.6%)	333 (31.7%)	< **.001**
	3+ years ago	644	39 (6.1%)	121 (18.8%)	484 (75.2%)	
	Unknown	9	1 (11.1%)	2 (22.2%)	6 (66.7%)	
Necessity of lifelong cardiac care discussed as a teenager or young adult	No	557	40 (7.2%)	75 (13.5%)	442 (79.4%)	< **.001**
	Yes	1,107	323 (29.2%)	425 (38.4%)	359 (32.4%)	
	Unknown	40	10 (25.0%)	8 (20.0%)	22 (55.0%)	
Comorbidities	Congestive heart failure	186	98 (52.7%)	44 (23.7%)	44 (23.7%)	< **.001**
	Diabetes	75	24 (32.0%)	15 (20.0%)	36 (48.0%)	**.045**
	Hypertension	206	75 (36.4%)	53 (25.7%)	78 (37.9%)	< **.001**
	Clotting problems (stroke, pulmonary embolism, other)	148	72 (48.6%)	34 (23.0%)	42 (28.4%)	< **.001**
	Malignancy (cancer)	50	10 (20.0%)	10 (20.0%)	30 (60.0%)	.201
	Arrhythmia	557	211 (37.9%)	180 (32.3%)	166 (29.8%)	< **.001**
	Endocarditis	28	13 (46.4%)	10 (35.7%)	5 (17.9%)	**.001**
	Myocardial infarction	25	13 (52.0%)	6 (24.0%)	6 (24.0%)	< **.001**
	Kidney disease	35	14 (40.0%)	6 (17.1%)	15 (42.9%)	**.024**
	Liver disease	49	34 (69.4%)	8 (16.3%)	7 (14.3%)	< **.001**
	Pulmonary hypertension	49	30 (61.2%)	8 (16.3%)	11 (22.4%)	< **.001**
	Mental Health (depression, anxiety)	827	234 (28.3%)	220 (26.6%)	373 (45.1%)	< **.001**
Number of comorbidities	Median (IQR)	2 (1, 3)	3 (2, 5)	2 (1, 3)	1 (1, 3)	< **.001**
Number of comorbidities	0	309	23 (7.4%)	108 (35.0%)	178 (57.6%)	< **.001**
	1	447	69 (15.4%)	135 (30.2%)	243 (54.4%)	
	2	351	53 (15.1%)	111 (31.6%)	187 (53.3%)	
	3	262	71 (27.1%)	78 (29.8%)	113 (43.1%)	
	4	164	61 (37.2%)	51 (31.1%)	52 (31.7%)	
	5+	171	96 (56.1%)	25 (14.6%)	50 (29.2%)	

Bold p-values are significant.
Abbreviations: 2V, two ventricles; CHD, congenital heart disease; IQR, interquartile range.

ter age 17 were not counseled ($P < .001$). Discussions during teenage and young adult years on the need for lifelong cardiac care was reported to be done in 65% of women respondents, and 62% of women had reported seeing a heart doctor within the last 2 years. Women who were not informed about the necessity of lifelong cardiac care as teenagers or young adults were significantly more likely to be uninformed about pregnancy risks later in life than those who were informed about the necessity of lifelong cardiac care (79.4% vs 32.4%, $P < .001$). Women who had seen a heart doctor in the past 2 years had higher rates of being advised against pregnancy (31.7%) or informed of concerns (36.6%). In contrast, 75.2% of those who had not seen a heart doctor in 3 or more years received no counseling ($P < .001$).

At least 1 comorbidity was present in 82% of women respondents, with the most common being depression or anxiety (48.5%). Women who were told to avoid pregnancy had a median of 3 comorbidities compared to 1 comorbidity in those who did not receive any pregnancy counseling ($P < .001$). Among the comorbidities, only malignancy was not associated with differential counsel-

Table 3. Family planning and reproductive intentions by congenital heart disease severity and sex

	Overall N (%)	Mild N (%)	Moderate N (%)	Severe 2V N (%)	SV N (%)	Unclassified N (%)	*P*-value
Males (n = 1,369)							
Have biological children	462 (33.8)	89 (34.0)	190 (33.0)	74 (32.2)	30 (25.0)	79 (43.4)	< **.0001**
No children but plan/hope to in the future	499 (36.5)	86 (32.8)	202 (35.1)	111 (48.3)	52 (43.3)	48 (26.4)	
No children and not interested in having children	348 (25.4)	76 (29.0)	163 (28.4)	36 (15.7)	29 (24.2)	44 (24.2)	
No children and tried unsuccessfully	25 (1.8)	5 (1.9)	7 (1.2)	4 (1.7)	3 (2.5)	6 (3.3)	
No children and advised not to due to heart condition	10 (0.7)	0	1 (0.2)	2 (0.9)	4 (3.3)	3 (1.7)	
No children and advised not to due to noncardiac condition	25 (1.8)	6 (2.3)	12 (2.1)	3 (1.3)	2 (1.7)	2 (1.1)	
Females (n = 1,701)							
Have biological children	688 (40.4)	263 (46.1)	243 (38.1)	86 (37.2)	18 (14.4)	78 (57.4)	< **.0001**
No children but plan/hope to in the future	490 (28.8)	180 (31.5)	185 (29.0)	68 (29.4)	26 (20.8)	31 (22.8)	
No children and not interested in having children	290 (17.0)	93 (16.3)	129 (20.2)	39 (16.9)	17 (13.6)	12 (8.8)	
No children and tried unsuccessfully	57 (3.4)	21 (3.7)	20 (3.1)	4 (1.7)	8 (6.4)	4 (2.9)	
No children and advised not to due to heart condition	141 (8.3)	5 (0.9)	44 (6.9)	27 (11.7)	55 (44.0)	10 (7.4)	
No children and advised not to due to noncardiac condition	35 (2.1)	9 (1.6)	17 (2.7)	7 (3.0)	1 (0.8)	1 (0.7)	

2V, two-ventricles; SV, single ventricle. Women who were currently experiencing their first pregnancy were excluded from this analysis. Bold p-values are significant.

ing responses ($P = .201$). Notably, 24% of women with congestive heart failure, 48% with diabetes mellitus, 38% with hypertension, and 22% with pulmonary hypertension reported not being told about pregnancy concerns.

Significant age differences were observed across groups ($P < .001$). Women under 30 years were more likely to receive no advice regarding pregnancy. Women over 40 had the highest reported rates of having ever been advised against pregnancy. Greater educational attainment, higher annual household incomes, and having ever been married were correlated with receiving pregnancy counseling (all $P < .001$). Women with lower incomes (under $50,000 per year) were more likely to report not being told about pregnancy concerns, while those with higher incomes (over $75,000 per year) were the most likely to be informed of pregnancy concerns. Similarly, women who perceived themselves as financially poor were more likely to report not being told about pregnancy concerns. Most female participants (95%) had insurance, with military/private insurance being the most common (59.7%). Insurance status and race did not affect counseling outcomes.

To extend the descriptive findings, regression analyses were performed to identify factors independently associated with the type of reproductive counseling received (Table 4). Several clinical and demographic characteristics remained independently associated after adjustment. Women who underwent surgery at older ages were more likely to receive counseling, and CHD severity was among the strongest predictors, with those who had any CHD severity other than mild disease substantially more likely to receive pregnancy-related counseling. Pregnancy-associated comorbidities also retained significance, as did being ever married and completing the survey independently rather than by proxy. Notably, several variables that showed significant associations in unadjusted analyses—including mental health conditions, education level, income, and insurance status—were no longer significant in the multivariable model.

Building on these findings, a second set of regression analyses evaluated pregnancy-related and care-engagement factors (Table 5). Recent cardiology follow-up and prior discussions about lifelong cardiac care

Table 4. Likelihood of covariates associated with type of reproductive counseling received

Variable		Univariable analysis*		Multivariable analysis**	
		PR (95% CI)	*P*-value	Adj. PR (95% CI)	*P*-value
Age at survey (years)	<25	ref.		Ref.	
	25-29	1.05 (0.87-1.27)	.618	1.14 (0.92-1.40)	.226
	30-34	1.36 (1.14-1.62)	**.001**	1.24 (1.01-1.53)	**.043**
	35-39	1.49 (1.25-1.78)	**< .001**	1.18 (0.95-1.46)	.133
	40+	1.47 (1.24-1.74)	**< .001**	1.03 (0.82-1.28)	.820
Age at last surgery (years)	<1	ref.		ref.	
	1-5	1.01 (0.87-1.18)	.864	0.98 (0.85-1.14)	.820
	6-17	1.28 (1.10-1.49)	**.002**	1.18 (1.01-1.37)	**.035**
	Over 17	1.80 (1.58-2.06)	**< .001**	1.30 (1.13-1.50)	**< .001**
CHD severity	Mild	ref.		ref.	
	Moderate	2.32 (1.97-2.74)	**< .001**	2.23 (1.86-2.66)	**< .001**
	Severe 2V	3.27 (2.77-3.86)	**< .001**	2.97 (2.48-3.56)	**< .001**
	Single ventricle	4.02 (3.44-4.70)	**< .001**	3.46 (2.88-4.15)	**< .001**
	Unclassified	3.46 (2.92-4.11)	**< .001**	2.71 (2.24-3.28)	**< .001**
Race/ethnicity	NH White	ref.		ref.	
	NH Black	0.87 (0.68-1.10)	.247	1.06 (0.84-1.34)	.607
	Hispanic	1.09 (0.89-1.33)	.427	1.27 (1.00-1.62)	.050
	NH Other	0.86 (0.66-1.12)	.274	0.93 (0.73-1.19)	.583
Comorbidities	Pregnancy-associated comorbidities***	1.64 (1.49-1.81)	**< .001**	1.19 (1.07-1.32)	**.001**
	No	ref.		ref.	
Comorbidities	Mental health comorbidities (depression, anxiety)	1.13 (1.03-1.24)	**.010**	1.03 (0.94-1.13)	.494
	No	ref.		ref.	
Highest education	No college degree	ref.		ref.	
	College degree	1.23 (1.11-1.36)	**< .001**	1.08 (0.97-1.21)	.181
Income	< $24,999	ref.		ref.	
	$25,000-$49,999	1.04 (0.88-1.23)	.656	0.95 (0.82-1.11)	.554
	$50,000-$74,999	1.16 (0.98-1.37)	.086	0.98 (0.84-1.15)	.813
	> $75,000	1.25 (1.09-1.44)	**.002**	0.97 (0.84-1.12)	.689
Insurance status	Insured	1.21 (0.91-1.59)	.185	1.20 (0.84-1.71)	.318
	Uninsured	ref.		ref.	
Marital status	Ever married	1.49 (1.35-1.64)	**< .001**	1.32 (1.18-1.48)	**< .001**
	Never married	ref.		ref.	
Survey response	Self-response	2.69 (1.87-3.85)	**< .001**	1.90 (1.28-2.81)	**.002**
	By proxy	ref.		ref.	

$n = 1{,}321$, 383 missing values were deleted. Bold p-values are significant.

* Univariable analysis by log-binomial regression.

** Multivariable analysis by Poisson regression with log link and robust sandwich estimator due to nonconvergence in log-binomial.

*** Pregnancy-associated comorbidities include congestive heart failure, diabetes, hypertension, clotting problems, malignancy, arrhythmia, endocarditis, MI, kidney disease, liver disease, and pulmonary hypertension.Abbreviations: Adj. PR, adjusted poisson regression; CHD, congenital heart disease; CI, confidence interval; 2V, two-ventricles; NH, Non-Hispanic; PR, poisson regression.

emerged as 2 of the strongest independent predictors of receiving pregnancy-related counseling. Delaying pregnancy due to heart health and having biological children also remained significant predictors after adjustment. In contrast, the number of prior pregnancies or births did not retain independent significance.

Pregnancy outcomes

Among women with congenital heart disease, reproductive decisions varied substantially based on the type of counseling received (Figure 3). The majority of participants across all reproductive outcomes, except those advised against childbearing due to cardiac reasons, reported receiving no specific reproductive counseling. A significant proportion (65.9%) of women who were advised to avoid pregnancy decided not to have biological children due to cardiac reasons. Meanwhile, those who were informed of pregnancy concerns but had no prohibitive counseling were more likely to have or plan to have biological children.

Table 5. Likelihood of pregnancy associated factors associated with type of counseling received

Pregnancy associated factors		Univariable analysis*		Multivariable analysis**	
		PR (95% CI)	*P*-value	Adj. PR (95% CI)	*P*-value
Last visit with cardiologist	0-2 years ago	2.75 (2.39-3.16)	**< .001**	1.86 (1.59-2.19)	**< .001**
	3+ years ago	ref.			
The necessity of lifelong cardiac care discussed as a teenager or adult		3.27 (2.77-3.87)	**< .001**	2.27 (1.86-2.77)	**< .001**
Ever delayed or avoided getting pregnant due to heart health		2.27 (2.11-2.44)	**< .001**	1.43 (1.32-1.56)	**< .001**
Ever been pregnant***		1.30 (1.19-1.42)	**< .001**	1.19 (1.07-1.33)	**.001**
Number of times pregnant	1†	1.08 (0.89-1.30)	.457	0.92 (0.76-1.13)	.437
	2	1.11 (0.92-1.33)	.291	0.90 (0.74-1.10)	.316
	3	1.08 (0.88-1.32)	.486	1.01 (0.82-1.25)	.909
	4+	ref.			
Number of times given birth	0†	1.47 (1.03-2.10)	**.032**	1.23 (0.87-1.75)	.245
	1-2	1.35 (0.97-1.87)	.072	1.10 (0.79-1.52)	.569
	3	1.27 (0.88-1.82)	.198	1.19 (0.83-1.70)	.336
	4+	ref.		ref.	

Bold p-values are significant.

* Univariable analysis by log-binomial regression. Necessity of lifelong cardiac care, pregnancy delay, safest birth control, and ever been pregnant variables are modeled as Yes vs No.

** Multivariable models of each factor by Poisson regression with log link and robust sandwich estimator due to nonconvergence in log-binomial. Each factor was individually modeled with covariates [age at survey, age at last surgery, CHD severity, race/ethnicity, pregnancy-related comorbidities (congestive heart failure, diabetes, hypertension, clotting problems, malignancy, arrhythmia, endocarditis, MI, kidney disease, liver disease, and pulmonary hypertension), depression/anxiety, college degree, income, insurance status, marital status, and proxy survey response] through backwards model selection if $P < .2$. Missing values were deleted.

*** Number of those who have ever been pregnant ($n = 758$). †41 patients were pregnant at the time of the survey.Abbreviations: Adj PR = Adjusted Poisson regression; CHD = congenital heart disease; PR = Poisson regression.

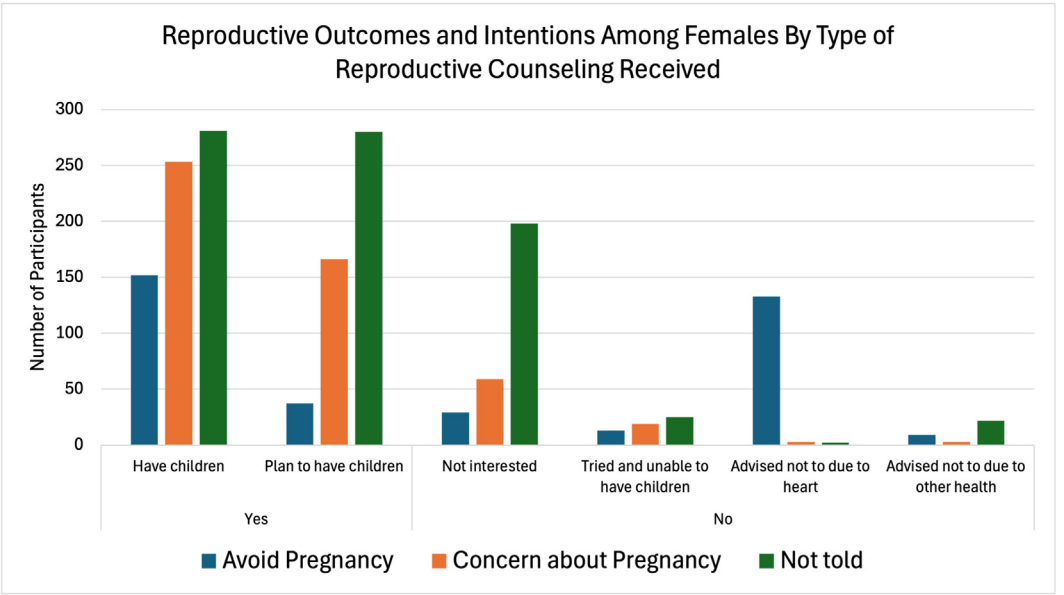
Pregnancy and birth rates of biological children were highest among women informed of pregnancy concerns compared to those told to avoid pregnancy and those not informed ($P < .001$) (Table 6). Half of the women who told of reproductive concerns had biological children, and 33% planned to have children in the future. Of the female respondents who were not told about pregnancy concerns, 35% reported having biological children and 35% reported plans to have children in the future. Of those told to avoid pregnancy, 41% reported having biological children and 10% had plans to in the future. There were no significant differences in the number of times women became pregnant or gave birth across the groups. Additionally, 75.3% of women who were advised to avoid pregnancy were also counseled on the safest birth control methods, compared to 46.7% of those who were informed of concerns and 10.2% of those who were not told ($P < .001$).

Discussion

This study explores the experiences, behaviors, and reproductive health outcomes of adults with CHD. A notable gender difference in reproductive intentions and health outcomes is observed among CHD survivors, emphasizing the need for tailored reproductive counseling programs for both genders. Despite the need for all women with CHD to receive reproductive health counseling, half of our female cohort reported not receiving any kind of counseling, highlighting a crucial gap in female patient care. Although birth control advice was correlated with cautionary pregnancy counseling, 25% of those told to avoid pregnancy did not receive guidance on the safest contraception methods for their heart condition.

Demographic, socioeconomic, and health factors also influence the counseling provided to women with CHD. The most vulnerable groups—such as single, younger women, those with lower incomes, those with fewer comorbidities, those less engaged in regular follow-up, and those who underwent surgery at an early age—were the least likely to receive any pregnancy counseling in the descriptive analyses. However, several of these associations did not persist in multivariable models. Income, education level, insurance status, and mental health conditions were no longer independent predictors of counseling once CHD severity, age at last surgery, and pregnancy-associated comorbidities were taken into account. This suggests that some apparent sociodemographic disparities may primarily reflect underlying differences in disease complexity and healthcare utilization rather than true inequities in how providers deliver counseling. Prior research has shown similar disparities.[10,17] Although adolescents with CHD usually engage in sexual activity later than their healthy peers and report lower rates of sexual activity overall,[18,19] the AHA still recommends precon-

Figure 3. Reproductive outcomes and intentions among females by type of reproductive counseling received. Figure 3 represents reproductive outcomes categorized by type of reproductive counseling received. The 3 groups include women who were advised to avoid pregnancy (blue), who were informed about pregnancy concerns (orange), and who reported not being provided with any counseling (green). Outcomes include rates of having children and planning to have children versus lack of interest in having children, inability to have children despite trying, and being advised not to have children due to cardiac or other health conditions. The majority of participants across the reproductive intention categories—specifically those who reported having children, planning to have children, or not being interested in childbearing—belonged to the "Not told" group. In contrast, those who were explicitly advised to avoid pregnancy were predominantly represented in the "Advised not to due to heart" category and were less frequently found in the affirmative reproductive intention groups.



ception counseling for all teenagers starting at age 12.[20] However, many adolescents do not receive this counseling, and this lack of knowledge frequently persists into young adulthood. [9] Hinze et al. found that age was a significant predictor of whether a woman received counseling regarding pregnancy on their health, with older women more likely to report receiving such counseling.[10] This study also found that the absence of reproductive counseling was more prevalent among younger women, potentially reflecting either a lack of awareness on their part or healthcare providers' perceiving them as less likely to become pregnant, leading to delays in important education and family planning guidance.

The association between age at the last recent surgery and counseling type likely reflects several overlapping factors. Surgery during adolescence or adulthood often involves multidisciplinary perioperative care, which can provide opportunities for reproductive counseling as part of broader health planning. In contrast, patients whose last surgery occurred in early childhood may have had fewer structured touchpoints at the time when reproductive counseling would be most relevant. These patterns may also reflect calendar-era changes, as reproductive health counseling has become more systematically emphasized in recent guidelines.[2,21,22] Finally, disease severity and health-care utilization can confound this relationship, and recall bias cannot be excluded: individuals requiring recent or recurrent interventions may have a more severe disease, prompting stronger recommendations.

Women who were educated about the necessity of lifelong cardiac care as teenagers or young adults were more likely to engage in reproductive health discussions with their doctors, highlighting the importance of early and ongoing patient education. This pattern remained strong even after multivariable adjustment. Prior discussions about lifelong cardiac care were among the most robust independent predictors of receiving pregnancy-related counseling. Conversely, women who had not seen a doctor for 3 or more years were less likely to receive such counseling. Lapses in follow-up are especially common during the transition to adulthood, a period when patients begin to take responsibility for their own care, separate from parental support, and also face new challenges such as independence, relationships, and sexual activity. Up to 70% of adults with CHD experience follow-up gaps, which are linked to increased morbidity and reduced quality of life.[23,24] Preventing these lapses

Table 6. Comparison of pregnancy and contraceptive outcomes of female participants by type of reproductive counseling received

Pregnancy outcome		Overall N (%)	Avoid N (%)	Concern N (%)	Not told N (%)	*P*-value
Ever delayed or avoided getting pregnant due to heart health	Yes	391 (23.1%)	244 (65.9%)	111 (22.0%)	36 (4.4%)	< **.001**
Advised about safest birth control due to heart problem	Yes	601 (35.4%)	281 (75.3%)	237 (46.7%)	83 (10.2%)	< **.001**
Have biological children		686 (40.7%)	152 (40.8%)	253 (50.3%)	281 (34.8%)	< **.001**
No children but plan/hope to in the future		483 (28.7%)	37 (9.9%)	166 (33.0%)	280 (34.7%)	
No children and not interested in having children		286 (17.0%)	29 (7.8%)	59 (11.7%)	198 (24.5%)	
No children and tried unsuccessfully		57 (3.4%)	13 (3.5%)	19 (3.8%)	25 (3.1%)	
No children and advised not to due to heart condition		138 (8.2%)	133 (35.7%)	3 (0.6%)	2 (0.2%)	
No children and advised not to due to noncardiac condition		34 (2.0%)	9 (2.4%)	3 (0.6%)	22 (2.7%)	
Ever been pregnant	Yes	758 (44.8%)	173 (46.8%)	277 (54.6%)	308 (37.7%)	< **.001**
Number of times pregnant*	1	230 (30.5%)	51 (29.7%)	86 (31.0%)	93 (30.4%)	.927
	2	253 (33.5%)	58 (33.7%)	97 (35.0%)	98 (32.0%)	
	3	151 (20.0%)	38 (22.1%)	52 (18.8%)	61 (19.9%)	
	4	121 (16.0%)	25 (14.5%)	42 (15.2%)	54 (17.6%)	
Number of times given birth*	0**	82 (10.8%)	25 (14.5%)	29 (10.5%)	28 (9.1%)	.281
	1	244 (32.2%)	59 (34.1%)	88 (31.8%)	97 (31.6%)	
	2	287 (37.9%)	60 (34.7%)	113 (40.8%)	114 (37.1%)	
	3	97 (12.8%)	19 (11.0%)	36 (13.0%)	42 (13.7%)	
	4	47 (6.2%)	10 (5.8%)	11 (4.0%)	26 (8.5%)	

Bold p-values are significant.

* Of those who have ever been pregnant ($n = 758$).

** 41 patients were pregnant at time of survey.

seems essential not only for cardiac outcomes but also for reproductive health, as early and continuous education can help patients navigate this critical life stage with greater knowledge, preparedness, and confidence. This aligns with prior transition-care research showing that inadequate preparation during adolescence contributes to lapses in care and increased risks as patients assume adult responsibilities.[20,25] The transition to adulthood might therefore be viewed as a key reinforcement point, where structured reproductive counseling can be reemphasized and tailored to the patient's emerging needs.

Several studies have identified a significant association between CHD complexity and the likelihood of receiving pregnancy or contraception counseling.[9,10] Our findings similarly highlight that disease severity strongly shapes both the type and frequency of counseling provided: women with more severe CHD were more likely to receive cautionary advice, whereas those with milder forms often received little to no counseling. Another important consideration related to CHD severity is its influence on the likelihood of successful childbirth, linking reproductive counseling with outcomes. A large nationwide cohort study found that women with moderate or severe CHD were less likely to have children and had a lower average number of childbirths compared to women without heart disease, while birth rates for women with mild CHD appeared unaffected by their condition.[24] Notably, this study found that women with mild, moderate, severe 2-ventricle, and unclassified CHD had similarly high successful childbirth rates, with no significant differences between these groups. In contrast, women with single-ventricle CHD had a significantly lower rate of successful childbirth, suggesting that this group faces greater challenges in achieving successful childbirth compared to other severity groups. Taken together, these findings highlight how counseling is often influenced by perceived disease severity, yet risk may be underestimated in mild cases and overestimated in some severe cases. While caution is appropriate to minimize maternal and fetal risk, excessive restriction may unnecessarily limit options for women who could safely pursue pregnancy with individualized, multidisciplinary care.

Comorbidities might further complicate counseling practices. Reproductive counseling for adults with CHD

primarily focuses on cardiac-related issues; noncardiac chronic conditions also contribute meaningfully to maternal and fetal morbidity and therefore warrant attention. Moreover, the adult CHD population faces excess morbidity than the general population, including extracardiac morbidities such as anxiety, hepatic, and pulmonary diseases.[26] These pre-existing chronic conditions increase the risk of severe maternal morbidity [27] and adverse birth outcomes, such as preterm birth, low birth weight, and stillbirth, either due to the chronic disease itself [28-30] or the medications used to manage it.[31,32] In our cohort, pregnancy-associated comorbidities were strongly correlated with counseling patterns, and multivariable analyses confirmed that these comorbidities independently predicted the type of reproductive counseling received. In contrast, mental health conditions did not retain significance after adjustment, suggesting that clinicians may selectively prioritize certain comorbidities—particularly those with clearer physiologic implications—when discussing reproductive risks. However, counseling on conditions like diabetes, hypertension, and mental health issues was less consistent, with many women not receiving specific advice despite the potential risks. This underscores the need for coordinated multispecialty care during preconception and pregnancy to address the complexities of maternal chronic conditions. [33]

Beyond risk communication, our findings indicate that reproductive counseling may substantially influence future childbearing intentions among women with CHD. Women advised to avoid pregnancy were less likely to express a desire for children in the future, suggesting the influence of medical advice on reproductive decisions. However, 41% still have biological children, indicating a potential conflict between personal desires to conceive and medical recommendations regarding the seriousness of their CHD. This aligns with Ngu et al.,[5] who reported that women with mild and severe CHD had similar motivations to conceive. Notably, the highest percentage of women with children was among those who were informed of pregnancy concerns but not explicitly advised to avoid pregnancy.

While counseling appears to influence reproductive choices, it remains uncertain whether women fully understand the advice provided or whether the recommendations themselves are always accurate. Hinze et al.[10] found that 18 of 98 women did not receive appropriate counseling regarding the severity of their CHD and overall health. Similarly, another study found that only about half of women with CHD accurately knew their cardiovascular risk classification, with substantial proportions underestimating or overestimating their risk.[23] To address these gaps and misconceptions, a standardized, comprehensive counseling protocol tailored to CHD severity could improve consistency in guidance. This protocol should ensure that all women with CHD receive accurate, accessible information about pregnancy risks and safe contraception options, empowering them to make informed reproductive choices.

The findings also revealed notable gender differences in reproductive health outcomes and intentions among individuals with CHD. According to the Centers for Disease Control and Prevention (CDC), the median age of men at the time of their first child is generally higher than that of women in the U.S.,[34] yet the median ages of male and female participants in our cohort were similar. Males might perceive greater flexibility in delaying parenthood, whereas females face tighter biological time constraints, or in some cases, stronger medical discouragement from pregnancy. This imbalance in counseling reflects the differing physiological implications of parenthood, particularly pregnancy, for men and women with CHD. Despite being more frequently advised against childbearing, women in this study were more likely than men to have biological children, except in cases of single-ventricle CHD. This paradox may reflect societal pressures on women to pursue motherhood even when medical risks are present. Clinicians should account for the personal, social, and cultural influences on women's reproductive decisions and provide individualized counseling that respects these factors while aiming to prevent unplanned pregnancies.[11] Individualized care plans are also recommended for women during pregnancy.[7] Barriers to achieving these goals, including inadequate insurance coverage, limited education, and financial instability, should also be addressed.

This study has several strengths. It uses a large U.S. sample of adults recruited from multiple clinical sites to compare reproductive health practices and outcomes between male and female patients. Participants were sent a survey to see if they had an intervention for their CHD at one of the included centers and met the inclusion criteria. Thus, we were able to include participants who may have limited access to healthcare or gaps in care. The inclusion of males with CHD in a study on reproductive health adds value, as they also carry the risk of heritability and unplanned pregnancy. Finally, the large sample size provides high statistical power.

This study has several limitations. The survey primarily focused on reproductive health counseling for women with CHD, as most of the reproductive health questions were directed toward females. The predominantly white, non-Hispanic population responded to the survey, which may limit the generalizability of findings to more diverse groups. As a cross-sectional design, it was not possible to assess the temporality of pregnancy, counseling, and other variables such as comorbidities or socioeconomic status. We also lacked information on whether the patient or the physician initiated reproductive health discussions. Reliance on self-reported data introduces potential recall bias, particularly among participants treated at a young age or with gaps in care. However, assess-

ing whether patients accurately recalled physician guidance and how that related to their reproductive decisions remains critical. Additionally, this study did not collect information on the use of assisted reproductive technologies or surrogacy, which limits our ability to evaluate these reproductive choices in relation to counseling subgroups. Future prospective studies should incorporate these data to provide a more comprehensive understanding of reproductive decision-making in this population. Future research incorporating objective risk classification and direct counseling documentation is needed to validate the appropriateness of pregnancy recommendations in this population. Survivor bias may arise from focusing only on women with CHD who survived to reproductive age, potentially excluding those with more severe conditions and skewing the findings toward better outcomes. Finally, the survey response rate represents an important limitation. As detailed sociodemographic data on nonresponders were not available, we cannot exclude the possibility that they differed systematically from responders (eg, lower income or educational attainment), which may have led to an overestimation of the counseling rates. Although this limits precision, evaluating how accurately patients recall physician guidance and how reproductive decisions shape remains important. Lastly, some surveys were completed by proxies rather than patients, which may introduce misclassification for factual variables and recall-related limitations. Because the reason for proxy completion was not captured, the extent and direction of this potential reporting bias are uncertain. Future prospective studies that incorporate objective risk classification, documentation of counseling, and comprehensive clinical and sociodemographic data will be essential to validate and extend these findings. This manuscript does not include a comparison with a control group, but a comparison paper is planned to report comparisons in reproductive outcomes between women with CHD and their healthy female siblings who also completed the survey.

Conclusion

Significant gender differences in reproductive health outcomes and intentions emphasize the necessity of gender-specific counseling and support for individuals with CHD. This research offers valuable insights into the factors influencing reproductive counseling for women with CHD. Equitable healthcare is achievable through education, improved access to care, and standardized counseling to enhance reproductive health outcomes for all individuals with CHD. Particular attention should be directed toward vulnerable groups, including single women, younger individuals, those with lower incomes, limited regular follow-up, or those who underwent early-age surgery. Engaging these groups in reproductive health discussions and empowering them to make informed decisions is essential for improving care.

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Disclaimer

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.

Conflict of interest

None reported.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.ahj.2025.107338.

CRediT authorship contribution statement

Sukran Erdem: Writing – review & editing, Writing – original draft, Conceptualization. **Caroline Yunhua Shi:** Writing – review & editing, Formal analysis, Data curation. **Andrew Dailey Schwartz:** Writing – review & editing. **Jesica Flores:** Writing – review & editing. **Jessica Knight:** Writing – review & editing. **Osamah Aldoss:** Writing – review & editing. **Susan C. Anderson:** Writing – review & editing. **Charles E. Canter:** Writing – review & editing. **Gurumurthy Hiremath:** Writing – review & editing. **Tarique Hussain:** Writing – review & editing. **Anitha S. John:** Writing – review & editing. **Bradley S. Marino:** Writing – review & editing. **Kimberly E. McHugh:** Writing – review & editing. **Geetha Raghuveer:** Writing – review & editing. **Logan G. Spector:** Writing – review & editing. **James D. St Louis:** Writing – review & editing. **Lazaros Kochilas:** Writing – review & editing. **Matthew E. Oster:** Writing – review & editing, Supervision, Project administration, Methodology, Investigation, Funding acquisition, Conceptualization. **Mansi Gaitonde:** Writing – review & editing, Visualization, Supervision, Project administration, Methodology, Conceptualization.

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