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Lifetime Prevalence of Sexual Intercourse and Contraception Use at Last Sex Among Adolescents and Young Adults With Congenital Heart Disease

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Abstract

Purpose—Because of the increased risks associated with unplanned pregnancy for males and females with congenital heart disease (CHD), we investigated sexual intercourse and contraception use in these adolescents and young adults (AYA) and compared the same with national and state population data.

Methods—We recruited 337 AYA with structural CHD aged 15–25 years ($M_{age} = 19$ years, standard deviation = 3.1; 53% male, 84% white) from an outpatient cardiology clinic to participate in a larger study assessing genetic knowledge and health behaviors. Cumulative lifetime prevalence of adolescent (aged 15–18 years) sexual intercourse was compared with the 2011 Youth Risk Behavior Surveillance System and the 2007 Ohio Youth Risk Behavior Survey. Cumulative lifetime prevalence of young adult (aged 19–25 years) sexual intercourse and contraception use at last sex were compared with the 2006–2008 National Survey of Family Growth.

Results—Reported rates of ever having sexual intercourse, 26% of adolescents and 74% of young adults with CHD, were significantly lower than general population rates (47% and 86% respectively; $p < .001$). Similar to the general population, 77% of previously sexually active young adults with CHD reported using at least one effective method of contraception at last intercourse, whereas 25% used dual effective methods and 23% used no effective method.

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Conclusions—Lower rates of ever having sexual intercourse in this population suggest that the psychosexual development of AYA with CHD may lag behind their peers. As nearly one in four participants reported using no effective method of contraception, health care providers should increase discussions of contraception with males and females with CHD.

Keywords

Adolescents; Congenital heart disease; Contraception; Pregnancy; Psychosexual development; Sexual behavior; Young adults

Congenital heart disease (CHD) is the most common birth defect, affecting nearly 1% of live births worldwide and resulting in approximately 36,000 new cases each year in the United States alone [1]. Advancements in surgical and catheter interventions and medical management over the past several decades have resulted in survival rates to adulthood of more than 85% [2]. As a result, there are more than a million adults living with CHD in the United States today, meaning that there are now more adults than children living with CHD [3].

As individuals with CHD enter adolescence and young adulthood, a new set of health concerns arises. One such concern is sexuality and reproduction. Women with CHD can experience increased cardiac complications during pregnancy that can affect both mothers and their offspring [4,5]. Additionally, individuals with CHD also face the risk of passing CHD onto their children. Although few specific genes have been determined to cause CHD directly, heart defects are multifactorial in etiology with a clear genetic component [6,7]. A meta-analysis determined that the risk to offspring of individuals with CHD is as high as 12% depending on the specific defect and the sex of the parent [8]. Although males with CHD do not have the same personal health risk as women, the reproductive risk for having a child with CHD is the same, thus warranting equal attention.

These recurrence risks are even more concerning given the high rates of sexual activity [9] and unplanned pregnancy [10] among adolescents in the United States. Approximately half of all pregnancies in the United States are unplanned [11], and more than one in every 20 young adult women experiences an accidental pregnancy each year [12]. Although use of dual method contraception (both a condom and a hormonal method) provides optimal protection against pregnancy and appears to be increasing among adolescents and young adults (AYA) [13], the 2006–2008 National Survey of Family Growth (NSFG) found that only 7.3% of sexually active women used dual contraception [14].

Although the literature suggests that the psychosexual development of children with a chronic illness may differ from their peers [15,16], research with the CHD population has been mixed. Studies have shown that rates of ever having had sexual intercourse among AYA with CHD are lower than those of their healthy peers [17], men aged 18–39 years with CHD are less likely to be engaged in sexual relationships [18], and both men and women with CHD report it is difficult to experience satisfying sexual relationships [19]. However, other research has suggested that adults with CHD may not experience differences in their sexual functioning when compared to controls [20] and may actually engage in high levels of sexual risk-taking [17,21].

Because of the increased risks of unplanned pregnancy for males and females with CHD and conflicting research findings regarding sexual behavior in this population, the aims of this study were (1) to determine reported cumulative lifetime prevalence of sexual intercourse among AYA with CHD compared to rates in the general population and (2) to determine rates of reported contraception use at last sexual intercourse among sexually active young adults with CHD compared to rates in the general population. Based on trends of sexual behavior in chronic illness populations, we hypothesized that (1) AYA with CHD would report lower cumulative lifetime prevalence of sexual intercourse than their peers in the general population and (2) that sexually active young adults with CHD would report lower rates of effective contraception use at last sexual intercourse than their peers in the general population. Additionally, we explored differences in cumulative lifetime prevalence of sexual intercourse and contraception use at last sex by gender and CHD severity within the sample.

Methods

Participants

Participants were recruited between May 2012 and July 2013 from the outpatient cardiology clinic at a large tertiary children's hospital in the Midwest. Eligible participants were (1) being seen for an appointment in the cardiology clinic; (2) between the ages of 15 and 25 years at the time of recruitment; and (3) diagnosed with a structural heart defect. Patients were excluded if they had a genetic syndrome known to be associated with a heart defect (i.e., DiGeorge syndrome and Marfan syndrome), did not speak English, and/or were unable to read or understand the surveys. Eighty-eight percent of eligible patients were approached for participation by a study team member during their clinic visit. We consented 350 AYA to participate in the study, as a result of an 84% consent rate. On review after participation in the study, 13 participants were removed—11 participants had a genetic syndrome and 2 had completed less than half of the study surveys. This yielded a final sample of 337 AYA ($M_{\text{age}} = 19$ years, standard deviation = 3.1; 53% male, 84% white) for analysis. Detailed demographic information can be found in Table 1.

Measures

Survey questions to assess sexual behavior were taken from the 2011 National Youth Risk Behavior Surveillance System (YRBSS), a national survey of adolescent risk behaviors performed in U.S. high schools [22]. Participants were asked the following questions from the YRBSS: (1) Have you ever had sexual intercourse? and (2) The *last time* you had sexual intercourse, what method(s) did you or your partner use to *prevent pregnancy*? Participants were also asked (1) Do you think you will ever have biological children? and (2) Females—Have you ever been pregnant? Males—Has your partner(s) ever been pregnant with your baby? Participants were also asked to provide their age, sex, race, and ethnicity. CHD diagnosis was obtained from electronic medical records and categorized as either simple (e.g., ventricular septal defect), moderate (e.g., tetralogy of Fallot), or complex (e.g., hypoplastic left heart syndrome) in severity based on classifications proposed by Jenkins et al. [23].

Procedure

AYA were recruited along with their parents as part of a larger study assessing the effect of genetic knowledge on health behaviors. This study and its procedures were approved by the hospital's institutional review board. Verbal consent was obtained from individuals aged 18 years or older, whereas parents or legal guardians verbally consented for individuals younger than the age of 18 years with verbal assent from minors. AYA were asked to complete a series of surveys either on paper or electronically before leaving clinic, which took about 20 minutes to complete. For their participation, AYA received one movie pass.

Data analysis

Descriptive analyses and chi-square tests ($\alpha = .05$) were used. Cumulative lifetime prevalence of sexual intercourse for adolescents (ages, 15–18 years) was compared with national sexual intercourse rates obtained from the YRBSS [22] and state sexual intercourse rates obtained from the 2007 Ohio Youth Risk Behavior Survey [24]. Cumulative lifetime prevalence of sexual intercourse for young adults (ages, 19–25 years) was compared with national sexual intercourse rates obtained from the 2006–2008 NSFG male and female raw datasets for ages 19–25 years [25]. Rates of contraception use at last intercourse among young adults were also compared with contraception use rates obtained from the NSFG. Because of a small sample size, rates of contraception use among sexually active adolescents in this sample could not be compared with those of general population data.

Results

Aim 1: cumulative lifetime prevalence of adolescent and young adult sexual intercourse

Ever having had sexual intercourse was reported by 26% ($n = 43$) of adolescents with CHD, which was significantly lower than rates from both national [22] (47%; $\chi^2(1) = 28.89$; and $p < .001$) and state [24] (45%; $\chi^2(1) = 21.67$; and $p < .001$) population data. This difference was found for both adolescent male (26%; $n = 25$) and adolescent female (28%; $n = 18$) intercourse rates (Figure 1.) Ever having had sexual intercourse was reported by 74% ($n = 118$) of young adults with CHD, which was also significantly lower than the rate from national population data [25] (86%; $\chi^2(1) = 17.80$; and $p < .001$). This difference was found for both young adult males (76%; $n = 53$) and young adult females (73%; $n = 65$) (Figure 2.) These data supported our first hypothesis that AYA with CHD would report lower cumulative lifetime prevalence of sexual intercourse than their peers. Additionally, sexual intercourse within the sample did not differ by CHD severity for either adolescents ($\chi^2(2) = 4.54$; $p = .104$) or young adults ($\chi^2(2) = 1.29$; $p = .525$).

Aim 2: rates of young adult contraception use at last sexual intercourse

Of the sexually active young adults who were not trying to get pregnant and were not currently pregnant ($n = 101$), more than three quarters (77%; $n = 78$) reported using at least one effective method of contraception at last intercourse. More specifically, 53% ($n = 53$) reported using one effective method (i.e., condom or hormonal) and 25% ($n = 25$) reported using dual effective methods (i.e., condom and hormonal), whereas 23% ($n = 23$) reported using no effective method at all (i.e., neither condom nor hormonal). The most common

methods used were condoms (50%; $n = 50$) followed by contraceptive pills or patches (39%; $n = 39$) (see Table 2 for a listing of rates for all methods.) Of those who were classified as using no effective method of contraception, 12% ($n = 12$) used only an ineffective method (e.g., withdrawal or rhythm), whereas 11% ($n = 11$) reported using no method at all. Our sample of young adults with CHD reported similar rates of effective contraception use ($\chi^2(1) = .29$; $p = .588$) and dual contraception use ($\chi^2(1) = 1.98$; $p = .160$) as their national peers [25]. Additionally, rates did not differ from national data when analyzed individually for males or females. The only exception was that females in this sample were more likely to report dual method contraception use (25%, $n = 13$) than their peers (15%; $\chi^2(1) = 3.92$ and $p = .048$) (Table 3.) These data did not support our second hypothesis that sexually active young adults with CHD would report lower rates of effective contraception use at last sexual intercourse than their peers. Additionally, rates of effective contraception use within the sample did not differ by gender ($\chi^2(1) = .16$; $p = .689$) or CHD severity ($\chi^2(2) = .58$; $p = .747$).

Discussion

Because of the increased risks of unplanned pregnancy for males and females with CHD, this study determined cumulative lifetime prevalence of sexual intercourse and contraception use at last sex among AYA with CHD and compared these findings to general population data. Rates of ever having sex reported by AYA with CHD were lower for the whole sample and also males and females separately when compared to applicable population data. These findings supported our first hypothesis and were similar to those found by Canadian and German studies of AYA with CHD [17,18] and studies of other chronic illnesses [15].

There are a number of potential explanations for these findings. Parents were often present during data collection. Fearing that their parent(s) would see their responses, AYA may have underreported having had sexual intercourse before. Lower cumulative lifetime prevalence of sexual intercourse in this population may suggest that the psychosexual development of adolescents with CHD may lag behind their peers. We found that this disparity is present among young adults as well, suggesting that this psychosexual delay may continue into young adulthood as other studies have suggested [16]. Although previous research has suggested that adolescents with CHD are not lonelier than controls [26], future studies should determine if there are other areas of psychosocial development that may lag among individuals with CHD, such as childhood friendships and adolescent romantic relationships.

Lower cumulative lifetime prevalence of sexual intercourse among AYA with CHD may also be the result of more protective parenting and increased interaction with the medical community throughout these individuals' lives. As early as the 1980s, health care providers noticed a tendency for parents of adolescents with CHD to treat their children as "asexual" [27]. It is debatable, of course, as to whether this possible psychosexual lagging is desirable. Although delayed sexual intercourse reduces the risk of potentially dangerous unplanned pregnancy, it may point to a larger problem in healthy relationship development.

Another potential explanation is that AYA with CHD experience poorer sexual functioning than their peers. Although some studies have suggested that sexual functioning among adults

with CHD is no worse than controls [20], research has found that individuals with CHD experience poorer adjustment in their sexual relationships than their peers [19], are often fearful or insecure about sex [18,28], and feel self-conscious about their body image due to surgical scars [29]. For young men with CHD, erectile dysfunction has frequently been reported [30]. Future research should seek to determine the factors related to why nonsexually active AYA with CHD remain abstinent and how these individuals feel about delaying sexual activity, how delaying sexual activity impacts their quality of life, and their level of satisfaction with intimacy once they begin engaging in sexual relationships.

Although we found that most young adults with CHD who were not trying to get pregnant used at least one effective method of contraception at last sexual intercourse, nearly one in four participants put themselves at risk for an unplanned pregnancy using no effective method. These rates were not statistically different from rates obtained from the NSFG [25] and were also similar to those from the National Longitudinal Survey of Youth [31]. Therefore, our data did not support our second hypothesis that sexually active young adults with CHD would report lower rates of effective contraception use at last intercourse than their peers. Although better than we expected, our data suggest that young adults with CHD practice contraception nonuse at the same rates as their healthy peers despite their increased risks associated with an unplanned pregnancy.

One explanation for this finding could be that AYA with CHD may not be aware of the increased physical and/or genetic risks they face should an unplanned pregnancy occur, or they might not be concerned with these risks [17]. Previous research has found that contraception and reproductive counseling for women with CHD are inadequate [32], as evidenced by 59% of women with CHD reporting that they have never received reproductive or contraceptive counseling from a health care provider [33]. Health care providers may also be less inclined to discuss pregnancy risks with their male patients because they do not face the immediate physical health risks that female patients with CHD do (i.e., cardiac complications during pregnancy). In light of our findings, we recommend that health care providers increase their discussions of contraception and increased pregnancy risk with both males and females with CHD.

This recommendation is especially important given that rates of effective contraception use may have been lower than our data suggest. Social desirability bias has been shown to be especially problematic in studies of contraception use in that participants are more likely to report using contraception when they did not [34]. Our data were collected by different methods than the population data we compared our sample to, such that the degree of social desirability bias may have differed. The YRBSS [22] and the Ohio Youth Risk Behavior Survey [24] each collect data on paper in high school classrooms using anonymous computer-readable scoring sheets. In the NSFG [25], data were collected verbally by private in-person interviews in the participant's home with an interviewer who recorded the data electronically. Social desirability bias may have been increased in our sample as parents were often present during data collection. Our use of paper surveys that required manual entry by research personnel may have reduced confidence in anonymity. Future studies should better counter social desirability bias by administering surveys in electronic format only and ensuring parents are not present during data collection.

Nonetheless, the present study possessed a number of strengths. This is the first study using a large U.S. sample of AYA with CHD to compare cumulative lifetime prevalence of sexual intercourse and contraception use at last sex to U.S. population data. This study included males with CHD as they also face a genetic risk of passing CHD onto their children. Many studies regarding sexuality in this population only focus on women's pregnancy risk. Furthermore, our large sample size provided us with more statistical power than that is usually possible in studies of chronic illness populations.

However, this study had a number of limitations that should be improved on in future research. Because we recruited from a single clinical site, our findings cannot be generalized to AYA with CHD in other regions of the country and do not include those who do not attend clinic appointments. Additionally, our analysis was limited in that we did not have a sufficient number of sexually active adolescents in our sample to conduct inferential analyses on their contraception use. Therefore, in future studies, we would suggest oversampling adolescents to overcome this issue. The scope of our data was also limited in that we only asked participants about their last sexual intercourse and used a cross-sectional study design. Although it was implied that "sexual intercourse" referred to vaginal sex because the other survey questions pertained to biological children and pregnancy prevention, this was not specified and could have been interpreted incorrectly. Future studies should ask more sexual behavior questions (e.g., age of first sexual intercourse, types of sexual acts performed including oral and anal sex, number of lifetime sexual partners, and history of drug and alcohol use before sex) and use a longitudinal design to assess early predictors of sexual intercourse and contraception use over time. Although this study was focused on pregnancy risk, it is also important to study sexually transmitted infections (STI) given that AYA account for nearly half of all new STI in the United States, although they only make up a quarter of sexually active Americans [35]. Future studies should assess STI rates and risk behaviors among AYA with CHD.

Despite these limitations, this is the first large study of cumulative lifetime prevalence of sexual intercourse and contraception use at last sex among AYA with CHD in a U.S. sample. Based on these findings, future research should work toward understanding the factors that influence sexual behaviors in this population. These studies should determine how much knowledge AYA with CHD have about their increased pregnancy and genetic risks and how this knowledge influences their contraception use. Structured interventions should be implemented in clinical settings to better educate this population about their risks and how to protect themselves. Increasing genetic counseling and the presence of genetic counselors in the clinical setting could greatly assist in this effort.

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IMPLICATIONS AND CONTRIBUTION

Cumulative lifetime prevalence of sexual intercourse is lower among adolescents and young adults with congenital heart disease, suggesting a possible delay in psychosexual development. Given the increased pregnancy risks and rate of ineffective contraception use (one in four) in this population, health care providers should routinely discuss contraception with both males and females with congenital heart disease.

Figure 1.

Cumulative lifetime prevalence of sexual intercourse reported by adolescents with CHD compared to national (2011 Youth Risk Behavior Surveillance System [YRBSS] [22]) and state (2007 Ohio Youth Risk Behavior Survey [OYRBS] [24]) population data. No gender differences in adolescent cumulative lifetime prevalence of sexual intercourse within the CHD sample ($p = .757$).

Figure 2. Cumulative lifetime prevalence of sexual intercourse reported by young adults with CHD compared to national (2006–2008 National Survey of Family Growth [NSFG] [25]) population data. No gender differences in young adult cumulative lifetime prevalence of sexual intercourse within the CHD sample ($p = .701$).

Table 1

Demographic information for study participants with congenital heart disease by age group

	<u>Entire sample (ages, 15–25 years); mean (standard deviation [SD])/%(N)</u>	<u>Adolescents (ages, 15–18 years); mean (SD)/% (N)</u>	<u>Young adults (ages, 19–25 years); mean (SD)/% (N)</u>
	n = 337	n = 172	n = 165
Age	18.96 (3.09)	16.41 (1.12)	21.62 (2.09)
Sex			
Male	53.1 (179)	61.0 (105)	44.8 (74)
Female	46.9 (158)	39.0 (67)	55.2 (91)
Race/ethnicity			
White	83.7 (282)	84.9 (146)	82.4 (136)
Nonwhite	15.4 (52)	15.1 (26)	15.8 (26)
Preferred not to answer	.9 (3)	.0 (0)	1.8 (3)
Highest education attained			
Less than high school	6.5 (22)	11.6 (20)	1.2 (2)
Some high school	35.0 (118)	65.7 (113)	3.0 (5)
High school graduate	28.2 (95)	16.9 (29)	40.0 (66)
Some college	21.7 (73)	2.3 (4)	41.8 (69)
College graduate	7.1 (24)	.6 (1)	13.9 (23)
Preferred not to answer	1.5 (5)	2.9 (5)	.0 (0)
Heart defect severity			
Simple	30.6 (103)	29.7 (51)	31.5 (52)
Moderate	37.7 (127)	38.4 (66)	37.0 (61)
Complex	31.8 (107)	32.0 (55)	31.5 (52)

Table 2Contraception use at last intercourse reported by young adults with congenital heart disease (CHD)^a

	Overall sample; % (N)	Males; % (N)	Females; % (N)	<i>p</i> value^b
	n = 101	n = 49	n = 52	
Condom	49.5 (50)	49.0 (24)	50.0 (26)	.918
Pill/patch	38.6 (39)	46.9 (23)	30.8 (16)	.095
Injection/implant	15.8 (16)	6.1 (3)	25.0 (13)	.009
Withdrawal	6.9 (7)	12.2 (6)	1.9 (1)	.041
Rhythm	2.0 (2)	4.1 (2)	.0 (0)	.141
Other	3.0 (3)	.0 (0)	5.8 (3)	.088
Not sure	5.9 (6)	8.2 (4)	3.8 (2)	.359
None	10.9 (11)	12.2 (6)	9.6 (5)	.672

^aPercent of sexually active young adults with CHD who endorsed using any of the following methods at last intercourse.^bChi-square comparison of males and females with CHD.

Table 3
Contraception use rates for young adults with congenital heart disease (CHD)^a compared to national data^b

	Overall sample			Male			Female		
	CHD; % (N)	NSFG; % (N)	p value ^c	CHD; % (N)	NSFG; % (N)	p value ^c	CHD; % (N)	NSFG; % (N)	p value ^c
	n = 101	n = 2,380		n = 49	n = 1,067		n = 52	n = 1,313	
Condom	49.5 (50)	49.7 (1,182)	.975	49.0 (24)	56.0 (629)	.156	50.0 (26)	42.1 (553)	.250
Any hormonal	52.5 (53)	49.0 (1,166)	.484	51.0 (25)	47.8 (510)	.652	53.8 (28)	50.0 (656)	.575
Effective method	77.2 (78)	79.4 (1,890)	.588	75.5 (37)	82.5 (880)	.200	78.8 (41)	76.9 (1,010)	.742
Single effective	52.5 (53)	60.2 (1,432)	.113	51.0 (25)	58.2 (621)	.308	53.8 (28)	61.8 (811)	.238
Dual effective	24.8 (25)	19.2 (458)	.160	24.5 (12)	24.3 (259)	.971	25.0 (13)	15.2 (199)	.048
No effective method	22.8 (23)	20.6 (490)	.588	24.5 (12)	17.5 (187)	.200	21.2 (11)	23.1 (303)	.742
Ineffective only/not sure	11.9 (12)	8.6 (205)	.241	12.2 (6)	7.5 (80)	.207	11.5 (6)	9.5 (125)	.620
None	10.9 (11)	12.0 (285)	.738	12.2 (6)	10.0 (107)	.606	9.6 (5)	13.6 (178)	.406

^aPercent of sexually active young adults with CHD whose reported contraception use at last intercourse fell into any of the following categories.

^b2006-2008 National Survey of Family Growth (NSFG) [25].

^cChi-square comparison of CHD and NSFG.