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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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A B S T R A C T

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.
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.

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.

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

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Table 1
Demographic information for study participants with congenital heart disease by age group

	Entire sample (ages, 15–25 years); mean (standard deviation [SD])/% (N)	Adolescents (ages, 15–18 years); mean (SD)/% (N)	Young adults (ages, 19–25 years); mean (SD)/% (N)
	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)

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,