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Adolescent Women with Congenital Heart Disease Self-Reported Reproductive Health Discussions with Health Care Providers

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Abstract

Study Objective: This study evaluated self-reported discussions with health care providers (HCPs) among adolescent and young adult (AYA) women with congenital heart disease (CHD).

Design: Data collected from a one-time survey by AYA women.

Setting: Participants were recruited from pediatric cardiology clinics.

Participants: AYA women with CHD, ages 14-21 (N=107).

Interventions: None.

Main Outcome Measures: Questionnaires assessed adolescent characteristics and specific HCP discussions regarding transmissibility of cardiac condition to the infant, risk of pregnancy and hormonal contraception. Outcome measures were self-reported discussions with HCPs about these reproductive health topics.

Results: Mean age was 16.8 years (SD=2.1). Self-reported reproductive health discussions were infrequent, including transmissibility of a heart condition to offspring (37%), risk of pregnancy on their offspring (34%), risks of pregnancy to their health (46%) and risks of hormonal contraception given their heart condition (21%). Reported discussions were most commonly with a cardiologist.

Conclusions: AYA women with CHD reported limited discussions about reproductive health topics important to those with CHD. Lack of appropriate and timely counseling could lead to poor maternal and child health outcomes. Targeted interventions that improve reproductive health discussions between HCPs and AYA women with CHD are needed to close critical information and service gaps.

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Authors have nothing to disclose.

Keywords

Adolescent and Young Adult (AYA); Congenital Heart Disease (CHD); Reproductive Health

Introduction

Adolescent and young adult (AYA) women with congenital heart disease (CHD) are living well into adulthood, increasing their need for appropriate reproductive health care and services.¹⁻⁶ The American Heart Association (AHA) recommends that clinic-based reproductive health counseling should be introduced in early adolescence (~12 years).^{1,7} Women with CHD should receive education in all areas of reproductive health, specifically CHD recurrence risk in offspring, possible cardiac complications during pregnancy and appropriate use of contraception.^{6,8}

Prior research suggests young people with CHD generally have a poor understanding of their heart disease and that adult women with CHD receive limited education and lack sufficient knowledge surrounding reproductive health.⁹⁻¹⁶ Knowledge deficiencies may lead to behaviors associated with both pregnancy and with contraception that have increased risk of worsening of cardiac function, arrhythmia, or possible stroke.^{10,17,18} Reproductive health education and counseling is needed in young women with CHD to improve knowledge and awareness of these risks and ultimately decrease adverse outcomes. Despite this, there is limited research exploring important reproductive discussions suggesting a need for evidence-informed tailored interventions.^{15,19}

The aim of this study was to evaluate reproductive health discussions between health care providers (HCPs) and AYA women with CHD with regards to transmissibility, pregnancy and hormonal contraception risk. Secondary analysis examined which HCPs (i.e. cardiologist, primary care provider [PCP], gynecologist, etc.) engaged in these discussions and patient-reported readiness to have them.

Materials and Methods

Recruitment.

AYA women with CHD (aged 14-21 years) and their female parent/guardian were recruited from two university-associated pediatric cardiology clinics from September 2015 to August 2018. For adolescents under the age of 18 years, parents provided consent and adolescents provided assent. AYA women who were 18 years or older provided their own informed consent. For this study, only AYA surveys were used in data analyses.

Of the 138 AYA women approached to participate in the study, 29 declined participation. Reasons included: disability/not fit for study (N=15, 51.7%), not interested (N=12, 41.4%), or not enough time (N=2, 6.9%). Compared to the study sample, there were no differences in regards to race, age or education level in those who declined to participate. Surveys that were incomplete were excluded from the study sample (N=2), leaving 107 eligible AYA women as the final sample size. This study was approved by Indiana University's Institutional Review Board.

During a scheduled clinic appointment, participants completed a one-time, web-based questionnaire. Attempts were made to have the study questionnaire completed prior to the scheduled cardiology visit but, in some cases, the study questionnaires were completed after the visit.

Data Collection.

Participants answered questions about demographics (e.g. age, race/ethnicity, education level), their reproductive health experiences (e.g. ever had a period [yes/no], ever had sex [yes/no], past and current use of birth control), and previous discussions about transmission of a cardiac lesion, risks surrounding pregnancy, and risks of contraception use. AYA women were also asked if they had achieved menarche. Post-menarchal participants were queried about use of hormones for a menstrual problem or for a pubertal issue (e.g. cramps, irregular periods, etc.). For those who reported any hormonal use, a table containing eight hormonal options was provided for participants to indicate their use of each method (i.e. 'in the past', 'currently using', or 'never used'). All participants were queried about lifetime sexual experience (yes/no), if they had used contraception to prevent a pregnancy and if so, asked to indicate the method(s) used in a similar table.

Survey questions were adapted from Hinze et al.¹¹ Participants responded either 'yes' or 'no' to each discussion topic provided in the survey. For example, "Has a medical health professional ever discussed with you the risks of pregnancy on your health given your heart disease/condition?" (Table 1). Participants responding 'yes', were then asked to identify HCP(s) (e.g. pediatric or adult cardiologist, registered nurse, pharmacist, PCP, obstetrician/gynecologist, and/or other) with whom the discussion(s) occurred. Participants were also queried about their readiness to have these discussions, such as ability to use birth control, get pregnant or carry a pregnancy. Response categories included 'never' versus choosing one of the following age ranges: 13-14 years, 14-15 years, 15-16 years, 16-17 years, or 18 years and older. All AYA women answered this question.

For each participant, an additional survey was generated to be completed by one of the study cardiologists (SL or NS). Prior to the start of enrollment, a predefined list of contraindications (i.e. to pregnancy or estrogen containing contraception) was compiled from current literature. These determinations and risk evaluations were based on consensus drawn from the American College of Cardiology (ACC) and AHA Guidelines, World Health Organization and U.S. Medical Eligibility Criteria.^{14,20-22} The cardiologists accessed patient's electronic medical record to report the adolescent's CHD diagnosis and severity, risk of transmitting a cardiac lesion in offspring (yes/no), contraindication(s) to pregnancy/at high risk for pregnancy related morbidity and mortality (yes/no), and contraindication(s) to estrogen containing hormonal contraception (yes/no).

Data Analysis.

For data analyses, cardiac lesions were classified as simple, moderate, or complex based on ACC criteria.²⁰ Heart transplant recipients were categorized separately. For pregnancy assessment, women were classified into three risk groups: contraindicated, at high risk (of maternal morbidity or mortality), or at low/no additional risk with pregnancy based

on criteria set forth by the ACC and AHA.²⁰ Pregnancy contraindications and women at high risk included those with pulmonary arterial hypertension, Eisenmenger's syndrome, severe systemic ventricular dysfunction (NYHA class III or IV), severe left sided obstructive lesions, systemic right ventricle, cyanotic heart lesions, and severe aortic root dilation. Although heart transplant is not an absolute contraindication to pregnancy, AYA women with transplanted hearts at our institution are highly discouraged from pregnancy and therefore classified as high risk when assessing discussions about a future pregnancy with a provider.

Presently, a genetic etiology for CHD is identified in 20-30% of cases.²³ However, our understanding of genetic etiology continues to evolve and mothers with CHD are counseled that there is a general risk of recurrence in offspring. Questions regarding the risk of transmissibility of CHD to their offspring were asked of all participants. Women to be considered not at risk included those with mild variants of normal cardiac anatomy including such lesions as patent foramen ovale or trivial mitral valve prolapse.

Contraindications to estrogen included AYA women with functional class III and IV heart failure, Eisenmenger's syndrome, history of thromboembolism or at high risk for thromboembolic events, including those with cyanosis, Fontan physiology, mechanical valves, and pulmonary arterial hypertension.^{14,20-22} For data analysis purposes, participants were categorized based on cardiac condition(s) at the time of enrollment.

Statistical Procedure.

Data were analyzed by Statistical Package for Social Sciences (v.26). Descriptive statistics of the population are reported as totals and percentages. Bivariate analysis (i.e. chi-squared and t-tests) assessed for associations between adolescent factors/characteristics (i.e. age, lesion/cardiac complexity, ever had sex) and self-reported discussions with providers.

Results

Population Characteristics.

The mean age at enrollment was 16.8 years and the majority of AYA females were White, Non-Hispanic (N=90, 84.1%). Most had achieved menarche (N=100, 93.5%) at an average age of 12.4 years (SD=1.6) and 34 (33%) women reported ever having sex. Many cardiac lesions and complexity levels were represented in this population. The three most common lesions reported were ventricular septal defects (N =17, 8.7%), bicuspid aortic valves (N=16, 8.2%), and coarctation of the aorta (N=16, 8.2%). Over half (65.5%) of these women had either simple or moderately complex lesions; seven women had received a transplanted heart (Table 2). Twenty-seven women (25.2%) had either a contraindication to pregnancy or would be considered high risk if they were to become pregnant; 18 women (16.8%) had contraindications to estrogen use (Table 3).

Discussions about Transmission.

Of the entire sample, 40 (37.4%) AYA women reported discussing risk of transmission of cardiac lesion(s) to offspring (Table 4). However, 87 (81.3%) were at risk of a cardiac lesion recurring in future offspring. Participants at risk of transmission were half as likely as

those without transmission risk to report discussing this with a HCP (34.5% vs. 65.5%). Among participants that reported discussing transmissibility, a high proportion (N=31, 77.5%) reported it with a single provider, most commonly a cardiologist (N=30). Of the six women who reported this discussion with a non-HCP, four reported discussing transmission risk with a parent instead.

Older adolescents (17.9 years vs. 16.5 years, $P = <.001$) and those who were sexually experienced were more likely to report a discussion with a HCP about risk of transmitting their heart condition to their offspring (52.9% vs 47.1%, $P = .018$), whereas participant cardiac lesion complexity was not associated with having a discussion regarding transmissibility (Table 5).

Discussions and Contraindications to Pregnancy.

Fewer than half of all participants (N=47, 45.6%) reported discussing the risk of pregnancy with a HCP. Just over one third (N=35, 34%) reported they were told that if they were to become pregnant, their heart problem(s) may affect their offspring (Table 4). These two discussions were reported most frequently with a cardiologist and less often than with a PCP, or an obstetrician/gynecologist. Few (N=3 in total) reported discussing them with a parent/non-provider.

Older adolescents were more likely to have discussed pregnancy risks (17.9 years vs. 16.3 years, $P = <.001$) and have been told that their lesion could affect their offspring if they were to become pregnant (18.1 years vs. 16.5 years, $P = <.001$). Participants with a complex lesion or transplanted heart were more likely to report a discussion about pregnancy risk (although not statistically significant) and about their heart condition affecting their offspring ($P = <.001$) with a HCP.

Based on study cardiologist surveys, 27 women carried either contraindications or were at high risk with pregnancy. One participant failed to answer the survey discussion items surrounding pregnancy risk, leaving 26 women for analyses (Table 4). Fifteen (57.7%) reported discussing the risks of pregnancy and 16 (61.5%) recalled being told that their heart problem(s) may affect their offspring if they were to get pregnant. Although not shown in Table 4, only eight AYA women reported they had been told not to become pregnant. Of these eight participants, seven had cardiac lesions with significant pregnancy-associated risks (N=4) or had a transplanted heart (N=3); however, one participant did not have a significant lesion or transplanted heart that would put her at risk.

Discussions and Contraindications to Hormonal Contraception.

Among post-menarchal AYA women (N=99), 22 (22.2%) reported a discussion about risks of birth control with a single HCP, most commonly a cardiologist (N=14) or PCP (N=9). No adolescent reported this discussion with a parent. Older participants (18.1 years vs. 16.7 years, $P = .010$) reported more discussions of hormonal contraception. However, among sexually experienced participants, more than half (N=21, 61.8%) did not report discussing the risks of hormonal contraception with a HCP (Table 5).

Eighteen women had a medical condition that met criteria for a contraindication to estrogen-containing contraception (Table 3). Among these 18 women, seven (39%) reported use of an estrogen containing birth control at some time despite contraindication(s). Only eight of these participants reported discussing the risks of hormonal contraception with a HCP. AYA women who carried a contraindication to estrogen were less likely (55.6% vs. 44.4%, $P = .022$) to discuss the risks of hormonal contraception with a HCP (Table 4).

Participant Readiness to Discuss Reproductive Health

Twenty-five AYA women (24.3%) considered 14-15 years of age appropriate for initiation of reproductive health discussions by a HCP, including their ability to use birth control, get pregnant, or carry a pregnancy. About one-half ($N=55$, 53.4%) of the participants reported that they would fully understand their heart condition and the associated risks of pregnancy and be comfortable asking questions about these topics. Only eight (7.8%) said they would have a hard time understanding such discussions and would likely not ask questions.

Discussion

This study examined self-reported discussions with HCPs about potential for transmission of cardiac lesions, pregnancy risks and risks of hormonal contraception among a sample of AYA women with CHD. We found that reproductive health discussions were infrequent in this population. There were significant differences by age, lesion complexity and sexual experience.

Older AYA women reported more discussions with HCPs. Research on reproductive health in adult women has been more promising, though still lacking. Studies have reported counseling on the risks of pregnancy in 52-64% of adult women with CHD and contraceptive counseling in less than 50%.^{12,14,24} Reasons for this could be many. Providers may see discussions about reproductive health issues unnecessary if adolescents are younger, less mature and not close to perceived childbearing years, or seen as nonsexual secondary to their chronic medical condition.²⁴⁻²⁷ In addition, sensitive topics like reproductive health may be less comfortable for providers when talking to adolescents, especially if a parent is present. Similarly, AYA women may not initiate discussions concerning their reproductive or sexual health because of concerns about confidentiality, especially if parents are involved in their care.^{24-26,28} Despite these potential barriers, adolescents who are more knowledgeable about their heart condition are more likely to communicate with their providers directly than through a parent.²⁹ Earlier and repeated communication surrounding reproductive health may improve self-efficacy and knowledge about reproductive health which could improve provider-patient relationships and improve transition to adult care.²⁹

A significant association was found between adolescents with greater cardiac complexity and those who were more likely to report a discussion, specifically relating to pregnancy and hormonal contraception. It stands to reason that CHD complexity may play a role in discussions that occur during adolescence due to more frequent clinic visits and/or recognizable potential for poor reproductive outcomes for those with more complex lesions. Research has also shown that AYA women with moderate and complex CHD lack knowledge about life-long cardiac care and desire to learn more about this type of

care necessary in adulthood.³⁰ However, to promote greater self-advocacy, it is important for women with any cardiac lesion to understand their level of risk relating to pregnancy complications and safety in using estrogen-containing contraceptives. In addition, AYA women should understand that their current risk level may change due to acquired risk factors (such as hypertension) or sequelae from previous repairs or palliation.

AYA women who reported sexual experience were not more likely to have HCP discussions. In fact, they reported less discussions about hormonal contraception (sexually experienced 38.2% vs. non-sexually experienced 61.8%) as well as how their heart conditions may affect their offspring if they were to get pregnant (sexually experienced 38.2% vs. non-sexually experienced 61.8%). Research shows there are no significant differences in reported sexual outcomes, such as age at first sex, when comparing individuals with and without CHD.¹⁷ Given the absence of differences, the lack of these discussions becomes disconcerting. This is because women who have already engaged in sexual activity are at risk for pregnancy and may be prescribed estrogen containing contraception in the face of contraindication(s).

While more than half of AYA women with contraindications to estrogen in our study reported a discussion concerning the risk of hormonal contraception, 39% reported use of an estrogen containing birth control at some time despite contraindication(s). Similar findings have been found in adult women with CHD with 20-60% reporting use of a contraindicated birth control method.^{11,12,24} AYA women lack comprehensive knowledge of appropriate contraceptive methods regarding their cardiac condition. Studies, for both AYA as well as adult women cite inadequate education, advice and counseling as contributory factors to this finding.^{16,31,32} This is troubling given thromboembolic risk among women with CHD with use of estrogen-containing oral contraceptives.¹⁶ The unacceptable risks associated with the addition of hormonal contraception in some young women with CHD makes this counseling imperative.

Beyond the fore mentioned communication barriers associated with the adolescent's age, lack of adequate reproductive health discussions could be due to several additional factors. HCP barriers, such as lack of time or discomfort with sexual and reproductive health counseling may play a role.^{13,25} Subspecialty providers may not feel equipped to have these discussions and, instead, defer to primary physicians or obstetrician/gynecologist. Brown et. al found that most cardiology fellows felt their fellowship training had not prepared them to counsel patients on contraception and preconception planning.²⁶ However, in our study, the cardiologist was the most commonly cited provider discussing reproductive health and adolescents reported being ready and willing to have these discussions with their HCP. In addition, AYA women with CHD will use their cardiology clinic as their medical home that will provide the needed care and education for most health matters.²⁹ A potential solution is the development of a specialized care team working in tandem with the cardiologist. This team can implement evidence-based guidelines, tailored healthcare services and improve the timing and delivery of these discussions.^{17,33}

This study has some limitations. First, this was a convenience sample of tertiary care patients and primarily a population of White, Non-Hispanic individuals. Therefore, its generalizability may be limited. Second, advice or counseling may have been provided in a

way that was not captured by our survey items and our survey did not capture information on the quality of the counseling given. Finally, there may be recall bias as the study focused on patient-recalled information; however, the age of this study population is likely to be in close proximity to the timing of these discussions.

Conclusion

For AYA women with CHD, reproductive health counseling including discussions about disease transmission, risk of pregnancy and risk of hormonal contraception are limited. Though more discussions may not directly equate to retained knowledge, our study highlights a need for research to address barriers of HCPs in providing reproductive health counseling. Systems and policies need to be implemented to address sexual reproductive health in specialized populations either through specific HCP education and training and/or through use of other team members (i.e. social workers, health educators, etc.).

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Table 1.

Discussions assessed with healthcare providers

Has anyone ever discussed whether your heart condition can be transmitted to your baby if you were to get pregnant?
Has a medical health provider ever discussed with you the risk of pregnancy on your health given her heart condition?
Has your medical health provider ever told you that you should never become pregnant?
Has a medical provider ever told you that if you got pregnant, that your heart problem(s) may affect the baby?
Has a medical provider every discussed the risk of using hormonal contraception on your health given your heart condition or disease?

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Table 2.

Demographics and Population Characteristics (N=107)

Characteristic	Adolescent Mean [SD] or N (%)
Age (years, range 14-21)	16.8 [2.1]
Race/ethnicity	
White, Non-Hispanic	90 (84.1)
Black, Non-Hispanic	7 (6.5)
Asian, Non-Hispanic	1 (0.9)
Native American	1 (0.9)
Hispanic or Latino	4 (3.8)
Multiracial	4 (3.8)
Education Level	
Middle School (6 th – 8 th)	11 (12.1)
High School (9 th – 12 th)	58 (63.7)
Graduated high school, in college or specialized training program	22 (24.2)
Ever had sex (yes) *	34 (33.0)
Lesion Complexity ^a	
Simple	25 (23.4)
Moderate	45 (42.1)
Complex	30 (28.0)
Transplanted	7 (6.5)

* N= 103

^aComplexity determined by American College of Cardiology

Table 3.

Cardiac Lesions Associated with High Risk or Contraindications to Pregnancy (N=27) and Contraindications to Use of Estrogen (N=18)

High Risk or Contraindications to Pregnancy	N
Fontan circulation	13
Transplant	7
Truncus arteriosus (aortic root dilation)	2
Aortic Regurgitation	1
Transplant/Pulmonary Hypertension	1
Pulmonary Hypertension	1
Dilated Cardiomyopathy	1
Cyanosis/pulmonary atresia	1
Contraindications to Use of Estrogen	
Fontan Repair	13
Pulmonary Hypertension	3
Cyanosis/Pulmonary Atresia	1
Aortic Regurgitation	1

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Table 4.

Participant Reported Discussions with a Provider

Discussion	Participant Reported Discussion with Provider(s)	Participant Reported Discussion by Risk Factor	
		At Risk for Transmission (N=87)	
	Yes N (%)	Yes N (%)	No N (%)
Ever discussed whether heart condition can be transmitted*	40 (37.4)	30 (34.5)	57 (65.5)
1 provider	31 (77.5)		
2 or more providers	3 (7.5)		
Parent/non-provider/other	6 (15)		
		High Risk or Contraindication to Pregnancy (N=26) ^b	
Ever discussed risk of pregnancy ^{a, **}	47 (45.6)	15 (57.7)	11 (42.3)
1 provider	34 (72.3)		
2 or more providers	11 (23.4)		
Parent/non-provider	3 (6.4)		
Ever been told if got pregnant heart problems may affect the baby ^{**}	35 (34)	16 (61.5)	10 (38.5)
1 provider	26 (74.3)		
2 or more providers	7 (20)		
Parent/non-provider	2 (5.7)		
		Contraindication to Estrogen (N=18)	
Ever discussed risk of hormonal contraception ^{**}	22 (21.4)	8 (44.4)	10 (55.6)
1 provider	15 (68.2)		
2 or more providers	6 (27.3)		
Parent/non-provider/No provider	1 (4.5)		

^a 1 participant reported both a provider and parent/non-provider as source of conversation

^b 1 participant did not respond to this survey discussion item

* N=107

** N=103

Table 5. Bivariate Analysis of Associated Adolescent Factors and Adolescent Reported Discussions with a Provider

Adolescent Characteristic/ Factor	Reported Discussion									
	Transmission Risk ^a		Pregnancy Risk ^b		Heart condition may affect your baby ^b		Never become pregnant ^b		Hormonal contraception ^b	
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
Mean Age [SD]	17.9 [2.0]	16.5 [2.2] ***	17.9 [2.0]	16.3 [2.2] ***	18.1 [2.0]	16.5 [2.1] ***	17.8 [1.7]	17.0 [2.3]	18.1 [2.3]	16.7 [2.2] *
Lesion Complexity N (%)										
Simple	8 (32.0)	17 (68.0)	9 (37.5)	15 (62.5)	0	24 (100)	7 (29.2)	17 (70.8)	0	24 (100)
Moderate	14 (31.1)	31 (68.9)	16 (37.2)	27 (62.8)	1 (2.3)	42 (97.7)	8 (18.6)	35 (81.4)	7 (16.3)	36 (83.7)
Complex	14 (46.7)	16 (53.3)	17 (56.7)	13 (43.3)	4 (13.3)	26 (86.7)	16 (53.3)	14 (46.7)	11 (36.7)	19 (63.3)
Transplant	4 (51.7)	3 (42.9)	5 (83.3)	1 (16.7)	3 (50.0)	3 (50.0) ***	4 (66.7)	2 (33.3) **	4 (66.7)	2 (33.3) ***
Ever had sex N (%)	18 (52.9)	16 (47.1) *	17 (50)	17 (50)	13 (38.2)	21 (61.8)	2 (5.9)	32 (94.1)	13 (38.2)	21 (61.8) **

^aN=107

^bN=103

* p<.05,

** p<.01,

*** p<.001