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Reproductive Health of Women with Congenital Heart Defects

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Abstract

This report provides an overview of the unique reproductive health issues facing women with congenital heart defects (CHDs) and of the clinical care and professional guidelines on contraception, preconception care, and pregnancy for this population. It describes Centers for Disease Control and Prevention (CDC) activities related to surveillance of reproductive health issues among females with CHDs. It also describes CDC's work bringing awareness to physicians who provide care to adolescents and women with CHDs, including obstetrician/gynecologists, about the need for lifelong cardiology care for their patients with CHDs.

Keywords

congenital heart defect; pregnancy; contraception; preconception health; reproductive health

Introduction

Congenital heart defects (CHDs) affect ~1 per every 110 infants annually in the United States.¹ Owing to advances in detection and medical and surgical treatment, individuals with CHDs are living longer, well into adulthood. In 2010, the number of women of ages 18–44 years in the United States with CHDs totaled 340,000.² For women with CHDs, reaching reproductive age prompts decisions about reproductive health, including contraception and pregnancy.

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Overview of Reproductive Health Issues Among Women with CHDs

Contraception

Overall, women with CHDs have an increased risk of maternal and infant morbidity and mortality, and risk varies by CHD type and comorbidities.^{3–5} However, over half of pregnancies among women with CHDs are estimated to be unintended.^{6,7} In addition, approximately two-thirds of women with CHDs report using no contraception or less effective contraceptive methods (*e.g.*, barrier, withdrawal, and fertility awareness-based methods),⁸ associated with typical use failure rates of 13 per 100 women per year.⁹

Little data exist on contraceptive safety among women with CHDs, and contraceptive safety concerns differ by contraceptive method, CHD type, and comorbidities.^{8,10} Concerns include certain contraceptive methods affecting a woman's risk of complications associated with her CHD, as well as interactions between oral contraceptives and cardiac medications possibly resulting in reduced effectiveness of either drug.^{8,10} For example, some studies suggest that combined hormonal contraceptives, which contain estrogen plus progestin, may increase a woman's risk of arterial and venous thrombosis, fluid retention, and interactions with cardiovascular medications.^{11,12}

Thrombosis risk may be highest with use of combined hormonal contraceptives by women already at high risk for thrombosis (*e.g.*, cyanosis, Fontan physiology, mechanical valves, prior thrombotic events, and pulmonary arterial hypertension).¹³ Cardiac medications, such as bosentan and warfarin, may interact with hormonal contraceptives decreasing the effectiveness of either or both medications.^{11,14,15}

There are theoretical concerns with insertion of intrauterine devices (IUDs) such as arrhythmia, vasovagal response, and infection leading to endocarditis; however, studies have not shown an increased risk of endocarditis among IUD users with CHDs. Given these complexities, women with CHDs need clinician counseling on risks and benefits of different contraceptive methods within the context of potentially significant risks associated with pregnancy.

Yet, existing information on receipt and content of contraceptive counseling among women with CHDs is sparse and limited to women receiving care at adult CHD clinics, a minority of all women with CHDs.^{7,16–18} These studies reported that ~50%–80% of women received contraceptive counseling,^{7,16,17} with only a quarter to half receiving contraceptive counseling from their CHD provider and/or specific to their CHD.^{7,17,18} Younger women and those who were not Hispanic were more likely to receive contraceptive counseling.¹⁷

Pregnancy

CHD is the most common maternal cardiovascular condition during pregnancy,⁶ and the physiological changes that occur during pregnancy, labor and delivery, and postpartum may pose unique challenges for a woman with CHD. During pregnancy, blood volume, maternal cardiac output, cardiac rhythm, and tidal volume increase and edema is more common.¹⁹ Labor further increases heart rate and cardiac output. During the postpartum period, the

abrupt rise in cardiac output, elevated mean arterial pressure, and blood loss may increase the risk of cardiac complications for a woman with CHD.

Owing to these physiological changes, pregnant women with CHDs are at increased risk of cardiovascular complications, such as arrhythmias and heart failure, and adverse pregnancy and infant outcomes, such as preterm delivery.³⁻⁵ Given these greater demands on the heart during and after pregnancy, some have speculated that pregnancy itself is a risk factor for longer term declines in cardiovascular health for women with CHDs; however, that association is unclear.^{20,21}

Several pregnancy risk scoring systems exist for women with maternal cardiovascular risk factors, including specific types of CHDs.^{4,22-24} Risk category varies by type of CHDs, comorbidities, and complications, and prior surgical repair. Risk of maternal morbidity and mortality is highest for women with severe CHDs, such as coarctation of the aorta or CHD with pulmonary arterial hypertension, severe mitral stenosis, or severe symptomatic aortic stenosis.¹⁹ Most women with mild and moderate CHDs can have safe healthy pregnancies.³

Similar to contraceptive counseling, limited information exists on receipt of pregnancy counseling among women with CHDs. In two studies conducted at adult CHD clinics, about two-thirds of women with CHDs received counseling on the risk of pregnancy to their heart and just over half reported counseling on the risks to their fetus.^{7,16} However, these findings may not be generalizable to all women with CHDs, since a substantial percentage of people with CHDs fall out of cardiology care.²⁵

Clinical care and guidelines

The American Heart Association (AHA), American College of Cardiology (ACC), and American College of Obstetricians and Gynecologists (ACOG) have published recommendations and guidelines for the reproductive health care of women with CHDs.^{13,19,26,27} In a 2017 scientific statement, the AHA noted that pregnancy counseling and management are among the major noncardiac issues facing congenital cardiac care providers.¹⁹

The reports by AHA, ACC, and ACOG, referred to above, recommend age-appropriate reproductive health counseling starting in adolescence, and include information on safe effective contraceptive options. Estrogen-containing contraceptives may not be safe for women with CHDs at high risk for thromboembolic events, such as those with cyanosis, Fontan physiology, mechanical valves, prior thrombotic events, and pulmonary arterial hypertension, according to the 2018 AHA/ACC guidelines for the management of adults with CHDs, and no data exist as to whether warfarin offsets that increased risk.¹³

However, ACOG recommends not delaying initiation of contraception due to concerns about contraceptive safety.²⁶ Progestin-only methods are generally considered safe for women with risk factors for thromboembolism.²⁶ In addition, women with CHDs do not require antibiotic prophylaxis with IUD insertion, due to the low risk of pelvic infection.²⁶

These reports further discuss the importance of preconception counseling on each woman's unique risks associated with pregnancy, including the potential long-term effect that

pregnancy may have on the woman's cardiac health.^{13,19,26,27} The AHA recommends that women with CHDs receive specific tests and assessments to determine risk of maternal and fetal pregnancy complications, such as echocardiogram and liver function, as well as treatment for repairable lesions before a pregnancy occurs.¹⁹ Women should additionally receive counseling before pregnancy on the risks and benefits of potentially teratogenic or fetotoxic medication use during pregnancy and possible alternatives as well as counseling on the risk of CHD for their infant.^{19,26,27}

All three organizations recommend that pregnant women with CHDs receive prenatal care from both an obstetrician and cardiologist.^{13,19,26,27} The woman's pregnancy risk classification determines whether care is needed by a maternal–fetal medicine subspecialist. For women with World Health Organization (WHO) pregnancy risk classifications III and IV, indicating higher risk of maternal morbidity and mortality compared with risk classifications I and II, the prenatal care team may also include an interventional cardiologist, cardiac surgeon, neonatologist, geneticist, mental health specialist, and pharmacist. In addition, these women should be referred to a hospital with an appropriate maternal level of care for her risk category.^{27,28}

Centers for Disease Control and Prevention Surveillance and Research on Reproductive Health Among Women with CHDs

Overview

Because of these issues, and the gaps in knowledge, the National Center on Birth Defects and Disabilities at the Centers for Disease Control and Prevention (CDC) identified reproductive health as an area of focus for its work related to CHD. Specifically, CDC aims to improve the understanding of reproductive health practices, outcomes, and associated factors among women with CHDs. One of the ways CDC fills these gaps is through funding programs across the United States to conduct population-based surveillance of people living with CHDs, and reporting findings on reproductive aged and pregnant women.

Beginning in 2012, CDC funded two state health departments and an academic center to determine the feasibility of conducting population-based surveillance of adolescents and adults with CHDs at three sites (GA, MA, and NY; DD12–1207).²⁹ Grantees linked clinical and administrative health care data, such as electronic health records and Medicaid data, and vital records to identify individuals with CHD-related health care encounters. All health care encounters for the individual were linked, including obstetric and gynecology encounters. One focus of the surveillance project was pregnancy experiences and outcomes of women with CHDs. Of adolescents and adults in the surveillance system, >26,000 were female.

In 2015, CDC increased the number of funded organizations to five (GA, NY, CO, UT, and NC; DD15–1506). These sites validated International Classification of Disease 9th edition CHD codes, identified children and adults with CHDs, and surveyed parents of children with CHDs on barriers to transition to adult care. As of 2020, CDC funds seven organizations to conduct surveillance of CHD at seven sites (AZ, GA, IA, NC, NY, SC, and UT; DD19–1902) and has implemented methods to improve information on timing of pregnancy.³⁰

To complement surveillance based on electronic health record and administrative data, in 2016, CDC funded the Congenital Heart Survey To Recognize Outcomes, Needs, and well-being (CH STRONG; chstrong.org; U38OT000199).³¹ This project, conducted by CDC, March of Dimes, University of Arizona, and Arkansas Center for Birth Defects Research, surveyed young adults of ages 19–38 years who were born with a CHD in metropolitan Atlanta, Arizona, and Arkansas. The survey, completed by >1,600 individuals (54% women), asked about health, health care access and barriers to care, quality of life, disability status, and educational outcomes.

Each female participant also answered questions about her reproductive health experiences and concerns, specifically, receipt of clinician counseling on safe contraceptive methods and pregnancy, the woman's experience delaying or avoiding pregnancy because of her CHD, and whether she had ever been pregnant.

CDC also uses other data sources, such as Merative™ Marketscan® Commercial Claims and Encounters and Multistate Medicaid databases, to examine contraception, preconception care, pregnancy, and other outcomes among privately and publicly insured women with CHDs.^{3,32,33}

Contraceptive safety and use

In 2019, CDC published a systematic review on contraceptive safety among women with CHDs, which identified only five published studies, all of poor quality, to address this issue.¹⁰ Two out of three studies found that women with Fontan palliation or transposition of the great arteries using oral contraceptives had greater risk of thromboembolic complications than those not using oral contraceptives.^{17,34,35} In addition, two studies examining women with CHDs using IUDs found no endocarditis.^{34,36} The paucity of information highlights the need for additional studies examining safety of contraceptive methods among women with CHDs.

CDC also examined female sterilization and reversible prescription contraceptive method use among ~6,500 privately insured women ages 15–44 years with CHDs and who were not pregnant.³² Overall, <4 in 10 women with CHDs had undergone sterilization or were using reversible prescription contraceptive methods, such as an IUD or oral contraceptives. Only about 1 in 10 women with CHDs used the most effective contraceptive methods (failure rates <1%; implant, IUD, and female sterilization), and 1 in 4 used moderately effective methods (failure rates 6%–12% with typical use; injectables, oral contraception, patches, and rings).

Among women with CHDs who had a gynecology encounter in the previous year, ~60% used any permanent or reversible prescription contraceptive methods; among women with CHDs who had a cardiology encounter, <40% used any permanent or reversible prescription contraceptive methods. These findings suggest that there may be missed opportunities for providers to counsel women with CHDs on safe and effective contraceptive methods if they wish to avoid pregnancy.

Preconception care

CDC also examined preconception care according to the AHA recommendations that women with CHDs receive certain care, tests, and assessments, such as echocardiogram and liver function, and that they visit an obstetrician and a cardiologist in the year before pregnancy to discuss cardiac health and pregnancy risks.^{19,33} Using 2007–2013 data on privately insured women, authors examined receipt of AHA-recommended preconception care in the year before pregnancy among >2,000 women with CHDs who became pregnant.

The percentage of women with CHDs receiving AHA-recommended tests and assessments before pregnancy varied by type of test or assessment and ranged from 54% for complete blood count to 3% for cardiopulmonary test. Among women with CHDs who had documented health care encounters at obstetric and cardiology practices, >2 in 10 had not received any AHA-recommended tests and assessments and <1% received all of them. In addition, ~1 in 10 women filled prescriptions for cardiac-related medications that may increase the risk of birth defects in the year before conception, highlighting the importance of visits with obstetricians and cardiologists before pregnancy to discuss risks and benefits of current medications.

Pregnancy outcomes

CDC examined pregnancy outcomes among women with CHDs based on population-based information for >26,000 women of ages 11–50 years with CHDs in Georgia, New York, and Massachusetts, among whom nearly 1 in 5 became pregnant over 3 years.³⁷ Findings showed that pregnant women with CHDs had higher risk of anemia, hemorrhage, and chronic hypertension than nonpregnant women with CHDs. In addition, a higher proportion of pregnant women with CHDs had documented diabetes mellitus, infectious diseases, and mental health conditions in their health records than women with CHDs who were not pregnant.

Using Merative MarketScan data for 2007–2014, privately insured women with CHDs were almost twice as likely as women without CHDs to experience any adverse condition during pregnancy.³ Women with CHDs were 1.3 times as likely to experience obstetric complications, such as obstetric shock and preterm labor, and 10 times more likely to experience cardiac complications, such as heart failure and myocardial infarction, compared with women without CHDs (Fig. 1). The increased risk was especially prominent among women with severe CHDs, although women with nonsevere CHDs also had increased risk compared with women without CHDs.

Women with CHDs were 1.6 times more likely to experience stillbirth and preterm delivery than women without CHDs. Fewer than 6 in 10 pregnant women with CHDs received an ACOG-recommended comprehensive echocardiogram to evaluate cardiac health during pregnancy and 4% used potentially teratogenic medications. Although some use of potentially teratogenic cardiac medications may be unavoidable during pregnancy for women with CHDs, these findings show the need for discussions of risks and benefits of medications between providers and patients before a pregnancy begins.

These studies^{3,37} underscore the importance of AHA and ACOG recommendations that cardiologists, obstetrician-gynecologists, and primary care providers talk to women with CHDs who are considering pregnancy about their overall health and work together to care for women with CHDs during and after pregnancy.

Generating awareness

Surveillance of people with CHDs has shown that many interact with the health care system around primary care, emergency care, and obstetric care, but gaps in cardiology care of >10 years are common.^{25,38} Therefore, in partnership with the American Academy of Pediatrics, CDC developed the CHDs Toolkit for Physicians to generate awareness of CHD as a lifelong condition among primary care, emergency care, and obstetrics and gynecology providers, the physicians who most often come into contact with people with CHDs.

These toolkit materials will help physicians discuss with their patients the need for lifelong cardiac care by a congenital cardiologist and refer them to that care, as needed. The toolkit, which is easily accessible and free on CDC's webpage (cdc.gov/ncbddd/heartdefects/toolkit-for-physicians.html), provides social media graphics, physician talking points, and continuing medical education videos, specific to the different provider groups.

Conclusion

CDC surveillance activities have contributed to the public health and scientific knowledge on contraceptive safety, use, and counseling, as well as pregnancy experiences and outcomes among adolescents and women of reproductive age with CHDs. Further surveillance activities will examine receipt of contraceptive and reproductive health counseling, pregnancy concerns, and updated pregnancy-related health care utilization and outcomes among women with CHDs. The findings from CDC surveillance have informed clinical guidelines and recommendations on the reproductive and cardiac-related health care of adolescents and women with CHDs.^{13,26}

Surveillance findings have informed the development of materials to help physicians, including obstetricians and gynecologists, to better care for women with CHDs. Findings are disseminated in plain language to the public to empower women with CHDs to understand their unique reproductive health needs. Building public health practitioners', health care providers', and women's knowledge and awareness of the reproductive health needs of women with CHDs will help ensure optimal reproductive health outcomes for this growing population.

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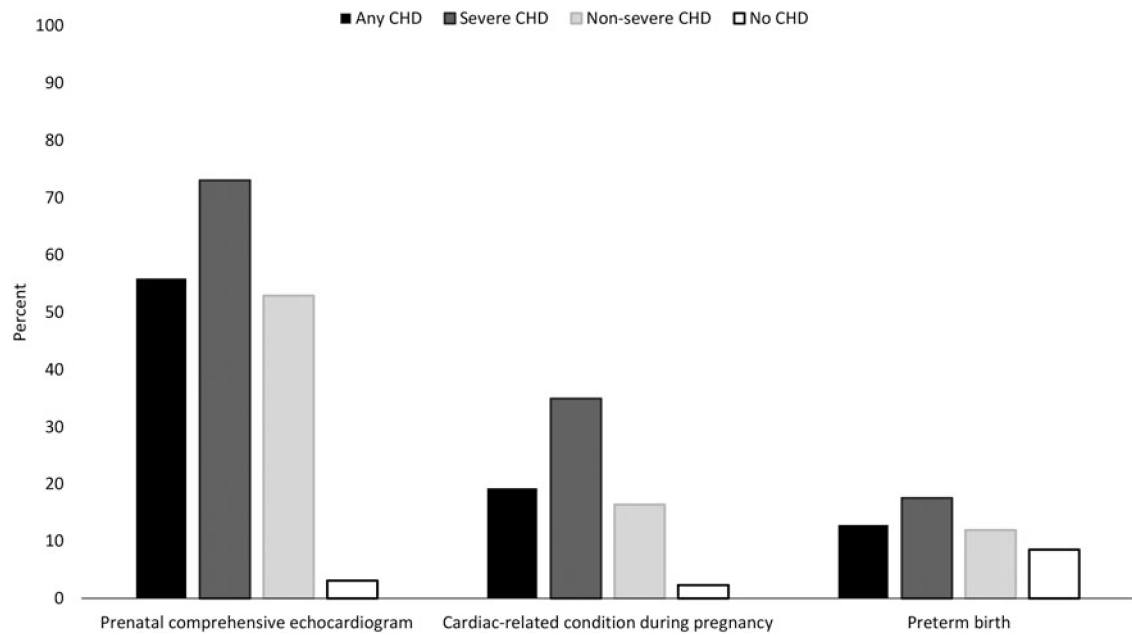


FIG. 1. Prevalence of prenatal comprehensive echocardiogram, cardiac-related pregnancy conditions, and preterm birth among privately insured women with CHDs in the United States, 2007–2014.³ CHDs, congenital heart defects.