Contraception in Women With Congenital Heart Disease

Matthäus Vigl, MD[a], Mathias Kaemmerer, Cand Med[b], Vanadin Seifert-Klauss, MD[c], Eva Niggemeyer, MA[a], Nicole Nagdyman, MD[d], Vasiliki Trigas, MD[b], Ulrike Bauer, MD[a], Karl-Theo Maria Schneider, MD[c], Felix Berger, MD[d], John Hess, MD[b], and Harald Kaemmerer, MD[b,*]

The present study reports on contraceptive use, methods used, and counseling received on contraceptive issues for women with congenital heart disease and provides a brief review of current knowledge of the risks in relation to the different cardiac situations encountered with these specific patients. A total of 536 consecutive adult women with congenital heart disease (median age 29 years) were recruited from 2 tertiary care centers. They underwent a clinical assessment and completed a questionnaire regarding their contraceptive use. Oral contraceptives, condoms, and intrauterine devices were the most commonly used methods. Pregnancy occurred in almost every tenth woman despite the use of contraception. We identified a substantial number of women (20%) who were presently using contraceptive methods that were contraindicated for their specific cardiac condition. Additionally, a high proportion of patients (28%), in the group with high pregnancy-associated risks, were not using contraception despite having a sexual relationship. In our study, 43% of the women had not been counseled about contraception, and 48% had not been informed of the pregnancy-related risks by their treating physician. In conclusion, timely and competent counseling about contraception is important for women with congenital heart disease. Collaboration between cardiologists and gynecologists should be strengthened. Failure to give adequate family planning advice to this patient group could have hazardous consequences, causing an unnecessary risk to mother and child. **(Am J Cardiol 2010;106:1317–1321)**

The present study reports on the contraceptive use, methods used and, counseling received regarding contraceptive issues for 536 women with congenital heart disease (CHD) and provides a brief review of the current knowledge of risks related to contraception in this patient population.

Methods

During a 12-month period, 536 consecutive adult female patients with CHD, seen at the outpatient clinic of 2 tertiary care centers for adults with CHD, were included. On average, 13% of the eligible patients refused to participate at the 2 centers. The inclusion criteria were confirmed CHD, age ≥18 years, and written informed consent. The refusal to consent and the lack of cognitive competency to understand and complete the questionnaire were the exclusion criteria.

The participants were asked to complete a questionnaire designed for self-administration that covered the demographics, sexual maturation, use of contraceptives, and information-seeking behavior. A separate questionnaire was completed by the treating physician and included cardiac and noncardiac diagnoses and surgical and pharmacologic treatment. The medical records were obtained from all participating patients and reviewed for anatomic characteristics before repair and for the details on surgical repair and reoperation.

From the medical history and clinical assessment, the attending physician classified the patients according to 1 of 4 functional classes.[1] To allow statistical analysis. the 2 patients with functional class IV were grouped with the 39 patients with functional class III, forming the functional class III-IV group, a group of symptomatic patients with restrictions in performing daily activities. For additional analysis, the patients were assigned to 1 of 3 degrees of severity (simple, moderate, and severe), depending on the underlying cardiac anomaly, according to the recommendations of the American College of Cardiology.[2]

Severe heart failure (functional class III and IV), cyanosis, Eisenmenger syndrome, and/or a history of thromboembolism were considered absolute contraindications for the use of combined oral contraceptives (COC); arterial hypertension and/or smoking were considered relative contraindications for the use of COCs. Women with severe cardiac heart failure (functional class III and IV), cyanosis, or Eisenmenger syndrome were grouped as at high risk of pregnancy-related complications.

[a]Competence Network for Congenital Heart Defects, Deutsches Herzzentrum Berlin, Berlin, Germany; [b]Deutsches Herzzentrum Muenchen, Technische Universitaet Muenchen, Muenchen, Germany; [c]Frauenklinik, Technische Universitaet Muenchen, Muenchen, Germany; and [d]Department of Congenital Heart Defects and Pediatric Cardiology, Deutsches Herzzentrum Berlin, Berlin, Germany. Manuscript received March 3, 2010; manuscript received and accepted June 9, 2010.

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*Corresponding author: Tel: (+49) 89-1218-3006; fax: (+49) 89-1218-3003.

E-mail address: kaemmerer@dhm.mhn.de (H. Kaemmerer).

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Table 1
Congenital heart disease (CHD) diagnoses of study participants (n = 536)

Leading Cardiac Diagnosis	Patients (n)	Native/ Operated	Median Age (yrs)
Tetralogy of Fallot	67 (12%)	0/67	30 (18–48)
Transposition of the great arteries	52 (10%)	0/52	28 (18–46)
Ventricular septal defect	50 (9%)	28/22	27 (18–54)
Atrial septal defect	46 (9%)	10/36	30 (19–75)
Coarctation of the aorta	39 (7%)	1/38	27 (18–60)
Aortic stenosis	34 (6%)	15/19	28 (18–46)
Ebstein's anomaly	25 (5%)	6/19	45 (19–70)
Pulmonary stenosis	24 (4%)	10/14	27 (19–68)
Patent foramen ovale	22 (4%)	7/15	40 (22–66)
Marfan syndrome	15 (3%)	11/4	34 (20–51)
Atrioventricular septal defect (total)	15 (3%)	4/11	30 (20–65)
Tricuspid atresia	13 (2%)	3/10	29 (18–42)
Mitral valve prolapse	12 (2%)	9/3	27 (19–41)
Pulmonary atresia and ventricular septal defect	10 (2%)	2/8	31 (23–47)
Atrioventricular septal defect (partial)	10 (2%)	0/10	31 (19–43)
Truncus arteriosus communis	9 (2%)	2/7	30 (19–41)
Congenitally corrected transposition of the great arteries	9 (2%)	1/8	37 (24–60)
Persistent ductus arteriosus	8 (2%)	3/5	26 (18–59)
Double inlet ventricle	8 (2%)	2/6	26 (21–51)
Other*	68 (13%)	23/45	28 (19–62)
Total	536	137/399	29 (18–75)

Data in parentheses are ranges.

* Aortic valve insufficiency (n = 7), subaortic stenosis (n = 6), double outlet right ventricle (Fallot-type, n = 6), congenital cardiomyopathies (n = 6), partial anomalous pulmonary venous connection (n = 6), aortic aneurysm, ectasia of the great arteries, kinking (n = 5), mitral valve insufficiency (n = 5), double outlet right ventricle (transposition of the great arteries-type, n = 4), pulmonary atresia (n = 4), tricuspid insufficiency (n = 4), cor triatriatum (n = 2), double chambered right ventricle (n = 2), Bland-White-Garland (n = 2), supravalvular aortic stenosis (n = 2), Wolff-Parkinson-White (n = 2), aorto-pulmonary window (n = 1), arrhythmogenic right ventricular dysplasia (n = 1), interrupted aortic arch (n = 1), atrioventricular block third degree (congenital, n = 1), noncompaction myocardium (n = 1).

The data were analyzed using the Statistical Package for Social Sciences, version 12.0 (SPSS, Chicago, Illinois). Appropriate statistical methods were used to describe the distribution of variables. Chi-square tests were used to detect differences in nominal variables between the groups. If >20% of the expected counts were <5, Fisher's exact test was used. Differences between continuous variables were measured using unpaired *t* tests, and the Mann-Whitney *U* test was used when the data did not meet the assumption of normal distribution.

The intimate nature of this questionnaire might have prevented some of the participants from answering some of the questions. This same reason made on-site control of the completeness of the questionnaires impossible, to guarantee maximum confidentiality. Therefore, the relative percentages of the answers were calculated, and the number with missing information has been reported for each question.

Table 2
Use of contraceptive methods of study participants (n = 473)

Contraceptive Method	Former Users (n)*	Current Users (n)†
Combined oral contraceptive	307 (60%)	132 (37%)
Condom	295 (58%)	94 (26%)
Intrauterine device	81 (16%)	43 (12%)
Progestin-only pill	103 (20%)	39 (11%)
Sterilization	37 (7%)	26 (7%)
"Coitus interruptus"	73 (14%)	19 (5%)
Vaginal ring, contraceptive patch	18 (3%)	9 (2%)
Natural family planning	35 (7%)	9 (2%)
Sterilization of partner	9 (2%)	7 (2%)
Depot progestin	16 (3%)	6 (2%)
Hormone implants	10 (2%)	5 (1%)
Diaphragm, cervical cap	17 (3%)	3 (1%)
Postcoital emergency contraception ("morning after pill")	35 (7%)	0

Multiple answers were possible.

* Percentage of all women who ever had used a contraceptive method (n = 507).

† Percentage of women currently using a contraceptive method (n = 354).

The institutional ethics committees of the 2 participating centers approved the study.

Results

During the 12-month period, 536 adult women with CHD with a median age of 29 years (range 18 to 75) were included in the present study. The diagnoses of the included patients are listed in Table 1. The severity of the diagnoses was categorized as simple, moderate, and severe in 24%, 51%, and 25% of the patients, respectively. According to the treating physician, 51%, 41%, and 8% of the participants were in functional class I, II, or III-IV, respectively.

Of the 536 patients, 35 (6%) reported never having had sexual intercourse. Of the remaining 501 women, 450 provided their age at first sexual intercourse. Their mean age was 17.7 ± 2.5 years (range 12 to 32); 69 of these women (15%) had their first sexual intercourse at ≤15 years old.

Of the 536 women, 29 (5%) had never used contraceptives. For the remaining 473 women (missing data for 34), the mean age at the first use of contraceptives was 17.8 ± 3.0 years (range 12 to 38).

The contraceptive methods used, formerly or at present, are listed in Table 2. Of the 478 women who had ever used contraceptives, 41 (9%, missing data for 29) indicated that they had become pregnant despite the use of contraception. Three of these patients did not comment on the method used. The other affected women had tried to avoid pregnancy using "coitus interruptus" (n = 7), COCs (n = 18), progestin-only pills (n = 2), natural family planning methods (n = 2), condoms (n = 8), and intrauterine devices (intrauterine device [IUD]; n = 1).

A total of 173 patients (37%; missing data for 67) were regarded to have a contraindication for the use of COCs. Despite this, 34 of the patients with known absolute (n = 20) or relative (n = 14) contraindications were presently using COCs for contraception.

Table 3
Current use of contraceptive methods in patients with high pregnancy-related risk (n = 39)*

Contraceptive Method	Patients (n)†
Condom	8 (20%)
Combined oral contraceptives	7 (18%)
Intrauterine device	4 (10%)
Coitus interruptus	3 (8%)
Sterilization	2 (5%)
Progestin-only pill	2 (5%)
Sterilization of partner	1 (3%)
Depot gestagens	1 (3%)
Currently no contraception	11 (28%)
Total	39

* Women >45 years or not living in a partnership were excluded.
† Percentage of women in high pregnancy-related risk group (n = 39).

A total of 66 women (13%; missing data for 39) were estimated to be in the group with high pregnancy-related risks. Women >45 years of age or not living in a partnership during the study period were not considered at high risk of becoming pregnant and were excluded from this group, leaving 39 women. Table 3 lists an overview of which contraceptive methods were used by the women in this high-risk group.

Information regarding pregnancy and pregnancy-related risks had been provided by the treating physician in 256 (52%) of 493 cases (missing data for 43). The physician had initiated the topic in 130 cases (56%), and in the remaining 101 cases (44%), the woman had to request information (missing data for 25). Even in the group with a high pregnancy-related risk (n = 66), only 38 women (65%, missing data for 8) had been informed by their physicians of the possible risks associated with pregnancy, and in only 16 cases were these women informed by the treating physician without having asked. Concerning the question of whether the patient had been informed about possibilities and risks of contraception by her doctor, only 287 (57%, missing data for 31) of 505 patients stated that they had received such information. For 136 (56%) of these 287 patients, the physician had addressed the topic; and for the remaining 107 (44%), the patient had had to initiate the topic (missing data for 44).

Discussion

The present study reports on the specific contraceptive counseling and methods in use for a large cohort of >500 sexually mature women with CHD, including nearly all types of CHD (either native or after cardiac surgery/interventional treatment), all degrees of severity and all age groups. Education about pregnancy and contraception should be mandatory for these patients, because an unplanned pregnancy can lead to severe health consequences or even the death of the mother or fetus.[3,4]

Available contraceptive choices and their particularities in women with CHD have been briefly reviewed. Condoms, diaphragms, and cervical caps will have no adverse pharmacologic effects but have had high failure rates in adolescents and outside of stable relationships. The same applies to adolescents using natural family planning methods, which depend on stable and reliable cycle characteristics. However, irregularities of the menstrual cycle seem to be increased in women with CHD.[5,6]

IUDs were long thought to be unsuitable for patients at risk of infective endocarditis because of the risk of ascending infections. However, such events have been shown to be rare.[7] It is unknown whether this can be applied to patients with CHD who have a greater risk of infective endocarditis than healthy women or to immunosuppressed patients with CHD after organ transplantation. To minimize the risk in such groups, cervical bacteriology (including *Chlamydia*) should be obligatory. Although several international recommendations for endocarditis prophylaxis have been recently revised, the insertion or removal of an IUD in CHD patients at risk of infective endocarditis can be conducted with antibiotic prophylaxis, because the recommendations are still very controversial.[8–11] Because transcervical application of the IUD can be painful, impaired women, particularly those with heart failure, arrhythmia, pulmonary hypertension, or Eisenmenger syndrome, should receive CHD-experienced anesthesiologist surveillance, in case vagal reactions occur.[12] Cyanotic patients often have coagulation defects and thrombocytopenia.[13] In such cases, a copper IUD might provoke heavy menstrual bleeding[14] and should therefore be avoided. Progestin-coated IUDs have a lower risk of the development of ascending infections than copper IUDs and might even prevent hypermenorrhea in cyanotic patients.[15] Women at risk of cardiac arrhythmias should undergo electrocardiographic monitoring during the procedure.[16]

Tubal ligation can be problematic for women with CHD, particularly because of the pneumoperitoneum induced by pressure carbon dioxide-insufflation into the abdomen while the patient's head is lowered. At particular risk are women with pulmonary hypertension, Eisenmenger syndrome, Fontan circulation, heart failure, and arrhythmias.

Male vasectomy can be considered once family planning has been concluded. However, the use has been limited by the likelihood that the male partner might outlive his spouse and desire to have children later.[14]

As our study results have confirmed, oral contraception—most often COCs—has been the most frequently used method. The reasons are presumably the high reliability and ease of use. The new generation of oral contraceptives contains considerably less ethinylestradiol than older preparations and presumably induces fewer cardiovascular complications and side effects, which have been considered dose dependent. For prescription, preparations containing low ethinylestradiol doses should therefore be favored. Important side effects and contraindications concern arterial hypertension, which can develop in patients taking oral contraceptives in ≤5% owing to an interaction with the angiotensin receptor.[17] This could be of importance for patients with aortic coarctation, even after successful interventional or surgical treatment. Estrogen-containing preparations should be avoided if thromboembolic complications (i.e., pulmonary hypertension, cyanotic defects with a high hematocrit, heart failure, atrial arrhythmias, additional ischemic coronary artery disease, earlier thromboembolism) are a risk. Problems can also occur in association with a low cardiac output and slow blood circulation (e.g., after a Fontan operation) or a greater risk of thrombophlebitis (e.g.,

varicose veins, venous insufficiency after an atrial switch operation, or after a Fontan operation). In such cases, progestin-only pills could be an alternative. Progestin-only pills, however, require high patient compliance, which should be addressed during counseling. Interactions between oral contraceptives and the lipid and carbohydrate metabolism, as well as the coagulation system, are of special importance for the rare patients with accompanying coronary artery disease.

Intramuscular injections of progestin can exacerbate fluid retention in women with impaired ventricular function. The risk of an intramuscular hematoma after intramuscular progestin application should be considered in women receiving anticoagulation therapy, although the risk seems low.[18]

The present study identified a substantial number of high-risk patients who were using contraceptives that were contraindicated in connection with their specific cardiac condition. In the light of these data, counseling and prescribing contraceptives to this high-risk population must be individualized and deserves special cardiologic and gynecologic considerations. Both patients with CHD and their treating physicians must be made aware of the specific indications and contraindications of the various contraceptive methods and the typical risk pattern described in our study. Furthermore, a large number of young patients in the group with high pregnancy-associated risks were not using any contraception, despite having a sexual relationship. This could be an expression of risk-taking behavior and might demand additional psychological counseling.

Many women have only limited knowledge about the relation between their CHD and sexual health and how to prevent unplanned pregnancies.[19,20] Therefore, they need detailed education about their medical risks, specific pregnancy-related risks, and contraceptive options. Disappointingly, the treating physicians often neglected to advise the affected women appropriately. In our study, 43% of the women had not been counseled about contraception, and 48% had not been informed of pregnancy-related risks before being seen at the 2 specialized study centers. Furthermore, in >40% of the cases in which the topic was addressed, it was brought up by the affected women, not the physician. This agrees with other studies that have reported that about 65% of young women with CHD had not received information about sexual health, pregnancy, or contraception from their treating cardiologist.[19,20] Women cared for by pediatric cardiologists had received even less information than those who were seen by physicians treating adults (47% vs 76%).[19] The reasons for such deficient counseling could in part be a result of a lack of information by the physicians themselves. In contrast, a referral to a gynecologist to obtain specialized contraceptive advice could also be difficult, because these physicians usually have only limited experience with CHD. Thus, a stronger collaboration between cardiologic and family planning experts is mandatory and, at least at tertiary care centers, would be possible to organize. Multidisciplinary guidelines with clear pathways for referral and counseling could help to disseminate the knowledge.[21]

The present study was limited because it was performed at 2 specialized tertiary care centers for adults with CHD. Thus, the sample of patients did not represent the typical population of CHD seen by a general practitioner, cardiologist, or gynecologist or within less-specialized institutions. The prevalence of more complex anomalies in our study was likely greater than in community-based hospitals and cardiology departments. Recall bias is an inherent problem of the study design. This might especially be true for older participants, for whom time had passed since contraceptive counseling; however, with a median age of 29 years, the great majority of the included women were still in reproductive age. The presented data derive from women living in Germany. Generalization of the conclusions and transmission to women living in other countries or different culture groups might be problematic.

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