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Pregnancy and Contraception in Congenital Heart Disease: What Women Are Not Told

To the Editor: As increased numbers of patients with congenital heart disease (CHD) survive to adulthood, more women with CHD are reaching reproductive age. Contraception and pregnancy have now become important issues in this population; however, both can be associated with increased risks in women with CHD (1). Other issues, such as adverse fetal outcomes in these women and transmission of CHD to offspring must be addressed. Current guidelines for the care of adults with CHD recommend proactive counseling regarding issues of contraception and pregnancy (2–5). The objective of this study was to evaluate whether women with CHD have adequate knowledge regarding risks of contraception and pregnancy.

Women with CHD completed a questionnaire with items pertaining to contraception history, perceived maternal and fetal risks of pregnancy, and information they recalled receiving from health care providers. An adult congenital cardiologist, blinded to questionnaire responses, reviewed medical records in order to determine maternal and fetal risks of pregnancy and whether there were contraindications to specific modes of contraception. Contraindications to various forms of contraception were considered based on recommendations and criteria from previously published recommendations (1). Pregnancy risk was determined by considering both global and lesion-specific risk factors (1–5). Pregnancy was considered contraindicated in women with what is considered to be a prohibitively high risk of maternal morbidity and mortality. Risks to offspring were based on published transmission rates.

The final cohort was comprised of 116 women (mean age 31 ± 9 years), of whom 62 (54%) had a college or university degree. The most common cardiac diagnoses were tetralogy of Fallot ($n = 18$), univentricular heart/Fontan circulation ($n = 17$), simple atrial or ventricular septal defects or patent ductus arteriosus ($n = 16$), or transposition of the great arteries with an atrial switch operation ($n = 10$).

Only 51% of women recalled receiving specific information from a nurse or doctor about birth control. For 31 women (27%),

the use of combined oral contraceptives was felt to be contraindicated (primary contraindications: Fontan physiology [$n = 16$], Eisenmenger/significant pulmonary hypertension/cyanotic heart disease [$n = 9$], and significant systemic ventricular dysfunction [$n = 2$]); 14 of these women had used this method of birth control.

More than one-half (55%) of the participants had been pregnant at least once. Forty-three women (37%) reported that they had never been informed that they were at increased risk for maternal cardiac complications during pregnancy (Table 1). Of 80 women considered to be at intermediate or high risk for pregnancy complications, 27 (34%) did not recall receiving this information. Women with post-secondary degrees were more likely to recognize they were at increased risk (79% vs. 55%, $p < 0.01$). Forty-one women (37%) did not think their children would be at increased risk of having heart problems.

Based on medical record review, 18 women (16%) had contraindications to pregnancy: 8 had Eisenmenger syndrome/significant pulmonary hypertension/cyanotic heart disease; 6 were felt to require surgery before undergoing a pregnancy; 2 had Fontan circulation with systemic ventricular dysfunction or poor functional class; 1 had uncontrolled hypertension in the setting of coarctation of the aorta; and 1 had a mechanical valve with systemic ventricular dysfunction. Of 18 women who would currently be advised to avoid pregnancy, only 9 recalled having received this advice. Of 98 women for whom pregnancy would not be contraindicated, 18 said that a doctor or nurse had previously advised them to avoid pregnancy (Table 1).

In this study, we found that many women with CHD have a significant lack of accurate contraception and pregnancy knowledge. It is not evident why women have not acquired this knowledge. Are physicians not providing the information, are they providing inaccurate information, or are women not retaining the information? Beginning in adolescence, women with CHD should be provided with accurate information about contraception and the

Table 1 Current Versus Recalled Advice Regarding Pregnancy Risk

		Physician-Rated Current Risk of Maternal Cardiac Complications		
		Low Risk	Intermediate or High Risk	Total
Patient recalls being informed of increased risk of maternal complications	No	16	27	43 (37%)
	Yes	20	53	73 (63%)
		Physician-Rated Current Contraindication to Pregnancy		
		No	Yes	
Patient recalls being told to postpone or avoid pregnancy	No	80	9	89 (77%)
	Yes	18	9	27 (23%)

implications of heart disease on pregnancy. Appropriate advice and information likely fluctuates in accordance with cardiac or hemodynamic changes across time. There are several models to address this issue, including a collaborative approach between adult CHD and contraception clinics and the incorporation of contraception and pregnancy counseling by advanced practice nurses within CHD clinics. Responsible health care professionals working with women with CHD will provide information and guidelines, but final decision-making lies with patients and must be respected, even if it differs from medical advice.

This study has limitations. Because guidelines relating to pregnancy and contraception in women with CHD are not evidence-based, it is important that physicians weigh the risks and benefits for each individual. This study investigated *patient-recalled* information versus *physician-provided* information, as no data were available regarding the exact nature of the advice provided to women.

In conclusion, many women with CHD lack adequate knowledge regarding contraception and pregnancy risks. Accurate and continuing education should be a priority in order to ensure that both patients and healthcare professionals have access to the most current information.

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Letters to the Editor

Editor's Note

Our usual policy at *JACC* is to limit Letters to the Editor and their replies to a total of 400 words. However, we have recently encountered 2 letters which considerably exceeded this limit and provoked replies of similar length. Both interchanges dealt with issues of substantial current interest and importance: the role of intervention following infarction, particularly for patients with total coronary occlusion, and the role of percutaneous intervention versus surgery for unprotected left main coronary stenosis. Therefore, we have decided to make an exception and to publish the letters and replies as submitted. We believe that a thorough airing of these topics more than justifies this exception.

A Meta-Analysis That Misses the Mark

In the February 7, 2008, issue of the *Journal*, Abbate et al. (1) present a meta-analysis with a stated goal of including randomized controlled trials of late percutaneous coronary intervention (PCI) of the infarct-related artery (IRA) in stable patients >12 h after onset of myocardial infarction (MI) (1). A fundamental principle

of meta-analysis is inclusion of all studies that meet stated eligibility criteria with common end point definitions. The meta-analysis should address a relevant clinical question. Whether totally occluded IRAs should be opened in stable patients late after MI onset (the late open artery hypothesis) is an important question, and the authors introduce this concept early in the report. However, of the 10 studies included in the Abbate et al. (1) analysis, only 6 set out specifically to test the late opening of occluded IRA hypothesis, while 4 studies (TOPS [Treatment of Post-Thrombotic Stenosis], BRAVE 2 [Beyond 12 Hours Reperfusion Alternative Evaluation], SWISSI II [Swiss Interventional Study on Silent Ischemia Type II], and ALKK [Arbeitsgemeinschaft Leitende Kardiologische Krankenhausärzte]) were examining whether or not to perform PCI in patients beyond the acute phase of MI when the IRA was often patent after fibrinolytic therapy or patients were randomized in order to evaluate a global invasive versus selective, ischemia-driven, invasive care strategy (the BRAVE 2 trial). For example, the BRAVE 2 trial is not applicable to address the late open artery hypothesis, since one-half of those enrolled in the BRAVE 2 trial did not have initial angiography, one-half of those with angiograms had open arteries, and PCI, coronary artery bypass grafting, or no procedure was performed in the invasive group. The SWISSI II trial selectively enrolled patients with silent ischemia and 1- to 2-vessel disease, with no information on the status of the IRA provided, up to 3 months after ST-segment elevation myocardial infarction