Facilitated Mini Training – Story
"Reproductive Health Care and Congenital Heart Defects"

Instructions: The story below presents an example of providing reproductive health care to a young patient with congenital heart defect over different life stages. Throughout the story, the different life stages (as outlined in the accompanying training slides) are identified in green. It is recommended that this story be presented and discussed during the training. Refer to the discussion questions/possible answers below to guide the conversation in your practice.
Please note: in this story, *health care professional* refers to pediatricians, other physicians, and nonphysician clinicians (eg, nurse practitioners, physician assistants, nurses).

CHD Different Life Stages:

1. Family Planning / Sexually Transmitted Infections (STI) Prevention
2. Preconception Counseling
3. Pregnancy
4. Postpartum

"Jordan" is a 15-year-old with a congenital heart defect (CHD) who is in the office for a routine visit. During the visit, while "Jordan" and the health care professional (HCP) are alone in the exam room, the topic of contraception and pregnancy prevention is discussed, as it has been every year since Jordan was 10 years old. After having these discussions multiple times, "Jordan" is comfortable enough with the HCP to mention that they have a steady significant other and they are considering "going all the way". The HCP asks age-appropriate questions to address any gaps in knowledge or misinformation in a confidential manner. The HCP maintains an open honest demeanor to make the conversation as comfortable as possible knowing that the conversation can be awkward and embarrassing. Concerns regarding specific contraceptive methods, pregnancy, and reproductive health care are addressed, but also information regarding sexually transmitted infections (STI) is given. The HCP also recommends that "Jordan" discuss contraception and pregnancy with their cardiologist and parents. **[Life Stages 1 and 2]** "Jordan" understands the information, chooses not to start contraception at this time, and knows to contact the HCP if they decide to start a sexual relationship. "Jordan" continues through high school comfortable to ask questions of the HCP when needed.

Three years have passed. "Jordan" is now 18 years old, and a first-year college student and has continued routine health care with their same HCP. They chose condoms as the form of birth control for the past 2 years. One day "Jordan" emails the primary HCP through the patient portal requesting a call back. At the time of the call back "Jordan" states that during sexual activity a week ago a condom broke and "Jordan" is nervous about an unplanned pregnancy. The HCP advises "Jordan" to go to the local pharmacy and purchase a rapid pregnancy test, but also to make an appointment for STI testing and a human chorionic gonadotropin (HCG) blood test. The HCP also informs "Jordan" about the availability of emergency contraception if something like this were to happen in the future. **[Life Stage 3]**

When "Jordan" comes in for the face-to-face appointment "Jordan" discovers there is no pregnancy and is visibly relieved. "Jordan" also is notified of no evidence of any STIs at this time. However, the

HCP reviews the topics of more effective contraceptive strategies, emergency contraception, pregnancy prevention, and further discusses STI prevention. Additionally, the HCP asks questions to determine if "Jordan" feels safe in their surroundings and with their partner. **[Life Stages 1 and 2]** "Jordan" thanks the HCP for the information and for discussing the problem in a nonjudgmental way and with kindness and respect. Jordan states that before this discussion there were feelings of fear and embarrassment from what friends were saying about the situation. Now "Jordan" feels more confident with questions answered.

A few weeks later "Jordan" emails the primary HCP through the patient portal stating some questions were thought of after leaving the office. "Jordan" was thinking and discussing the previous conversation with their parents who are concerned about pregnancy and someday want grandchildren. Questions include: Would pregnancy be safe for "Jordan"? How does the CHD affect the ability to have a pregnancy? Are there other ways to have a family besides pregnancy? Can the CHD be passed onto the offspring? The HCP asks "Jordan" to make another appointment to discuss these questions. **[Life Stage 3]**

When "Jordan" comes in for the face-to-face appointment "Jordan's" parents are also present. Permission is granted for the parents to stay in the room during the conversation. The HCP discusses the patient and family questions about pregnancy and childbearing. The HCP discusses the risks and benefits of pregnancy and the potential of genetically passing on the CHD to offspring. Information discussed includes maintaining regular internal medicine and cardiovascular exams, and, if pregnancy is desired, assembling a multidisciplinary care team in advance. The HCP lists the team of providers and their roles. The HCP notes that a thorough evaluation would need to be completed prior to pregnancy so that the cardiac condition could be optimized, and a plan developed to address medication adjustments if needed. **[Life Stages 3 and 4]**

Postpartum potential issues, risks to baby and birthing parent, are outlined briefly. These include the potential for arrhythmias, hypertension and heart failure. Close follow up is needed up to one year after delivery. "Jordan" will be counseled to make sure to continue with regular cardiology visits along with other clinical visits to maintain health after delivery. "Jordan" will be counseled not to have a pregnancy within one year of the previous pregnancy as there is a higher risk for hypertension and heart failure with successive pregnancies that are close together. Breastfeeding is a viable option and not contraindicated in most cases if that is wanted by the parent. If "Jordan" would like to have a family but pregnancy is not desired after the conversation, then other options are discussed. **[Life Stages 3 and 4]**

Case study, Questions & Answers

Use the questions below to guide conversation following the story. Possible answers are bulleted below each question. The responses are by no means exhaustive.

1. How does an existing relationship between the HCP, patient, and family impact the reproductive health conversations?
    - Patient and family feel more comfortable with the topic by making it a routine part of the visit.
    - Ability to support the family in any potential next steps.
    - Previous conversations helped establish a trusting relationship.
2. What is the importance of introducing family planning and reproductive health specific to patients with congenital heart defects in early teen years?
    - Ensure the patient knows that the heart condition is a consideration for reproductive health.
    - Allow the patient and family to think about questions for future visits.
    - Certain heart conditions may pose higher risks than others for parent and fetus during pregnancy and postpartum.
    - Certain contraceptives have higher risks of adverse outcomes for specific congenital heart defects.
3. How would the case study progress differently if the first pregnancy test was positive?
    - Leaves patient with no time for a cardiac evaluation prior to the pregnancy, may make pregnancy higher risk.
    - Missed opportunity to educate the patient on the risks of pregnancy and childbirth.
4. How does the delivery of a baby to a young adult patient with CHD impact your care?
    - Ensuring the recommended follow up.
    - Collaborating with the multidisciplinary care team.
    - Expanding relationship with patient and family.

Evaluation Survey

- If you facilitated this presentation, please complete this evaluation survey and select facilitator.
- If you participated as a trainee, please also complete this evaluation survey and select trainee.

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