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Disease knowledge, perceived risk, and health behavior engagement among adolescents and adults with congenital heart disease

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ABSTRACT

Objective: Survivors of congenital heart disease (CHD) are at risk for life-threatening complications as they age. This study aimed to examine the association of knowledge of future health risks, perceived risk, and health behaviors among adolescents and adults with CHD.

Methods: CHD survivors ($N = 200$, ages 15–39; 23% simple, 44% moderate, 33% complex lesions) completed measures of risk knowledge accuracy and perceived risk for developing complications, and reported physical activity and saturated fat intake.

Results: CHD survivors reported poor risk knowledge and consuming high-fat diets. Adolescents reported more physical activity than young adults. Greater risk knowledge was associated with lower fat intake, and participants who exercised more expected fewer future complications, and this difference remained statistically significant when accounting for education and age.

Conclusions: CHD survivors, regardless of age, have poor risk knowledge and diets. Survivors may benefit from emphasis on future health risks and health behaviors from both pediatric and adult providers.

Introduction

Medical advancements have extended life expectancy for individuals with congenital heart disease (CHD) and over 1,000,000 adults with CHD currently reside in the U.S.[1,2] Cardiac lesions that comprise CHD vary in severity and are typically categorized as "simple," "moderate" or "complex." Some individuals need no surgical intervention (more commonly simple lesion types), while others require series of surgeries over the lifespan, medication and close monitoring. With the transition from adolescence to adulthood, individuals with CHD must assume responsibility for their health care, but many may lack knowledge about their condition which would help them accomplish this goal. Adults, as well as adolescents, often have difficulty recalling the name of their diagnosis,[3–5] and do not understand important general medical management issues, such as endocarditis prevention, the negative effects of smoking and alcohol, and contraception choices.[3–8] Despite these documented gaps, the relationship between disease knowledge and health behaviors has not been investigated among survivors of CHD.

Individuals with CHD are at heightened risk for multiple health concerns, including endocarditis, pregnancy complications, as well as life threatening cardiac-related complications such as aortic aneurysms, stroke, coronary artery disease, hypertension, and congestive heart failure. Some of these complications are even more pronounced for those with certain lesion types and surgical histories.[9,10] For example, all CHD patients are at greater risk for developing coronary artery disease and hypertension as compared to individuals without CHD. However, those with bicuspid aortic valves or coarctation of the aorta have the greatest risk for developing these complications.[9] Several of these cardiac-related complications are amenable to lifestyle changes, including coronary artery disease and hypertension. Therefore, engaging in positive health behaviors (e.g., eating a diet low in saturated fat, being physically active) may help prevent or slow the development of these complications.[11]

The Health Belief Model contains multiple factors that have been used to help explain health behavior engagement,[12] such as

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Abbreviations: CHD, congenital heart disease; CHD-AIM, Congenital Heart Disease Assessment of Information Measure; FIS, Northwest Lipid Fat Intake Scale; GLT, Godin Leisure-Time Exercise Questionnaire.

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undergoing screening for cancer detection. One component of this model includes believing in personal susceptibility (risk) to a particular negative health outcome if a certain behavior is not performed. Personal susceptibility beliefs may or may not be accurate, with some individuals underestimating and others overestimating their risk. Therefore risk can be delineated into accuracy of understanding potential complications and their symptoms (risk knowledge) and believing one is personally susceptible to complications (perceived risk). The association between risk knowledge and perceived risk has been inconclusive in the literature.[13–16] Recent evidence suggests that risk perception may differ by age such that young adults engage in more risky behaviors and perceive less risk than adolescents.[13] Other studies have found similar levels of perceived risk among adolescents as adults,[15,16] but differences in health risk perceptions among adolescents and young adults with CHD have not been substantiated. Adolescents with CHD, including those with complex lesion types, are unlikely to have experienced as many disease complications as adult CHD survivors and may differ in both risk knowledge and perceived risk. Thus, identifying levels of risk knowledge and perceived risk among both adolescents and adults with CHD may inform understanding health behavior engagement in this population.

The level of health behavior engagement among individuals with CHD remains understudied, despite evidence suggesting CHD survivors are at greater risk for developing cardiac-related complications that are amenable to lifestyle changes. One study assessed fat intake among older children and adolescents with CHD in Belgium and Germany, and results indicated that 40% of participants consumed whole milk daily and 50% ate French fries once per week.[17] Conflicting findings have been noted in the literature among adolescents and adults with CHD for physical activity.[18–21] Given the obesity epidemic in the United States among both children and adults,[22] CHD survivors living in the country may be at particular risk for poor health behavior engagement, and based on the Health Belief Model, perceptions of risk may contribute to the level of engagement.

The aims of the current study were to (1) compare the levels of personal (recall of diagnosis and treatment history, and risk knowledge) and general CHD disease knowledge among adolescents, emerging adults, and young adults with CHD of various lesion severities, (2) determine the level of engagement in positive health-behaviors (i.e., consuming a low-fat diet and being physically activity) and whether levels differ between age groups, and (3) explore the relationship between aspects of disease knowledge, perceived risk, and health behaviors among age groups. We hypothesized that the overall levels of personal and general disease knowledge would be low across all age groups. Younger individuals were hypothesized to have poorer risk knowledge than older CHD survivors. Perceived risk and level of engagement in positive health behaviors were not predicted to differ across age groups. Lastly, higher levels of risk knowledge and perceived risk were hypothesized to be associated with greater engagement in positive health behaviors than recall knowledge across all age groups.

Methods

Study design

This was a cross-sectional study conducted in both adult and pediatric outpatient cardiology clinics at a pediatric hospital in the Midwestern United States. Eligible patients were identified through schedules for future clinics, mailed a letter by their attending cardiologist notifying them of the study, and then contacted over the phone for recruitment or approached in clinic if they could not be reached by phone. Participants were asked to complete online self-report measures of disease knowledge, saturated fat intake and physical activity at home, on their own without help from others, prior to attending a cardiology outpatient clinic appointment. Participants who were unable to complete the measures before their clinic appointment were encouraged to complete the surveys during their appointment using a tablet computer. Medical chart reviews provided information to score the disease knowledge measure. Participants were compensated for their time. The study protocol was approved by the hospital Institutional Review Board.

Sample

Eligible patients (1) had a structural heart defect and (2) were between the ages of 15 and 39 years old. Both emerging adults (18–25 years old) and young adults (26–39 years old) were included because developmental research suggests these are unique developmental periods, each having particular challenges and opportunities for personal growth.[23] Patients were excluded if they were diagnosed with a genetic syndrome that had cardiac involvement (e.g., Down, Marfan, etc.), as well as had cognitive impairments or were not proficient in English since this would impede their ability to complete the measures. Of those approached for recruitment, 14 declined, resulting in a recruitment rate of 93%.

Measures

Disease knowledge

A 24-item measure, the CHD Assessment of Information Measure (CHD-AIM), was developed for this study to expand upon available CHD disease knowledge measures that do not assess understanding of future complications. The Leuven Knowledge Questionnaire[6] served as a foundation for the content of the CHD-AIM, and the newly created items were written with input from a panel of adult CHD specialists, including cardiologists, nurse practitioners, and nurses. Preliminary items were reviewed by 12 individuals with CHD of various ages (15–38 years) and cardiac lesion severities who provided feedback about item difficulty and reasons for choosing particular responses. Items were then edited to improve clarity.

Three aspects of disease knowledge were measured by the AIM. *Recall* knowledge was comprised of three free-response items that asked participants to recall personal information about their condition, including the name of their CHD diagnosis, current medications, and cardiac surgical history. Items were scored 0, 1, or 2 depending on the level of accuracy when compared to participants' medical chart. For example, a response of "heart problem" to the item asking for diagnosis would be scored 0, "hole in my heart" would receive a 1, and "ventricular septal defect" or "hole between my ventricles" would be scored 2. The final score was then converted to percent correct across all three items with the total number of points ranging from 0 to 6 (e.g., 3/6 = 50%). *Risk* knowledge assessed the accuracy of participants' ability to identify cardiac-related conditions for which they are at risk due to their cardiac lesion, including arrhythmia, heart failure, stroke, aortic aneurysm, coronary artery disease, and hypertension. While not an exhaustive list, these conditions were chosen because they require early identification. Accuracy was determined based on the participant's diagnosis. For example, individuals diagnosed with tetralogy of Fallot are more commonly at risk for arrhythmia and heart failure. Participants received a 0 if they identified $\leq$25% of the conditions for which they are risk, 1 if they identified 26–74%, and 2 if they identified $\geq$75%. Because arrhythmia, heart failure, stroke, and aortic aneurysm present with warning signs, participants at risk for these complication received an additional question about identifying symptoms of those conditions (e.g., "Which *best* describes the signs/symptoms of stroke?"), which was scored either as 0,