

Congenital Heart Disease in Adolescent Patients: Assessing Population Knowledge Levels of Disease Process and Follow-Up Care



Dorothy Otremba, DNP, APN, FNP-BC¹, Mary G. Heitschmidt, RN, PhD, APRN, CCRN-K²



¹ DePaul University School of Nursing ² Rush System for Health

Introduction

CHD survivors require lifelong disease management and surveillance in order to minimize adverse health outcomes. Adolescent's understanding of their disease process and management are important factors in successful transfers of care. The ACC/AHA advise initiating transition of care at the age of 12 and recommend initial patient knowledge assessment to address gaps in patient knowledge with developmentally appropriate patient education. Poor patient follow-up in an urban CHD clinic lead to the development of this descriptive cross-sectional study.

Objectives

The objective of this study was to determine the prevalence of knowledge deficits in established adolescent patients in an urban CHD clinic.

Methods

A modified Leuven Knowledge Questionnaire for Congenital Heart Disease was distributed to patients 12-18 years. The questionnaire knowledge variables were dichotomized as correct or incorrect answers. Knowledge levels and deficits of questionnaire knowledge domains were categorized as adequate knowledge (>80% correct answers), moderate knowledge (50-80% correct answers), and poor understanding (<50% correct answers).

Summary

Significant knowledge gaps were identified in established adolescent patients with CHD. These findings suggest the need for development of structured patient education modalities which may improve current knowledge levels and preserve maintenance of care. Further research on the development of organized transitional programs should be performed.

Results

		Adequate Knowledge	Moderate Knowledge	Poor Knowledge
Gender		<ul style="list-style-type: none"> Frequency of follow-up Special Diets Dental Practices Appropriateness of physical activity Appropriateness of vocational choices 	<ul style="list-style-type: none"> Name of CHD disease History of treatment to date Attention to bleeding gums Impact of alcohol on CHD 	<ul style="list-style-type: none"> Understanding the anatomy of patient's CHD Main purpose of follow-up care Medication regimen and side effects Ss/Sx of disease deterioration Definition of endocarditis Identifying common sign of endocarditis Knowledge of endocarditis recurrence Risk factors for endocarditis Impact of smoking on CHD Antibiotic use prior to dental visits of development of fevers
Male	2 (11.8%)			
Female	15 (83.3%)			
Race				
Caucasian	7 (41.2%)			
Hispanic	4 (23.5%)			
African American	5 (29.4%)			
Asian	1 (5.9%)			
Age Range of Child				
12-15 years old	14 (82.4%)			
16-18 years old	3 (17.6%)			
Primary Cardiac Diagnosis				
VSD	1 (5.9%)			
Coarctation of the aorta	3 (17.6%)			
Pulmonary Valve stenosis	1 (5.9%)			
Transposition of great arteries	2 (11.8%)			
Aortic Valve stenosis	2 (11.8%)			
Tetralogy of Fallot	6 (35.3%)			
ASD	1 (5.9%)			
Patent Ductus Arteriosus	0			
Other	4 (23.5%)			

Acknowledgements

We would like to acknowledge the support provided and thank the Rush Center for Congenital and Structural Heart Disease as well as the patients and families who participated in this project.