Investigation of Self-reported Transitional Health Care Needs of the Adolescent with Congenital Heart Disease

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DEDICATION

This thesis is dedicated to all families who encounter the challenges, both disappointments and triumphs, of the journey with a child growing up with congenital heart disease… a life not quite so ordinary.

To all of my family, I am so grateful for the never-ending patience, support and love that was a constant inspiration allowing me the opportunity to achieve the completion of a goal that has been an extremely rewarding experience in uncountable ways.

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## TABLE OF CONTENTS

DEDICATION........................................................................................................ii

ACKNOWLEDGEMENT......................................................................................iii

TABLE OF CONTENTS.......................................................................................v

LIST OF FIGURES AND TABLES.................................................................viii

CHAPTER I-INTRODUCTION.........................................................................2
  Background..................................................................................................2
  Statement of purpose....................................................................................6
  Identification of nursing theoretical framework.......................................6
  Research question.......................................................................................7
  Definition of terms.....................................................................................7
  Assumptions...............................................................................................9
  Limitations................................................................................................10
  Summary....................................................................................................10

CHAPTER II-LITERATURE...........................................................................11
  Theoretical framework.............................................................................11
  Review of research...................................................................................14
  Summary..................................................................................................21

CHAPTER III-METHOD..............................................................................24
  Design.......................................................................................................24
LIST OF FIGURES AND TABLES

FIGURE 1-Model of Theoretical Framework .............................................23
TABLE 1-Characteristics of the Study Sample ...........................................37
TABLE 2-Domain and Composite Self-Care Scores ....................................39
TABLE 3-Domain Variables and Age Group Analysis .................................40
TABLE 4-Domain Variables and Gender Analysis .....................................42
TABLE 5-Domain Variables and Education Analysis ..................................43
CHAPTER I
Introduction

Chapter 1 presents a description of the current view of the adolescent with congenital heart disease. A foundation is presented with rationale for the exploration of the adolescent’s perception of what his/her needs are as they transition from pediatric-centered health care to adult-centered health care. The research question is identified and conceptual and operational variables including adolescent, congenital heart disease, transition in health care, self care ability and perceived health care needs of adolescents are defined. The theoretical framework for the research question is based on the Roy adaptation model (Andrews & Roy, 1986), and the significance of the nursing research question is stated.

Background
It is estimated that in the United States, twenty-five to thirty-thousand children are born each year with congenital heart disease (CHD) (American Heart Association, 2002). These heart defects cover a large continuum between benign and sometimes self-resolving to severe and requiring multiple therapies, repeat surgeries, and potential residual and sequelae in the future.

Forty years of successful advancement in surgical interventions, medical management, diagnosis and pharmacotherapies have enhanced the survival, life expectancy, and quality of life for children born with CHD. In the year 2000, the number
of adults with CHD equaled those under pediatric care, and it is estimated that twenty
years from now, the number of adults with CHD will exceed pediatric patients by a wide

Though not the focus of this research, it is important in the discussion of
transitional health care needs of the adolescent with CHD to be aware of pathophysiology
and implications of the disease process. The diagnosis of CHD encompasses a wide
variety of disorders in which many vary in the degree of severity. The medical
management and surgical interventions necessary in the management of congenital heart
defects are specific to the type of defect. As most congenital heart defects are recognized
at birth or in infancy, the required medical regimen or surgical procedure is often initiated
prior to the period of adolescence. In addition, various defects which are more complex
require multiple surgeries in a staging sequence which occur with growth and physiologic
changes. The discussion of pathophysiology and implications of CHD are too extensive
to be covered as part of this research discussion. A brief overview of this chronic disease
is offered to better understand the impact of chronic disease management and its effects
for transitional health care needs.

Suddaby (2001) challenges nurses to improve their understanding of the
physiological effects of the varied types of CHD by using a categorical approach. As
congenital heart defects may be a variant of cyanotic or acyanotic disease due to
deviations in hemodynamic states, the traditional approach of using these two categories
does not encompass many factors. Suddaby suggests a view of understanding CHD by
using three physiologic categories: (a) increased pulmonary blood flow (i.e., patent
ductus arteriosus, atrial septal defects, ventricular septal defects, atroventricular canal defect, endocardial cushion defect, double outlet right ventricle, total anomalous pulmonary venous return and truncus arteriosus), (b) decreased pulmonary blood flow (i.e., tetralogy of Fallot, transposition of great arteries, pulmonary stenosis, pulmonary atresia, and tricuspid atresia), c) obstruction to systemic blood flow (i.e., coarctation of the aorta, aortic stenosis, hypoplastic left heart syndrome, mitral stenosis, Shone's Syndrome, and interrupted aortic arch).

Various clinical changes occur as a result of the altered physiologic and anatomical deviations. The result of increased pulmonary blood flow depends on various factors and effects are dependent on the volume of blood flow. Potential implications of this are resulting congestive heart failure, pulmonary vascular disease, pulmonary hypertension, and right ventricular hypertrophy.

In anatomical changes that result in decreased pulmonary blood flow, there is a failure to oxygenate with subsequent desaturation, cyanosis and potential pulmonary vascular disease produced by infarcts. An obstruction to systemic blood flow results in low cardiac output, left ventricular hypertrophy with resulting congestive heart failure and pulmonary edema based on the extent of the defect.

Improved survival and extended longevity of individuals with CHD now find this population entering the developmental stage of adolescence with a chronic disease. This history adds to the already key developmental task of the adolescent that is identity
versus role confusion (Kagan & Gall, 1998). The adolescent with CHD has dual challenges, (a) to achieve the process of defining identity and (b) to incorporate the implications of living with a chronic disease.

Achieving independence and identity as an adolescent, especially as an adolescent with a chronic disease such as CHD, can be a confusing and difficult time. Independence versus burden was a major theme identified in a multi-method inquiry study of adolescents in transition who had special health care needs by Hartman, DePoy, Francis, and Gilmer, (2000). Patterson and Lanier (1999) also identified a strong desire for control and management of care by adolescents with special health care needs as they transitioned to adult care.

The period of adolescence should culminate the period of care delivery directed at the parents or caregiver for the child and initiate a plan of transition and accountability for care by the adolescent (Patterson & Lanier, 1999). Barriers to the transition from pediatric-centered care to adult-centered care are described in a dimensional analysis grounded theory by Kools et al. (2001) and the findings revealed factors related to dissonance in care. The need to maintain control was described for the young adults as they work toward achieving more responsibility for their heart care.

The current body of nursing research includes data regarding physical and psychosocial needs of the adolescent with CHD, yet many of these needs are not clearly understood in the context of what is necessary in the transition from pediatric-centered health care to adult-centered health care (McMurray et al., 2001). The qualitative analysis of thirty-seven adolescents identified five themes of concern by the adolescent; coping,
limitations, exclusion, discrimination, and life improvement. In addition, historically, much of the nursing research data are collected from the perspectives of parents, direct care givers or informants. There are limited studies published that describe the direct views of the adolescent with CHD, and no studies were found that investigate the perceived needs of the adolescent with CHD as he/she transitions from pediatric-centered care to adult-centered health care.

The deficit of this body of knowledge impedes the ability of nursing to accurately understand and intervene to meet the care-giving needs of this population. Accurate interventions are key to empowering the adolescent with CHD to achieve developmental tasks and management of his/her own care in both the medical and social context.

Statement of Purpose

The purpose of this research study was to explore the perceived needs of adolescents with CHD as they prepare for transition from pediatric-centered health care to adult-centered care. The intent of this research was to gain a clear understanding of what degree of self-sufficiency exists in managing health care needs and what the adolescent with CHD feels is necessary to manage his/her own health care as they begin the journey into young adulthood.

Identification of Nursing Theoretical Framework

Adolescents with CHD face many needs for adaptation in their daily lives: physiological, psychosocial, and developmental. It is for this reason that the Roy Adaptation Model (Andrews & Roy, 1986) (RAM) was chosen as the guiding concept of this research study. The major concepts of the RAM are person, environment, nursing,
and health. The person, as an individual and as a member of a group, is considered by Roy to be an adaptive system. Environment is viewed as stimuli; both internal and external and the stimuli are further defined as focal, contextual, and residual. A focal stimulus is the stimulus most immediately confronting the person. Contextual stimuli include all other stimuli which contribute to the focal stimulus. Residual stimuli are something that may affect the person but may not be clearly observed as having an effect. The combined stimuli determine the person's adaptation level, and environmental changes are processed by the person using adaptive or ineffective responses. These responses result in reactions to the internal and external environment of the person, supporting the concept that the person and environment are in constant interaction with each other (Andrews & Roy). The adolescent with CHD will require a thorough understanding of what is necessary for the management of his/her health care as well as the ability to access the support and services to meet these needs. The adolescent can then effectively respond and adapt in an ever changing environment and to the changes that may occur in his/her body as a result of the CHD.

Research Question

The research question for this study is: what are the self care abilities and perceived needs of adolescents with CHD as they begin the transition from pediatric-centered health care to adult-centered health care?

Definition of Terms

For the purposes of this study, the following theoretical and operational definitions relevant to the research question are described. The conceptual definition is a
statement that defines the variable. The operational definition is a description of how the variable was measured in the study.

**Adolescence**

Conceptual definition: “a period of major transition in physical, psychological and social development.” (Newacheck, McManus & Fox, 1991, p. 1367) In the view of the theoretical framework, the adolescent was considered as a holistic adaptive system (Andrews & Roy, 1986).

Operational definition: adolescent was a person, male or female, who was not mentally disabled, and is between the ages of fourteen and twenty-one as documented in the medical record.

**Congenital Heart Disease**

Conceptual definition: “a broad spectrum of malformations ranging from mild lesions that produce only minimal symptoms until adult life, to severe anomalies that cause death in the perinatal period” (Kumar, Cotran & Robbins, 2003, p. 388).

Operational definition: a condition in which a heart defect was diagnosed and required medical management and/or cardiovascular surgery which may have result in residual deficits that affect physical, psychological and social functions. This concept was measured as male or female adolescent with a diagnosis of CHD as documented on the medical record.

**Transition in Heath Care**

Conceptual definition: is a process, not an event; it occurs over time” (Patterson & Lanier 1999, p. 56). “The purposeful, planned movement of adolescents and young
adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems” (Blum, Garell & Hodgman, 1993, p. 570).

Operational definition: the process of movement from pediatric-centered to adult-centered care, that required success in accomplishment of adolescent developmental tasks and acceptance for the responsibility in managing one’s own health care. The tool being used is described in the method section located in Chapter III.

**Self-care Ability**

Conceptional definition: self-care ability was implied as the process of health care self-management and demonstrated by constantly addressing the changing nature and meaning of the chronic illness experience (Andrews & Roy, 1986).

Operational definition: self-care ability was measured through the use of the Congenital Heart Disease Transition Health Care Assessment questionnaire.

**Perceived Health Needs of Adolescents**

Conceptual definition: perceived health needs of the adolescent included physiological and psychosocial elements. Perceived health is a descriptor of the patient’s view of his/her general health in comparison to others (Kendall, Lewin, Parsons, Veldtman, Quirk, & Hardman, 2001).

Operational definition: perceived health needs of the adolescent as measured by the CHD transition health care assessment questionnaire. The responses were given from the personal view of the adolescent.
Assumptions

CHD has the potential to affect all aspects of the adolescent’s daily life, and may also prove influential throughout his/her adult life span. The transition to adult-centered care requires the adolescent to be able to identify needs for accomplishing this transition as well as acceptance, ability and responsibility to manage his/her own health care. In addition, the necessary resources and support services must be available to meet the needs of this transitional process.

In the context of the RAM, the adolescent is an adaptive system. The ability to respond to stimuli with adaptive responses versus ineffective responses is key to maintaining a healthy state (Andrews & Roy, 1986). The response to stimuli will be impacted by accurate understanding of the disease process and health care needs.

Limitations

The results of this study may have been affected by the sample size as well as the use of a non-randomized sample. In addition, the use of self-reported data may have been affected by the understanding and interpretation of the participant. There is potential for the influence of the parent or significant other to impede responses as well as participants responding with what they believe was the accepted or desirable responses.

Summary

This chapter presented a description of CHD and the impact of burden for the child diagnosed with CHD. Current nursing research has limited knowledge of the direct perspectives of this population regarding their perceived needs as they begin the
transition to an adult oriented health care system. The adolescent remains in constant interaction with the environment and for the purposes of this study, the opportunity for choosing adaptive versus ineffective responses to stimuli will be better influenced by nursing interventions that result from a clear understanding of the adolescent's needs.
CHAPTER II

Literature

Chapter II presents the theoretical framework for this study using the Roy adaptation model (RAM) (Andrews & Roy, 1986) and defines the relationship to the stated research question. A schematic is included that guides the research question conceptualized within the RAM (Figure 1). Subsequent to the framework is the review of research. The presentation of the research review is divided by concepts. These concepts include; (a) transitional issues into adult-centered care (b) understanding of illness and levels of knowledge, and (c) state of health and social adaptation. A summary of findings of the literature concludes the chapter.

Theoretical Framework

The following content of the RAM (Andrews & Roy, 1986) are discussed; (a) major concepts, (b) responses, (c) coping mechanisms, and (d) adaptive modes. Application of the model to the adolescent living with congenital heart disease (CHD) is then discussed.

The major concepts of the RAM are person, environment, nursing, and health. The RAM views the person as an adaptive system receiving input, and processing the input to produce a response. These responses may result in adaptive behavior or ineffective behavior. The environmental input for the person are stimuli that may be (a) focal (internal or external) immediately confronting the person (i.e., CHD), (b) contextual, that is all other stimuli evident in the situation, or (c) residual (stimuli that may be affecting behavior but whose effects are not validated). The response to these
stimuli can be defined as the behavior of the person who shows coping mechanism activity. These may be adaptive or ineffective responses. The resulting adaptation level is determined by the sum effect of these stimuli (Andrews & Roy, 1986).

Stimuli and adaptation level serve as input to the adaptive system (person) after being processed via regulator (neural, chemical, and endocrine coping processes) and cognator (cognitive-emotive) channels. It is not possible to directly observe the function of these systems; only the responses produced can be observed. This is called the adaptive mode. The process of a person as an adaptive system allows for responses in a changing world (Roy, 1986).

The four adaptive modes are physiological, self-concept, role function, and interdependence mode. The physiological mode is the physical response of the person to environmental stimuli and includes cellular level and system responses of the human body. The self-concept mode includes the physical and personal self in contrast to the psychosocial mode that looks at psychological and spiritual aspects of the person. The social mode of role function is a view of the person’s social integrity which describes who a person is in differentiation to others. In addition, the second social mode is the interdependence mode. This mode encompasses aspects related to giving and receiving love, respect, and value that lead to affectional adequacy (Andrews & Roy, 1986).

The RAM (Andrews & Roy, 1986) was selected for this research study based on the adolescent's continuous need to adapt to a changing environment from two perspectives (Figure 1). First, the need to adapt involves achieving the developmental stage of adolescence in order to move into young adulthood. Second, the adaptation involves gaining the ability to understand and identify health care needs that are dictated by CHD. Adapting to a chronic illness such as CHD (focal stimulus) combines the processing of internal and external processes (stimuli) that influence responses and
behaviors (adaptive modes). Two additional types of stimuli include contextual and residual. Contextual stimuli are factors which impact the current health state such as understanding of disease symptoms and the severity of the heart defect and necessary medical therapies. Residual stimuli are factors which may affect the adaptation level of the person, but the results of which are not known yet (Andrews & Roy, 1986).

Aspects of health care transition process, life skills, abilities, and career are considerations as residual stimuli. The adolescent with CHD has the challenge of living with a chronic disease but must also remain cognizant of the issues and needs (contextual and residual stimuli), (i.e., ability to tolerate stress and adopting health promoting behaviors) that are imposed by the disease. These stimuli influence the perception of the adolescent regarding the impact of the illness.

A key goal in the developmental tasks of the adolescent is to achieve autonomy and identity through separation and to become his/her own individual as described by Erikson (Kegan & Gall, 1998). As an adolescent with CHD, this process requires adaptation in a manner which allows effective adjustments to changes in the environment. It is important to give consideration to differences in conceptual and cognitive development of the adolescent as they may vary with age as well as maturation level. Veldtman et al. (2001) identified that with regard to understanding of illness timeline and age, the stages of cognitive development was a largely attributable factor. The adolescent is challenged to identify needs of physiological integrity, a defined self
concept with integration of the CHD, and appropriate role function as well as maintaining relationships with support systems. The behavioral responses of the adolescent are then viewed in relation to these four adaptive modes.

Key in the use of the RAM framework for the adolescent with CHD is the ability of the nurse to assist the adolescent to integrate the disease process and health care management needs of CHD into his or her life. In order to accomplish the integration, the nurse must be able to determine the perceived needs of the adolescent in transition to adult-centered care and promote adaptation in any of the four adaptive modes. In doing so, the ability of the nurse to improve the process of self management by the adolescent contributes to physiologic and psychosocial adaptation. Improving the process of self management is essential in order to maximize the health potential of the adolescent with CHD.

Review of Research

Adolescents with CHD are children who live with a chronic disease and face unforeseen challenges throughout their life span. The normal process for achieving adolescent development tasks is independence that is now compounded with the impact of CHD. The adolescent with CHD has increased potential for both developmental and physical crises. The adolescent period normally addresses the challenges of changes in physical growth, sexual maturation and the pressure of choices regarding education and careers. The adolescent with CHD faces these challenges amidst the need to integrate past experiences, their personal characteristics and acceptance of a chronic disease in an effort to form a stable sense of self (Kagan & Gall, 1998). The review of literature
reflects factors affecting the adolescent with CHD and their transition from pediatric-centered health care to adult-centered health care. The following discussion is presented by topics including transitional care issues, understanding of illness and levels of knowledge of health care needs, state of health and social adaptation factors related to the adolescent.

*Transition to Adult-Centered Care*

Transition from pediatric-centered health care to the adult-centered health care arena is a distinct change for the adolescent with CHD. Transition in care was reviewed in the literature, mostly from the perspective of chronic illness and special health care needs. Hartman et al. (2000) did a multiple case study methodology relying on life history to assess issues related to transition. This study was done from the parent's view and was not the view of the adolescent. Limitations of the study were that the findings generated ideas for theory, but were not intended to represent the experiences of other parents. A major theme of the study included that of the adolescent's need for independence versus burden. This theme indicated the desire of the adolescent with chronic disease to achieve independence and view it as his/her right. Significant for the transition from pediatric-centered health care to adult-centered health care was independence building by the adolescent. This transition included key concepts such as knowledge and self care management skills.

Patterson and Lanier (1999) also studied adolescent health transition in a qualitative study of seven adolescents and young adults, 18-35 years of age with chronic illness. A significant barrier in health transition was the lack of transition planning at an
earlier age. Transition from one type of care to another took place during key developmental times when young adults were trying to adjust to new independence. Age seventeen was considered late for transition in health care. Adolescents wanted more involvement in the process earlier and they wanted more decision making responsibility. Lacking understanding of their illness and the use of medical jargon by health care professionals were defined as barriers by this population of adolescents. Success in this transition was measured by methods of mentoring to allow the adolescent to become expert in his/her own health care. The nurse was considered key as a facilitator for success in transition. This finding echos a study by Kyngas and Rissanen (2001) that described factors for predicting compliance among adolescents with chronic illness. The most powerful predictor of good compliance in health regimens was support from nurses. Those with support were 7.28-fold more likely to comply when compared to those who did not receive support by nurses ($p=0.00$). Negotiation was important to the adolescent in this process and directly related to moving forward with the concept of achieving adulthood.

It is clear that the transitional care issues of the adolescent with CHD are multifactorial and encompass continuity and planning which needs to start well before the point of transition. Many of these factors are from the perspective of physiological, psychosocial and educational concerns. Additionally, Higgins and Tong (2003), described the need for a combined approach of transition views to come from the patient, parent, pediatric cardiologist, and the adult cardiologist.
Betz, Redcay and Tan (2003) documented self-reported health care self-care needs of transitional-aged youth with special health care needs, though not specific to CHD. This pilot study, even with the limitations related to a non-randomized, small sample size, did add insight into the deficit of knowledge about health related needs of youth with special health care needs for transitional care. Specific areas of overall “yes” response score in the sample of Betz, Redcay and Tan's study included; limited knowledge of legal rights and protections ($M=18, SD=24.49$) by diagnostic group comparison ($p=0.15$); understanding need for environmental modifications and accommodations ($M=21, SD=29.47$) by diagnostic group comparison ($p=0.67$); management of special health care needs ($M=29.71, SD=26.0$) by diagnostic group comparison ($p=0.12$); and knowledge of health insurance concerns ($M=42.67, SD=26.39$) by diagnostic group comparison ($p=0.23$).

Understanding of Illness and Levels of Knowledge

Ferenz, Wiegmann, and Dunning (1980) assessed what young persons with heart disease understood about their cardiac status at the time when their health care was becoming their personal responsibility. Seventy-four subjects in a combined group of adolescents diagnosed with CHD or rheumatic heart disease were the target population. Deficiencies in knowledge of their heart condition were found in the younger sample population. Older participants were found to have a significantly higher knowledge base ($p < .005$) than younger participants. This finding was positively correlated with the level of education ($p < .01$) of the older participant. This finding is consistent with those of Veldtman et al. (2001), in a prospective cohort study of understanding illness in children.
and adolescents with heart disease. Findings revealed that understanding of the illness increased with age and reflected the mean age for good understanding of illness to be fifteen years old. Though this may clearly reflect the conceptual and cognitive development as a function of age, it suggests a need for better age-appropriate structure in the educational process.

Additionally, Veldtman et al. (2001) found lack of knowledge of the type of surgery needed in one half of the patients. There was a deficit of knowledge regarding prevention related to CHD; only two-thirds of the sample was found to understand the importance of dental care and issues related to the significance of endocarditis. These deficiencies of knowledge in care issues reflected concerns for the transition to self care management by the adolescent. Overall, good understanding of their illness was only demonstrated by 30% of the adolescent sample. Seventy-eight percent did not know the name of their medical condition and 33% had a wrong or poor understanding of the illness. As parents have been entrusted with the delivery of knowledge about CHD to the child, it was assumed that parent’s understood the illness and explained it appropriately. However, as evidenced in Veldtman et al.'s study, it is unclear if this perception is accurate.

To contrast the findings of the adolescents’ knowledge regarding CHD, a study by Moon et al. (2001), examined what adult patients with CHD know about their disease, treatment and prevention of complications. This descriptive, cross-sectional study of sixty-two adults in Belgium used the Leuven Knowledge Questionnaire (Moons et al.) for congenital heart diseases. Though some limitations were raised due to lack of internal
consistency of the questionnaire, the findings showed poor understanding (less than 50% of answers correct) of adult subject’s knowledge of heart disease. Moons et al. noted that areas of lack of knowledge, including the symptoms of deterioration of heart disease, the definition of heart disease, characteristics and risk factors of endocarditis which indicated the need for follow up care. Further more, less than fifty percent of the participants gave correct answers regarding the impact of smoking and alcohol use and the nature of heredity related to heart conditions.

Vessey and O’Sullivan (2000) used an exploratory, descriptive study of 50 children with CHD, ages 5 to 15 years, and a group of 50 children without CHD and a knowledge of their internal bodies. Findings indicated no significant differences between the two groups on knowledge of body parts or body part function ($p > .05$). The scores did not indicate that either group had exceptional body knowledge. It is necessary that adolescents with CHD understand anatomy and physiology as it relates to their diagnosis in order to assume responsibility for their own health care. These findings indicated that healthcare providers should not presume knowledge of the body’s interior as merely being familiar with individuals who are consumers of health care, and the use of the health care system did not equate understanding of illness. Nursing should be reminded to reinforce age-appropriate information at repeated visits.

*State of Health and Social Adaptation*

Kendall, Lewin, Parsons, Veldtman, Quirk, and Hardman (2001) did an observational study of fifty-seven adolescents with CHD in the United Kingdom regarding perceived state of health. Though only a limited number of cases at a single
center was reported on, the authors found that 66% of the adolescents felt themselves to be the same or only slightly different from their peers. The degree of difference was not related to complexity of cardiac defect as rated by their physician. The psychosocial themes of activity, exclusion and effect of condition on relationships were most strongly related to the perceptions of health.

An area of existing controversy was seen throughout the literature regarding parent’s, professional’s, and peer’s perceptions of limitations and restrictions for the child with CHD. Kendall et al. (2001) found it clear that many restrictions and social barriers were instituted by other people on adolescents with CHD, and that people frequently underestimated the capacity of the adolescent to live a normal life. Thomason (1997) used a phenomenological method to investigate the lived experience of ten adolescents with significant CHD. One-hundred percent described inability to participate in activities, especially sports, related to their CHD. This restriction was imposed by the physician, family, or peers even though the adolescent did not perceive significant physical limitations. Similar perceptions related to issues of the adolescents’ physical limitations and restrictions were noted by McMurray et al. (2001).

The concept of “normalization” as a significant desire of the adolescent with CHD is also discussed by Thomason (1997), Doucet (1981), Kendall et al. (2001), and Sparacino, et al. (1997). The desire to be normal is also noted historically by Glaser, Harrison and Lynn (1964). The adolescent with CHD reported not wanting to be different, to be treated like others, and to have no special treatment or privileges. The need for the adolescent to “fit-in” is a normal developmental desire. Compounded by a
chronic illness, is the increased need for coping by the adolescent. Meijer, Sinnema, Bijstra, Mellenbergh and Wolters (2001) evaluated the psychosocial adjustment in Dutch adolescents with chronic disease. Seeking social support was an important predictor for positive social adjustment ($B = 0.37$).

**Summary**

The review of research was completed for exploration of findings related to adolescents with CHD in transition from pediatric-centered to adult-centered health care. There is currently very limited research that reflects the perceived needs for this transition from the adolescent’s view point. Clear needs were found related to the lack of understanding of illness and risk factors and complications with CHD. In addition, there are inconsistencies in the understanding of limitations in physical activity and relationships related to the state of the adolescent’s heart disease. Further research in these areas is essential, as it is necessary for the adolescent to develop life plans of career, relationships, and activity levels appropriate to their specific disease process.

Though of limited scope, barriers to care for transition in health care were noted. A need exists to better define what the specific issues from the view of the adolescent with CHD are as he/she accepts responsibility for management of his/her own health care.

The RAM was used as the theoretical framework to guide this research study. The need for the adolescent to be successful in adapting to the ever-changing environment must be supported. The nurse was identified as a key instrument for assisting the adolescent with this transition.
Health education and understanding the management of his/her CHD are essential to promote wellness and limit risk factors that could further affect the cardiovascular status of the adolescent throughout his/her adulthood. The nurse’s accurate perception of the adolescents’ level of understanding of illness and perceived needs to accomplish health care transition are essential. Nursing cannot facilitate a successful transitional process without this knowledge. In processing interventions to meet these needs, nursing will enhance the ability of the adolescent for successful management of his/her own health care.
CHAPTER III

Method

The purpose of Chapter III is to describe the methods used in investigation and identification of the self-reported transitional health care needs of the adolescent diagnosed with congenital heart disease (CHD) as they transition from pediatric-centered health care to adult-centered health care. The research question: what are the self-care abilities and perceived needs of adolescents with CHD as they transition from pediatric-centered health care to adult-centered health care? The research question is investigated from the views and direct perspective of the adolescent. Chapter III begins with identification of the study design, followed by a description of the subjects, setting, sample size, and selection criteria. The data analysis addresses the research question and a summary concludes the chapter.

Design

An exploratory-descriptive research design was used to conduct the study that examined characteristics of multiple variables in a sample of adolescents with CHD. The variables of interest were measured using a modified version of the California Healthy and Ready to Work Transition Assessment questionnaire (CA HRTW) (Betz, 2000) named as CHD Transition Health Care Assessment. The domains, including variables to be examined, were included in the materials section of this chapter.
Subjects

The setting for the study included a single out-patient pediatric cardiology clinic that is part of large teaching hospital and academic research center. Permission was obtained from St. Vincent Mercy Medical Center and Medical University of Ohio’s Institutional Review Boards (Appendix A). The target population included adolescents, male and female, whose ages ranged from 14 to 21 years, and who were diagnosed with CHD at any time since their birth up to and including the current age of 21 years. This age range was chosen as it is consistent with the original tool inclusion criteria and examined the population which was faced with transitional health care issues. Sample size, inclusion and exclusion criteria were included under the data collection section.

Materials

The research study was completed using the administration of the CHD Transition Health Care Assessment questionnaire with documented approval for professional use by the Maternal Child Health Bureau, DHHS (Appendix B). The initial project was funded by Maternal Child Health Bureau, DHHS. This questionnaire was tested as a pilot study by Cecily Betz, PhD, RN, FAAN, University of Southern California, Department of Nursing and has demonstrated face and content validity. The tool has been adapted by the researcher to investigate a specific population of adolescents with CHD as noted in the inclusion criteria. The questionnaire content was reviewed by a pediatric cardiologist for validation of content relevant to the population of adolescents with CHD. Though a complete validation of the instrument would be beyond the scope of this study, a pilot study was completed to pre-test the instrument. The object was to
validate the content of the questions and scales used, as well as directions for the questionnaire and the length of time for questionnaire completion. Questions were reviewed for content validity in a convenience sample of 10 adolescents between the ages of 14 and 19 years which are consistent with the adolescent in transition from pediatric-centered health care to adult-centered health care, but not with a diagnosis of congenital heart disease. Only one participant had the diagnosis of CHD. There were 6 males in the convenience study between the ages of 14 and 19 years and 4 females between the ages of 14 and 19 years. The results demonstrated understanding of the question content with only a few exceptions in some minor terminology. The questionnaire was slightly adapted for improved terminology clarification by the researcher. All participants completed the questionnaire within a 10 minute period.

The assessment tool includes 68 questions which assesses the adolescent’s ability in self care skills and management of his/her health care needs. The 68 questions are organized into twelve different categories. Each domain or category contains anywhere from three to thirteen questions. The domains of variables and the number of questions in each domain included: a) knowledge of health condition and how to take care of yourself (n=7), b) what you do to keep healthy (n=10), c) what to do in an emergency (n=5), d) do you know how to monitor your special health care needs(n=4), e) do you know how to manage your special health care needs (n=7), f) do you know how to communicate effectively(n=4), g) do you know how to use community resources(n=4), h) understanding of responsible sexual activity (n=4), i) obtaining information and reproductive counseling when needed (n=3), j) keeping track of health records (n=4),
k) knowledge of health insurance concerns and issues (n=4), and l) transportation safety (n=12). Responses to the domain items were identified by the study participant by answering yes, no, or non-applicable. Affirmative responses (yes) were considered as a positive indicator of specific knowledge or skill in the specific domain area and negative (no) responses were considered an indicator for lack of knowledge or skill in the specific domain area. The higher the percentage of affirmative (yes) responses, the greater the skill and self-care ability related to the domain question. The lower the percentage of negative (no) responses, the less skill and self-care ability related to the domain question. The percentage reflecting non-applicable is an indicator of content and was not measurable for the specific domain question in that participant. The response of non-applicable denoted that the question did not apply to an individual participant if selected in a specific domain. The questionnaire, CHD Transition Health Care Assessment, adapted by the researcher from the Maternal Child Health Bureau, DHHS, includes a total of 68 questions divided into twelve domains. A copy of the questionnaire is included (Appendix C).

Participant demographics were collected by the researcher. The demographic data collected included information on age, gender, ethnicity, education level, marital status, employment status and was incorporated at the end of the data collection tool (Appendix C).

Data Collection

The participants included males and females within the age range of 14 years through 21 years of age. This age range was chosen as it is consistent with the original
tool inclusion criteria and examines the population that is faced with transitional health care issues. In addition, the age ranges for the study correlate with partial age parameters used in the educational process for Individualized Education Plans (IEP) (Betz and Redcay, 2003). Inclusion criteria were included that the participant must be able to read and write English, meet age requirements, have a diagnosis of CHD and not be mentally impaired. If parental consent was given for the minor, the minor had to be willing to participate and sign the assent form for consent. Exclusion criteria included any diagnosis of mental impairment.

Parental or custodial informed consents were obtained for all participants who were minors and participant informed consents were obtained from all non-minors. All participating minors signed assent forms. Clinic site approval and Institutional Review Board (IRB) approvals were obtained from Medical University of Ohio and St. Vincent Mercy Medical Center, William A. Suarez, M.D., F.A.C.C. (personal communication, January 11, 2006). The process maintained the Federal Health Insurance Portability and Accountability Act (HIPAA) regulations. The participants were assured that their names were not used. Participants were assured their rights to refuse participation would in no way affect the continuation of their medical care. Study data were stored in a locked file cabinet during collection and accessible only to the co-investigators and the principle investigator for the period of time directed by IRB guidelines. After the data were analyzed, all raw data and forms will be stored for six years (or longer until the adolescent reaches 21 years of age) in the locked file cabinets of the Center for Nursing Research and Evaluation.
A convenience and random sample process were used for the research study to obtain sufficient sample size, a minimum of 30, for statistical analysis based on statistical program analysis and general recommendations in nursing literature. A power analysis was not completed for this study. The level of statistical significance was defined as $p \leq .05$. The selection of participants occurred by the use of the inclusion and exclusion criteria. The participants were recruited from a single site pediatric cardiology office, from the principle investigators’ physician database, after identification using the inclusion and exclusion criteria and with approval by the physician. Recruitment techniques included a two-method process to enhance the opportunity for an adequate sample size. First, a convenience sample was used to collect data at a face-to face visit with the patient during a routine scheduled office visit. Participants were requested to participate and consents were obtained at this time. Second, a random sample process was used for patients not scheduled for an appointment in the clinic. An initial informational letter signed by the principal investigator physician was mailed to the participant’s home address explaining that they would receive an invitation in the mail in the very near future to participate in a study. The letter also explained the principal investigator physician’s support and approval of the study and explained that whether they participated or not, it would in no way affect the continuation of their care (Appendix D). Then the questionnaire and consent was mailed to the participant with a request for participation and to return the questionnaire and consent form in the enclosed, stamped, addressed envelope.
Following sample selection, a sequential numerical code was recorded on the questionnaire which correlated with the participant demographic data for correlation of questionnaire returns with the patient identifiers. The CHD transition health care assessment questionnaire was either presented in the office or mailed to the patient. To assure consistency in the delivery method, all questionnaires were distributed to participants in the office by the co-investigator. All mailed questionnaires included a cover letter (Appendix E) that introduced the researcher; explained the purpose of the study; requested signed consent for participation; gave directives for completion of the tool; and included a return stamped, self-addressed envelope. A postcard (Appendix F) was mailed approximately 2 weeks later as a reminder for questionnaire completion. In addition, researcher contact information was included for any clarification needed or concerns the participant had regarding the study. After receipt of the completed questionnaires, the data were coded using value and label identifiers for the responses. A value of 1 equaled a label of a “yes” response, a value of 2 equaled a label of a “no” response and a value of 3 equaled a label of non-applicable for the response. Any missing data were labeled with a value of zero. Data for the demographic identifiers were coded in the same process with specific values and labels assigned for each demographic category (Appendix G).

Controlling threats to internal validity

a) History. Assured that the subject had no concern regarding dates and times related to the study and document implications of any time related events.
b) Maturation. Followed the study design and steps without assumptions to minimize any investigator bias and documented any scope of identified bias and actions used to control for same.

c) Testing. Single assessment questionnaire process was used.

d) Instrumentation. No physical instrument was used. The CA HRTW has prior face and content validity as well as interrater reliability of one-hundred percent. A pilot study was completed by the researcher for content specific clarity using a convenience sample of adolescents; male and female; age range included 14-19 years of age.

e) Selection. Convenience sampling was listed as a limitation in the findings as well as implications of the use of a two-method recruitment process.

f) Mortality. Clear documentation of issues related to cause of mortality and that it was not study related and would not be included in data analysis.

g) Diffusion. No treatment of an experimental group was used.

Controlling for threats to external validity

a) Interaction of selection was addressed by reporting the number of subjects who refused to participate and if known, why, as well as documented factors of selection differences.

b) Interaction of setting included any notable issues related to access of sample availability. Clarification was documented regarding generalization of the population.

c) Interaction of history. Consideration was given to current trends and research with CHD that may be known to participants and impacted responses.
Assumptions of the Study

CHD has the potential to affect all aspects of the adolescent’s daily life throughout his/her adult life span. The transition to adult-centered health care requires the adolescent with CHD to identify (a) the needs required to accomplish this task as well as achieve acceptance, ability, and responsibility in the management of his/her own health care and (b) the necessary, available resources, and support services that must be available to meet the needs of this transitional process. In the context of the Roy adaptation model (Andrews & Roy, 1986) (RAM), the adolescent is an adaptive system. The ability to respond to the stimuli of the transition from pediatric-centered health care to adult-centered health care with adaptive responses versus ineffective responses is key to maintaining a healthy state.

Limitations of the Study

Using a convenience sample decreased the generalizability of the findings and may have allowed for bias of the sample which must be identified and described by the researcher. In addition, the use of a two-method recruitment process was a noted limitation. The sample size was projected to be 30 participants with a target goal of 50 participants. In addition, the potential existed for the adolescents’ responses on the questionnaire to be affected by the input of a parent or guardian.

Data Analysis

Data were analyzed using the Statview R computer program, version 5.01, by SAS Institute, Inc. Data were cleaned assuring all data were complete. Data were collapsed by limiting use of complete variable terminology which was replaced using a
single identifier word for labeling each domain variable. Univariate analyses were used to check the quality of the data that was entered into the computer program. Organization of the data was completed by use of measurement scales for each affirmative and negative response to the domain variables. The data are presented in table and chart formats in Chapter IV. The statistical analyses considered for utilization in the study included rank, order, descriptive statistics, percent measures and correlation analysis as indicated (analysis of variance and post-hoc comparisons).

Summary

IRB approval was received and the CHD transition health care assessment tool was utilized to complete a convenience and random sampling. The questionnaire responses were obtained from the view of adolescent participant regarding their perceived health care needs for readiness and transition to adult-centered health care. Strict attention was given to protect participant confidentiality and procedural process as the sample population was obtained and the study data were analyzed.
CHAPTER IV

Results

The objective of this study was to investigate the self-reported transitional health care needs of the adolescent with congenital heart disease (CHD) as they move from pediatric-centered health care to adult-centered health care. The study used the Congenital Heart Disease Transition Health Care Assessment questionnaire, as described in the methods section, to explore 12 areas (domains). Each domain has multiple questions with a composite total of 68 questions. The domain variables and the number of questions within each include the following: (a) knowledge of health condition \( n=7 \), (b) what to do to keep healthy \( n=10 \), (c) what to do in an emergency \( n=5 \), (d) how to monitor special health care needs \( n=4 \), (e) how to manage special health care needs \( n=7 \), (f) how to communicate effectively \( n=4 \), (g) how to use community resources \( n=4 \), (h) understanding of responsibility of sexual activity \( n=4 \), (i) obtaining information and reproductive counseling \( n=3 \), (j) keeping track of health records \( n=4 \), (k) knowledge of health insurance issues \( n=4 \), and (l) transportation safety \( n=12 \).

This chapter describes the sample population and the results of the measured level of self-care preparedness calculated as the percent positive (responses = yes) within each of the 12 domains and as an overall composite score over all of the study questions \( N=68 \). Affirmative responses (yes) were considered as a positive indicator of specific knowledge or skill in the specific domain area and a negative (no) response will be considered an indicator for lack of knowledge or skill in the specific domain area. The higher the
percentage of affirmative (yes) responses, the greater the skill and self-care ability related to the domain question. The lower the percentage of negative (no) responses, the less skill and self-care ability related to the domain question. The percentage reflecting non-applicable is an indicator of content and was not measurable for the specific domain question in that participant. The response of non-applicable denoted that the question did not apply to an individual participant if selected in a specific domain. The study data types are both continuous (i.e., age, domain scores, composite domain score) and categorical (i.e. derived age categories, gender, ethnicity, education, employment and marital status). Results are presented as mean, standard deviation and statistical significance is defined as \( p < 0.05 \). A minimum sample size of 30 was selected based on statistical program analysis and literature recommendations. A power analysis was not completed. The objective of the study, to measure the level of self-care preparedness and, therefore, the health care needs of adolescents in transition from pediatric to adult-centered care, was tested using analysis of variance (ANOVA) with planned post-hoc comparisons. The dependent variables were the 12 domain percent positive scores reflecting the level of self-care and the composite score derived from all the questionnaire items. The independent variable was the perception of self-care ability of the adolescent participants. Comparisons of the scores within each domain and overall were analyzed to detect significant differences between groups based on age, gender, ethnicity, education, employment and marital status. Data analysis was performed using the statistical program Statview R version 5.01 by SAS Institute, Inc.

Sample Characteristics
Table 1 summarizes the characteristics of the study sample. Sixty-one participants were contacted. Twenty-three (37%) individuals who met the study criteria returned the completed questionnaire. The sample was composed of 10 (43%) males and 13 (57%) females. The average age was $18.2 \pm 2$ and the distribution of respondents by age group was 14 to 16 years of age ($n=9$), 17 to 19 years of age ($n=8$), and 20 to 21 years of age ($n=6$). Ninety-one percent of the sample were Caucasian ($n=21$), 4% African-American ($n=1$) and 4% Native American ($n=1$). The entire cohort ($N=23$) were in high school or had completed high school, and 21% ($n=5$) were actively involved in college or community classes. All participants were single with 43% employed ($n=10$) and 57% unemployed ($n=13$). Representativeness of the sample is limited. A single site center was used with predominantly Caucasian ethnicity and all participants were educated at a minimum of a high school level. The participants’ age, gender and CHD diagnosis, however, is representative of the intended target population of the study, despite predominant Caucasian ethnicity and high school education.
Table 1
Characteristics of the Study Sample: N=23

<table>
<thead>
<tr>
<th>Variables</th>
<th>M</th>
<th>SD</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>18 ± 2</td>
<td></td>
<td>23</td>
<td></td>
</tr>
<tr>
<td><strong>Age Groups</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14-16</td>
<td>15 ± 1</td>
<td></td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>17-19</td>
<td>18 ± 1</td>
<td></td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>20-21</td>
<td>21 ± 0.5</td>
<td></td>
<td>6</td>
<td></td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>43</td>
<td></td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>57</td>
<td></td>
<td>13</td>
<td></td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>91</td>
<td></td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>African-American</td>
<td>4</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Native-American</td>
<td>4</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current high school</td>
<td>65</td>
<td></td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>Completed high school</td>
<td>13</td>
<td></td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Did not complete high school</td>
<td>0</td>
<td></td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>College/Community classes</td>
<td>22</td>
<td></td>
<td>5</td>
<td></td>
</tr>
<tr>
<td><strong>Employment</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed (full or part-time)</td>
<td>43</td>
<td></td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>57</td>
<td></td>
<td>13</td>
<td></td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>100</td>
<td></td>
<td>23</td>
<td></td>
</tr>
</tbody>
</table>

*Note.* Values are expressed as mean ± standard deviation and percents.
Results

The results of data analysis are reported in the following sequence (a) discussion of overall composite scores, (b) analysis of domain variables by age groups, (c) analysis of domain variables by gender, (d) analysis of domain variables by education and concludes with (e) analysis of specific domain variable results which relate to the management of the participant’s cardiac care.

Analysis of composite scores (all questions) was initiated by tabulation of responses to each of the 68 survey questions that were grouped by self-care domains (Table 2). The score reflects affirmative (yes) responses for the content of all 12 domains. The higher the percentage of affirmative (yes) responses, the greater the perception of self-care ability related to the domain question. The range for the overall composite self-care scores for the 23 study participants was from 46 to 82 percent \((M=66, SD=9)\). Composite score means for age groups 14-16, 17-19 and 20-21 were 62.6%, 68% and 68% respectively. In addition, comparison of the composite self-care scores and demographic variables (gender, ethnicity, education and employment) were not significant. No significant differences were determined in composite self-care scores within age groups \((p=0.44)\).
Table 2

Domain and composite self-care scores

<table>
<thead>
<tr>
<th>Domain Variables</th>
<th>(Questions)</th>
<th>N</th>
<th>Responses(Yes)</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Knowledge of health condition</td>
<td></td>
<td>7</td>
<td>4.3</td>
<td>62%</td>
</tr>
<tr>
<td>(b) What to do to keep healthy</td>
<td></td>
<td>10</td>
<td>6.4</td>
<td>64%</td>
</tr>
<tr>
<td>(c) What to do in an emergency</td>
<td></td>
<td>5</td>
<td>4.1</td>
<td>82%</td>
</tr>
<tr>
<td>(d) How to monitor special health care needs</td>
<td></td>
<td>4</td>
<td>3.3</td>
<td>82%</td>
</tr>
<tr>
<td>(e) How to manage special health care needs</td>
<td></td>
<td>7</td>
<td>4.2</td>
<td>60%</td>
</tr>
<tr>
<td>(f) How to communicate effectively</td>
<td></td>
<td>4</td>
<td>1.9</td>
<td>49%</td>
</tr>
<tr>
<td>(g) How to use community resources</td>
<td></td>
<td>4</td>
<td>1.8</td>
<td>45%</td>
</tr>
<tr>
<td>(h) Understanding of responsible sexual activity</td>
<td></td>
<td>4</td>
<td>3.8</td>
<td>97%</td>
</tr>
<tr>
<td>(i) Obtaining information and reproductive counseling</td>
<td></td>
<td>3</td>
<td>2.3</td>
<td>77%</td>
</tr>
<tr>
<td>(j) Keeping track of health records</td>
<td></td>
<td>4</td>
<td>2.3</td>
<td>58%</td>
</tr>
<tr>
<td>(k) Knowledge of health insurance issue</td>
<td></td>
<td>4</td>
<td>1.4</td>
<td>35%</td>
</tr>
<tr>
<td>(l) Transportation safety</td>
<td></td>
<td>12</td>
<td>8.0</td>
<td>67%</td>
</tr>
</tbody>
</table>

**Composite Self-Care Score**

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>63</td>
<td>43.9</td>
</tr>
<tr>
<td></td>
<td></td>
<td>66%</td>
</tr>
</tbody>
</table>

_Note._ Values represent the average range and percent of yes responses of the total questions within each domain and overall.
Domain variables and age group analysis (Table 3), though not statistically significant, revealed several results of interest. The 20-21 year-old group was found to have a lower mean score for percent yes responses for domain variable (b), what you do to keep healthy, than the other age groups. In addition, trending with the increase in age, the 20-21 year-old group responded affirmatively to the manage special health care domain (e), compared to the 14-16 year-old group. The domain of reproductive counseling (i), identified a variance between age group 14-16 year-old and the 17-19 year-old group.

Table 3
Domain Variables and Age Group Analysis

<table>
<thead>
<tr>
<th>Domain</th>
<th>Age Group</th>
<th>N</th>
<th>M</th>
<th>SD</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Knowledge of health condition</td>
<td>14-16</td>
<td>9</td>
<td>52.3</td>
<td>26.7</td>
<td>.3325</td>
</tr>
<tr>
<td></td>
<td>17-19</td>
<td>8</td>
<td>69.6</td>
<td>25.8</td>
<td></td>
</tr>
<tr>
<td></td>
<td>20-21</td>
<td>6</td>
<td>66.6</td>
<td>19.5</td>
<td></td>
</tr>
<tr>
<td>b) What you do to keep healthy</td>
<td>14-16</td>
<td>9</td>
<td>66.6</td>
<td>11.1</td>
<td>.1761</td>
</tr>
<tr>
<td></td>
<td>17-19</td>
<td>8</td>
<td>68.7</td>
<td>9.9</td>
<td></td>
</tr>
<tr>
<td></td>
<td>20-21</td>
<td>6</td>
<td>55.0</td>
<td>20.7</td>
<td></td>
</tr>
<tr>
<td>c) What to do in an emergency</td>
<td>14-16</td>
<td>9</td>
<td>86.6</td>
<td>14.1</td>
<td>.5236</td>
</tr>
<tr>
<td></td>
<td>17-19</td>
<td>8</td>
<td>75.0</td>
<td>12.9</td>
<td></td>
</tr>
<tr>
<td></td>
<td>20-21</td>
<td>6</td>
<td>83.3</td>
<td>32.0</td>
<td></td>
</tr>
<tr>
<td>d) Monitor special health care needs</td>
<td>14-16</td>
<td>9</td>
<td>75.0</td>
<td>21.65</td>
<td>.2790</td>
</tr>
<tr>
<td></td>
<td>17-19</td>
<td>8</td>
<td>90.6</td>
<td>12.9</td>
<td></td>
</tr>
<tr>
<td></td>
<td>20-21</td>
<td>8</td>
<td>79.16</td>
<td>24.58</td>
<td></td>
</tr>
<tr>
<td>e) Manage your special health needs</td>
<td>14-16</td>
<td>9</td>
<td>49.2</td>
<td>23.8</td>
<td>.1379</td>
</tr>
<tr>
<td></td>
<td>17-19</td>
<td>8</td>
<td>64.2</td>
<td>17.0</td>
<td></td>
</tr>
<tr>
<td></td>
<td>20-21</td>
<td>6</td>
<td>71.4</td>
<td>22.1</td>
<td></td>
</tr>
<tr>
<td>f) Communicate effectively</td>
<td>14-16</td>
<td>9</td>
<td>44.4</td>
<td>24.2</td>
<td>.3807</td>
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<td></td>
<td>17-19</td>
<td>8</td>
<td>46.8</td>
<td>16.0</td>
<td></td>
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<tr>
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<td>20-21</td>
<td>6</td>
<td>58.3</td>
<td>12.9</td>
<td></td>
</tr>
<tr>
<td>Domain</td>
<td>Age Group</td>
<td>N</td>
<td>M</td>
<td>SD</td>
<td>p</td>
</tr>
<tr>
<td>--------------------------------------------</td>
<td>-----------</td>
<td>----</td>
<td>------</td>
<td>-----</td>
<td>------</td>
</tr>
<tr>
<td>g) Use of community resources</td>
<td>14-16</td>
<td>9</td>
<td>38.8</td>
<td>35.6</td>
<td>.6015</td>
</tr>
<tr>
<td></td>
<td>17-19</td>
<td>8</td>
<td>53.1</td>
<td>20.8</td>
<td></td>
</tr>
<tr>
<td></td>
<td>20-21</td>
<td>6</td>
<td>41.6</td>
<td>30.2</td>
<td></td>
</tr>
<tr>
<td>h) Responsible sexual activity</td>
<td>14-16</td>
<td>9</td>
<td>97.2</td>
<td>8.3</td>
<td>.4147</td>
</tr>
<tr>
<td></td>
<td>17-19</td>
<td>8</td>
<td>93.7</td>
<td>11.5</td>
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</tr>
<tr>
<td></td>
<td>20-21</td>
<td>6</td>
<td>100.0</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>i) Reproductive counseling</td>
<td>14-16</td>
<td>9</td>
<td>66.6</td>
<td>23.5</td>
<td>.1961</td>
</tr>
<tr>
<td></td>
<td>17-19</td>
<td>8</td>
<td>91.6</td>
<td>15.4</td>
<td></td>
</tr>
<tr>
<td></td>
<td>20-21</td>
<td>6</td>
<td>72.2</td>
<td>44.3</td>
<td></td>
</tr>
<tr>
<td>j) Keeping track of health records</td>
<td>14-16</td>
<td>9</td>
<td>58.3</td>
<td>17.6</td>
<td>.6758</td>
</tr>
<tr>
<td></td>
<td>17-19</td>
<td>8</td>
<td>53.1</td>
<td>20.8</td>
<td></td>
</tr>
<tr>
<td></td>
<td>20-21</td>
<td>6</td>
<td>62.5</td>
<td>20.9</td>
<td></td>
</tr>
<tr>
<td>k) Health insurance and concerns</td>
<td>14-16</td>
<td>9</td>
<td>33.3</td>
<td>17.6</td>
<td>.4943</td>
</tr>
<tr>
<td></td>
<td>17-19</td>
<td>8</td>
<td>31.2</td>
<td>11.5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>20-21</td>
<td>6</td>
<td>41.6</td>
<td>20.4</td>
<td></td>
</tr>
<tr>
<td>l) Transportation safety</td>
<td>14-16</td>
<td>9</td>
<td>66.6</td>
<td>9.9</td>
<td>.4608</td>
</tr>
<tr>
<td></td>
<td>17-19</td>
<td>8</td>
<td>64.5</td>
<td>5.8</td>
<td></td>
</tr>
<tr>
<td></td>
<td>20-21</td>
<td>6</td>
<td>70.8</td>
<td>11.4</td>
<td></td>
</tr>
</tbody>
</table>

Domain variables and gender analysis (Table 4) were found not to be significant; however, two areas of variance based on gender were noted. First, the responses to the domain variable of reproductive counseling (i), found males did not have concerns regarding reproduction related to their heart disease in contrast to females reporting concerns regarding reproduction and their heart condition. The second area of variance by gender was the domain variable of use of community resources (g), which found a higher self-care level for males than for females meaning males would use community resources more than females.
<table>
<thead>
<tr>
<th>Domain</th>
<th>Gender</th>
<th>N</th>
<th>M</th>
<th>SD</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Knowledge of health condition</td>
<td>Male</td>
<td>10</td>
<td>68.5</td>
<td>24.0</td>
<td>.2868</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>13</td>
<td>57.1</td>
<td>25.4</td>
<td></td>
</tr>
<tr>
<td>b) What you do to keep healthy</td>
<td>Male</td>
<td>10</td>
<td>65.0</td>
<td>12.6</td>
<td>.8541</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>13</td>
<td>63.8</td>
<td>16.0</td>
<td></td>
</tr>
<tr>
<td>c) What to do in an emergency</td>
<td>Male</td>
<td>10</td>
<td>82.0</td>
<td>17.5</td>
<td>.9590</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>13</td>
<td>81.5</td>
<td>23.75</td>
<td></td>
</tr>
<tr>
<td>d) Monitor special health care needs</td>
<td>Male</td>
<td>10</td>
<td>87.5</td>
<td>13.17</td>
<td>.2220</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>13</td>
<td>76.9</td>
<td>23.85</td>
<td></td>
</tr>
<tr>
<td>e) Manage special health care needs</td>
<td>Male</td>
<td>10</td>
<td>68.5</td>
<td>17.5</td>
<td>.1196</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>13</td>
<td>53.8</td>
<td>24.1</td>
<td></td>
</tr>
<tr>
<td>f) Communicate effectively</td>
<td>Male</td>
<td>10</td>
<td>50.0</td>
<td>23.5</td>
<td>.8179</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>13</td>
<td>48.0</td>
<td>16.0</td>
<td></td>
</tr>
<tr>
<td>g) Use of community resources</td>
<td>Male</td>
<td>10</td>
<td>57.5</td>
<td>28.9</td>
<td>.0601</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>13</td>
<td>34.6</td>
<td>26.0</td>
<td></td>
</tr>
<tr>
<td>h) Responsible sexual activity</td>
<td>Male</td>
<td>10</td>
<td>97.5</td>
<td>7.9</td>
<td>.7192</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>13</td>
<td>96.1</td>
<td>9.3</td>
<td></td>
</tr>
<tr>
<td>i) Reproductive counseling</td>
<td>Male</td>
<td>10</td>
<td>90.0</td>
<td>16.1</td>
<td>.0551</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>13</td>
<td>66.6</td>
<td>33.3</td>
<td></td>
</tr>
<tr>
<td>j) Keeping track of health records</td>
<td>Male</td>
<td>10</td>
<td>60.0</td>
<td>21.0</td>
<td>.6104</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>13</td>
<td>55.7</td>
<td>18.1</td>
<td></td>
</tr>
<tr>
<td>k) Health insurance and concerns</td>
<td>Male</td>
<td>10</td>
<td>35.0</td>
<td>17.4</td>
<td>.9571</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>13</td>
<td>34.6</td>
<td>16.2</td>
<td></td>
</tr>
<tr>
<td>l) Transportation</td>
<td>Male</td>
<td>10</td>
<td>69.4</td>
<td>10.2</td>
<td>.3143</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>13</td>
<td>65.3</td>
<td>8.2</td>
<td></td>
</tr>
</tbody>
</table>
Analysis of domain variables and education (Table 5), identified two areas of statistical significance. The effect of education on the domain variable of health records (j), found a difference between the current high school group ($M=53$, $SD=18.5$) and the college/community group ($M=75$, $SD=0$) ($p=0.02$). This statistical finding is somewhat misleading in that the standard deviation for the post-high school group is zero. The self-care scores for the domain variable of manage special health care needs (e), analyzed by education, identified the current high school group ($M=53$, $SD=21$) compared to the college/community group ($M=77$, $SD=21$) ($p=0.03$).

Table 5
Domain Variables and Education Analysis

<table>
<thead>
<tr>
<th>Domain</th>
<th>Education</th>
<th>N</th>
<th>M</th>
<th>SD</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keeps track of health records</td>
<td>Current High School</td>
<td>15</td>
<td>53.3</td>
<td>18.5</td>
<td>0.02</td>
</tr>
<tr>
<td></td>
<td>Community/College</td>
<td>5</td>
<td>75.0</td>
<td>0.00</td>
<td></td>
</tr>
<tr>
<td>Manage special health care needs</td>
<td>Current High School</td>
<td>15</td>
<td>53.3</td>
<td>21.2</td>
<td>0.03</td>
</tr>
<tr>
<td></td>
<td>Community/College</td>
<td>5</td>
<td>77.1</td>
<td>21.6</td>
<td></td>
</tr>
</tbody>
</table>

A specific area of interest in relation to transitional issues for the adolescent with CHD was their view of who should be responsible for the management of their cardiac care as a young adult. Overall, 43% of respondents felt that their care should be
managed by an adult cardiologist after 21 years of age. However, 87% felt that they would be more comfortable remaining under the care of their pediatric cardiologist after 21 years of age.

Summary

The contents of this chapter provided descriptive analysis of demographics and self-reported, self-care assessment responses from a group of 23 adolescents with CHD. The 12 domains investigated (Tables 2-5) were analyzed in relation to the characteristics of the study sample (Table 1) with significant and non-significant results described.
Chapter V will conclude an integrative process of investigation, design, implementation and analysis of the research question: what are the self-care abilities and perceived needs of the adolescent with congenital heart disease (CHD) as they begin transition from pediatric-centered health care to adult-centered health care? The chapter content reflects the relationship of the study findings to relevant literature and in the perspective of the Roy Adaptation Model (RAM) (Andrews & Roy, 1986). Conclusions are stated with limitations, implications and recommendations for further research and a summary completes the chapter.

Findings

The concept of transitional issues related to movement from pediatric-centered care to adult-centered care is multifaceted. One of the key components of transition planning is the development of knowledge and skills in the adolescent in order to be independent in the management of health care needs (Betz, 2004). This study provides a descriptive analysis of the self-care abilities of adolescents with CHD within the RAM as discussed in detail in Chapter II. Results of the questionnaire data analysis identified both adaptive and ineffective descriptions of self care abilities. These responses are supported by the framework of the RAM which implies that the adolescent has a continuous need to adapt
to a changing environment (Andrews & Roy, 1986). Identification of the adolescent with CHD self-care needs allows the nurse to assist him or her with health promotion behaviors in order to adapt to CHD and achieve and maintain an optimal state of health.

The research question was evaluated by an overall self-care composite score which found that there was no difference in self-care ability scores between age groups. This finding correlates to those of Veltman et al. (2001) who found that understanding and knowledge of the adolescent with CHD was unrelated to age or gender. Additionally, Tong and Sparacino (1994) suggest the perspective that adolescent developmental and emotional maturity level may not be accurately predicted by chronological age. Findings in the present study suggest support for this perspective. As might be expected, the domain of ability to manage special health care needs (e) found the 20 to 21 year old group to have higher self care ability scores than the 14 to 16 year old group. In contrast, the older age group (20 to 21 year olds) were found to have a lower score for the domain of keeping healthy (b); skills which one would likely expand with increasing chronological age and maturity level. The 20 to 21 year old group is at an age which allows new freedom, frequently the first time they are living independent of their parents and may be a time they do not maintain the self-care abilities previously monitored by the parental environment.

Analysis of domains by gender was found not significant. However, two individual topics within the domain categories demonstrated results of interest. First, more than half of females expressed concerns regarding sexuality and pregnancy related to their heart condition. Similarly, in a sample of 25 young adults, Doucet (1981) found that 15
respondents had concerns about having children. The greatest concern of females was
the effect of pregnancy on their heart condition. The second area noted was that twice as
many males used community resources and supports than did females. The research by
Meijer et al. (2002) found that seeking social support was an important predictor for
positive social adjustment. This area is an example of the need for adaptation by the
female adolescent in the process of adapting to their health state and achieving the overall
state of health as described in the RAM framework.

Evaluation of the self-care domains by education in the present study found two areas
statistically significant. The two areas included the ability to keep track of health records
and the ability to manage special health care needs. The highest educated group (college/
community) had the highest self care score. Likewise, Ferenz et al. (1980) noted that
older adolescent participant’s had a significantly higher knowledge base than did younger
adolescents. This finding was positively correlated with the level of education of the
older participant. Also, as might be expected, this finding lends support for areas of self-
care needs which the adolescent must achieve to manage his/her health care state as an
adult.

In investigation of the emotional bond and long term relationship with the pediatric
cardiologist, nearly half of the participants believed it was appropriate for an adult
cardiologist to manage their care after twenty-one years of age. Independent of that
response however, 87% of participants affirmed they would be more comfortable
remaining under the care of their pediatric cardiologist after the age of 21 years old.
Clearly and understandably, the emotional bond is well cemented for the adolescent with
their pediatric cardiologist. Thus, the challenge for nursing becomes early facilitation of a process for transition to adult-centered care that maintains security and emotional stability, as well as optimal medical management for the adolescent and young adult with CHD.

Conclusion

A portion of the results of this study did reflect existing findings in the literature. In addition, supporting the RAM framework, areas of examples were given in which the self-care ability of the adolescent with CHD are identified as less than optimal. The statistically significant findings of areas related to keeping track of health records and managing special health care needs can easily be attributed to factors of age, maturity level and education. Subsequently, the opportunity to assist the adolescent to improve skills of management and organization in lifestyles, wellness and medical needs at a younger age may be beneficial at a time when transitional roadmaps should be initiated.

Limitations

Limitations in the present study can be identified. The descriptive design of the study is impacted by the limited sample size as well as not being able to identify causative factors. Inability to validate the adapted questionnaire has implications as well as the use of the yes / no scale versus a Likert-type scale which would allow for a more sensitive form of measurement. Representativeness of the sample is impacted by sample size and the use of single site as well as convenience sampling technique. Additionally, self-
reported responses may be impacted by lack of environmental control or inaccurate perceptions of the respondent. Potential for bias by the researcher related to personal experiences with CHD should be considered.

*Implications for Nursing Education, Nursing Administration and Nursing Research and Practice*

The results of this study give additional support to the existing literature in an attempt to better understand direct concerns and self-care ability of the adolescent with CHD. The findings related to management of health care records and special health care needs, which were statistically significant by age group, should remind nurses of the need to develop and tailor education for this population specific to the various levels of age in the transition process. The focus of education is now the adolescent and not the parent or caregiver. As the individual’s level of understanding increases, consideration should be given to expanding the depth of instruction given related to the specific defect and associated implications for self care as they mature. With respect to implications for nursing administration, increased focus of education and orientation in-services are needed that address the population of adolescents with CHD. This education is necessary due to the limited number of existing congenital transition care centers that leave these adolescents with specialty needs being more frequently cared for in the mainstream of the general population. The ability to offer joint pediatric cardiology and adult cardiology services for the adolescent and young adult with CHD is the ideal setting for care in meeting transitional health care needs. The insight to be gained from further research in this population is important in order to meet the ongoing health care needs and
educational instruction which will improve outcomes as adults. The opportunity to identify defect-specific data related to transitional health care needs would improve nurse’s ability to adapt education plans, policies and procedures specific to the adolescent with CHD and promote adaptation to maintain an optimal state of health.

**Summary**

The present study’s research identified self-care ability scores in a group of adolescents and young adults with CHD. Though only two areas of self-care ability were found statistically significant, several areas demonstrated limitations of the adolescent in ability to achieve some level of transitional health care needs.

The adolescent and young adult with CHD is a unique individual. Nurses have a unique opportunity to participate in the molding and shaping of the adolescent’s health care behaviors that will, in turn, enhance positive outcomes, as the adolescent and young adult transition to self care in the adult health care setting.
REFERENCES


East Norwalk, CT: Appleton-Century-Crofts.


Statview R Version 5.01 by SAS Institute, Inc. (Statistical Analysis)


January 11, 2006

Suarez, Smolen, Garris: Investigation of Self-Reported Transitional Health Care Needs of the Adolescent with Congenital Heart Disease (PIRB/ P-1105101)

The revisions you submitted, as requested 11/17/05 by the Designated Reviewers on behalf of the Pediatric Institutional Review Board of St. Vincent Mercy Medical Center (PIRB), have been reviewed. The following application materials for this study have been approved.

- Revised Application for Initial Less Than Full IRB Review, dated 10-25-05 [rec’d 1/5/06]
- Memo from Ms. Garris, dated 12/22/05, re removal of Drs. Oehrtman’s & Iczek’s names from Patient Letter
- Revised Patient Letter, undated [rec’d 1/5/06]
- Revised Informed Consent/Assent Form, version date 1/10/06
- Protocol, with Patient Questionnaire (Appendix A), undated [rec’d 11/4/05]

The protocol and informed consent form must be reviewed and re-approved by 1/10/07.

The SVMPC Pediatric IRB has affixed approval and expiration dates to the above approved consent document and stipulates that you can only use copies of the approved stamped and dated consent documents in obtaining consent.

It is this IRB’s understanding that there is no financial conflict of interest to report per Research Oversight and Education Policy ROE-015 “Financial Conflict of Interest Research”, and all study personnel have completed the required “Confidential Healthcare Information Training” per Mercy Health Partners Policy MR-117, “Training in Responsible Conduct of Human Subjects Research” per Research Oversight and Education Policy ROE-005, and submitted the “Principal and Co-Investigator Agreement.”

This study was reviewed by the expedited process for Category (5) Research involving materials that have been collected or will be collected solely for non-research purposes and Category (7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies [63 FR 60364-60367, November 9, 1998].

It is the Reviewers’ understanding that the research presents no more than minimal risk to human subjects [45 CFR §46.101(i) / 21 CFR §56.101(i)] and the identification of the subjects and/or their responses will not place them at risk of criminal or civil liability, or be damaging to their financial standing, employability, insurability, reputation, or be stigmatizing.

A MEMBER OF MERCY HEALTH PARTNERS
It is the principal investigator’s responsibility to ensure that all required institutional approvals (e.g., Legal, Pharmacy, departmental) are in place before beginning any research study. Please notify the Department Head or Section Chief that you have received IRB approval for this study.

The continuation of research after expiration of approval is a violation of St. Vincent Mercy Medical Center Policy. The Policy does not allow for a grace period and after the expiration of approval all research activities must cease immediately (including follow-up, review of medical records, and data analysis) and no additional subjects can be enrolled. In the case of medical studies, you may continue to treat subjects only when necessary to eliminate immediate safety and medical concerns to the subject.

You should have a reminder system in place to complete the re-approval materials and submit them to Research Oversight and Education at least one PIRB meeting before the expiration date. In addition, when the study is completed, a Final Report must be submitted to PIRB.

Any unanticipated problems involving risks to human subjects or new information that may adversely affect the risk/benefit assessment must be immediately reported to the PIRB. In addition, immediately report to the PIRB any unanticipated incidents that occur because of this study (such as adverse events, protocol deviations, or FDA citations).

You must report changes in the conduct of this study to the IRB for review and approval before the changes can be implemented. The only exception is the rare circumstance in which a change is necessary to eliminate apparent immediate hazards to the subjects. In this case, the IRB should be promptly informed of the change following its implementation. In addition, the IRB must approve changes of study personnel.

You are responsible for compliance with St. Vincent Mercy Medical Center’s policies and procedures, and federal regulations governing research. Also, you are responsible for compliance with federal law regarding the billing of research services and specifically, to ensure those services reimbursable through research funds are not billed to Medicare or other third-party payers. You are also responsible to ensure that the research budget covers any direct and indirect costs related to the research project and that any compensation received for research is reasonable and reflects fair market value for services rendered, and does not contemplate referrals for purchase of services or supplies.

All materials for the PIRB must be submitted to the Research Oversight and Education Department. If you have any questions, contact the Research Oversight and Education Department at 419-251-2962.

Sincerely,

Ellen Bernal, Ph.D., Chair
Pediatric Institutional Review Board
APPENDIX B

The key to promoting healthy transitions for adolescents with special health care needs and disabilities is to begin with a baseline of information as to what the adolescent does and doesn’t know about managing the chronic illness or disability on their own. That is, what does the adolescent need to know? What skills does the adolescent need to acquire to become self-sufficient in managing the chronic illness or disability?

The gaps identified in knowledge and skills will provide the starting point for developing a strategy to meet the goal of self-sufficiency for health care needs. This strategy or plan of action will be most successful if the adolescent is “in charge” of devising it. Family members, members of the specialized health care team and Individualized Education Plan (IEP) team are essential to the planning process.

The steps to achieving health care sufficiency will require support in only in the home, but in the other environments where the adolescent attends school, works and receives health care and other support services.

The CA HRTW Transition Health Care Assessment Guide is presented below. You are welcome to download this copy, however, this tool is copyrighted by CA HRTW. You are free to use this tool for personal use, professional purposes but please acknowledge that it was developed by this project, funded by the Maternal Child Health Bureau, DHHS.

Download the Health Care Assessment File as a Rich Text Format (RTF) file which you can then open in any program that can read RTF.

(Professional Version)

http://www.cahtwr.org/healthassess.htm
**Appendix C**

**Congenital Heart Disease**

**Transition Health Care Assessment**

**Directions:** Read each question and circle the response that best applies to your current daily lifestyle & abilities.  

**(N/A means not applicable for your situation)**

**Have knowledge of your health condition and how to take care of yourself:**

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you understand what caused your heart condition?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you understand the changes/symptoms caused by your heart condition?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you manage your daily treatment needs? (i.e. medications)</td>
<td></td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td>Do you have any problems obtaining items needed for your heart care?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you understand the action of the medications you take?</td>
<td></td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td>Do you have an understanding of the laboratory and diagnostic tests which your doctor orders?</td>
<td>Yes</td>
<td>No</td>
<td>N/A</td>
</tr>
</tbody>
</table>

**What you do to keep healthy:**

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you have a Primary Care Physician (Family Doctor) that you see regularly?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are you up-to-date with immunization and health care screenings?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you use any of the following: alcohol, cigarettes, drugs, or engage in unprotected sex?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Do you use self protection devices such as wearing a bike helmet?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you wear a Medi-Alert bracelet/necklace?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you exercise regularly?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you see a dentist on a regular basis?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
8. Do you brush and floss your teeth? Yes No

9. If your heart condition requires, do you take an antibiotic before dental care? Yes No N/A

10. Do you understand the reason for using the antibiotic before dental care? Yes No N/A

**What to do in an emergency:**

1. Do you have access to a phone to use in case of an emergency? Yes No
2. Do you have the phone numbers of family and friends to call in emergencies? Yes No
3. Do you have the phone numbers of health and non-health emergency services, poison control center? Yes No
4. Do you know where the closest ER is located? Yes No
5. Do you have an emergency evacuation plan in place in your home for a fire? Yes No

**Know how to monitor special health care needs:**

1. Do you know when to see the doctor? Yes No
2. Can you recognize when you're getting ill? Yes No
3. Do you know what action to take when you become ill? Yes No
4. Do you know what situations (increased elevations, large crowds, airport scanners) that you need to avoid for your cardiac health? Yes No N/A

**Know how to manage your special health care needs:**

1. Are you responsible for making appointments with your cardiologist? Yes No
2. Are you responsible for refilling medications and supplies? Yes No N/A
3. Do you know when to take your medications? Yes No N/A
4. Do you know what type of symptoms or changes in your health should be reported to your cardiologist? Yes No
5. Do you have plans for where and how you will follow the needs of your heart care as an adult? Yes No
6. Do you feel that by age 21 your heart care should be managed by an ADULT cardiologist?  
   Yes    No
7. Would you be more comfortable remaining under the care of your PEDIATRIC cardiologist after the age of 21yr. old?  
   Yes    No

**Know how to communicate effectively:**

1. Do you try to find answers for health related concerns?  
   Yes    No
2. Are you able to ask questions to your family doctor & cardiologist?  
   Yes    No
3. Are you aware of teen / young adult support groups / camps for your heart condition?  
   Yes    No
4. Have you participated in any support group or educational gatherings for your heart condition?  
   Yes    No

**Knows how to use community resources:**

1. Do you know how to get medical services in your area?  
   Yes    No
2. Have you used services in your community? (i.e exercise, teen organizations)  
   Yes    No
3. Are you able to use community transportation when you need it?  
   Yes    No    N/A
4. Do you have an individualized health plan developed by the school nurse that is used at your school?  
   Yes    No    N/A

**Demonstrates responsible sexual activity by:**

1. Are you able to avoid dangerous situations (exploitation and victimization)?  
   Yes    No
2. Are you able to provide a reliable sexual history?  
   Yes    No
3. Do you know what a sexual transmitted disease is and how it can affect you?  
   Yes    No
4. Do you have enough information about contraception and ways to prevent a sexually transmitted disease?  
   Yes    No

**Obtains information and reproductive counseling when needed:**

1. Do you know when to seek reproductive counseling?  
   Yes    No
2. Do you understand the problems associated with teenage/unplanned pregnancy?  
   Yes    No
3. Do you have any concerns about sexuality or pregnancy related to your heart condition?  
   Yes    No
**Keeps track of health records:**

1. Do you have a copy of your health records?  
   Yes   No
2. Does your doctor/therapist have a copy of your health records?  
   Yes   No
3. Do you have an insurance card or copy of it?  
   Yes   No
4. Do you have a method for keeping track of your health care appointments?  
   Yes   No

**Has knowledge of health insurance concerns and issues:**

1. Do you know what the eligibility requirements are for your health insurance?  
   Yes   No
2. Are you or your family able to cover health care expenses not covered by your health insurance?  
   Yes   No
3. Have you applied for income assistance (SSI) and other public services?  
   Yes   No   N/A
4. Are you currently covered by health insurance?  
   Yes   No

**Uses transportation safely:**

1. Do you have a driver’s license?  
   Yes   No
2. Do you use buses, trains or other types of public transportation?  
   Yes   No
3. Do you use bus or other travel schedules for getting rides?  
   Yes   No
4. Do you have the money you need to get bus passes/use your car?  
   Yes   No
5. Do you have any problems in getting to your travel destinations?  
   Yes   No
6. Do you knowing etiquette according to mode of transportation: waiting one's turn; getting up for elderly?  
   Yes   No
7. Do you let others know when you take trips or leave your home?  
   Yes   No
8. Do you carry phone numbers of family / friends when you travel?  
   Yes   No
9. Do you feel safe taking the bus, van, driving?  
   Yes   No
10. Do you usually arrive and leave on time?  
    Yes   No
11. Do you avoid sitting next to passengers with colds, cough?  
    Yes   No
12. Do you know how you should interact with strangers when traveling/using public transportation? Yes  No


Age: _____
Gender:  Male ___   Female ___
Ethnicity:  Caucasian (white) ___   Hispanic ___   African-American ___   Asian/Pacific Islander ___   Other _____________
Level of Education:  Currently in high school ______
Completed high school ______
Did not complete high school ______
Community, college/vocational training ______

Employment History:  Employed: ___
Unemployed: ___
Marital Status:  Single ____  Married ____  Divorced ____

#____ DOB_______
Appendix D

Introduction Letter
SVMMC Letterhead

Dear Patient,

This letter is to inform you that in one week you will receive a questionnaire packet in the mail offering you the opportunity to participate in a research study being conducted with me through the College of Nursing at the Medical University of Ohio. The study is entitled, “Investigation of self-reported transitional health care needs of the adolescent with congenital heart disease”. Dianne Smolen, Ph.D., RN, BC, CNS and Theresa Garris, BSN are nurse researchers at the College of Nursing at Medical University of Ohio. They will be conducting the study with my permission and the approval of the Institutional Review Boards of St. Vincent Mercy Medical Center and the Medical University of Ohio. Participation in the study includes the completion of a questionnaire only.

The purpose of this study is to explore the knowledge, health care concerns, and readiness of adolescents with congenital heart disease in the process of learning responsibility for management of their health care needs. Your participation is completely voluntary. If you decide not to participate in the study, your decision will not affect your future relations with myself or my office, SVMMC, or MUOT.

Sincerely,

____________________________
William A. Suarez, M.D., F.A.C.C.
Appendix  E

Questionnaire Cover Letter

Dear Patient,

Recently you were mailed a letter from Dr. Suarez stating that a questionnaire packet was going to be sent to you, giving you the opportunity to participate in a research study through St. Vincent Mercy Medical Center and Medical University of Ohio. The purpose of the study is to explore the knowledge, health care concerns and questions of adolescents and young adults with congenital heart disease as they become more independent in the management of their health care. You were selected as a possible participant in this study because you are an adolescent or young adult with history of congenital heart disease. Approximately 30-50 people are being asked to participate in the study.

If you decide to participate, you will be asked to fill out the questionnaire included in this packet. The questionnaire should take you approximately 15 minutes to complete. **The time you spend filling out the questionnaire is greatly and sincerely appreciated.** You can choose not to answer some questions, but please try to answer as many as possible. Two weeks from now, the researchers will call & send a postcard as a reminder to fill out the questionnaire and return it as soon as possible. If you have already returned the questionnaire, or do not wish to participate in the research study, please disregard the postcard.

The questionnaire is confidential; please do not write your name on the questionnaire. We have provided a stamped, self-addressed envelope for you to return the questionnaire. There are no foreseeable risks to you or your family. Results of this study will be reported for all subjects as a group. Your individual information will not be reported. All data, questionnaires and files related to this study will be locked in a file cabinet during the study and will be destroyed after the data are analyzed.

If you have questions regarding the study or the questionnaire, please contact Dr. Dianne Smolen at 419-383-5893 or Theresa Garris, BSN at 419-885-4313.

Thank you for your time!
APPENDIX F

SVMMC Letterhead
Reminder Postcard

This is a reminder notice requesting your consideration of completion and return of the research study questionnaire and consent which was mailed to you recently.

We thank you in advance for your time and participation in the study. If you have any questions regarding the study, please call Dianne Smolen, Ph.D., RN at 419-383-5893 or Theresa Garris, BSN, RN at 419-885-4313.

Thank You.
# APPENDIX G

Coding Data Key

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ABSTRACT

Ongoing medical advances contribute to the increasing number of patient’s today living with congenital heart disease (CHD). Adolescents and young adults with CHD must have knowledge and ability to take charge of their health care decisions as they begin transition from pediatric-centered health care to adult-centered health care. The purpose of this study was to investigate the self care ability and perceived needs of adolescents with CHD. Multiple self care variables were examined and the Roy adaptation model was used to direct the study. Analysis of domains by education found statistically significant findings in the areas of maintaining health records and managing special health care needs. Also, though not statistically significant, results implied concerns with some aspects of self care ability by the adolescent. Nursing implications are that the nurse can better assist the adolescent with CHD when they have more specific knowledge of their self care abilities.