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PILOT OF AN EDUCATIONAL MODULE

DNP Final Project Report

Pilot of an Educational Module for an Adolescent Congenital

Heart Transition Program in the Pediatric Setting

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College of Nursing

Fall, 2018

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Dedication

This work is dedicated to my baby girl Charlie Jane. Out of everything in life, you are my greatest accomplishment, and being your mom makes me most proud. May you always chase your dreams and never be afraid of hard work. This is also for my husband who was still willing to marry me during the middle of this program. I'm so glad that we will now get to spend time together without a computer or book in my face. Finally, this is for my parents who have been my greatest supporters and gave me 50,000 reasons not to quit.

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Abstract

PURPOSE: The purpose of this project was to pilot an educational module on a new congenital heart transition program to be instituted at a large Midwest medical system. The transition program is meant to assist pediatric cardiology patients in transferring from pediatric to adult care. An educational module was developed for inpatient health disciplines who will be involved in the transition program. Before offering the program throughout the medical system, a pilot was conducted to determine if the education was at the appropriate level. The educational module was modeled after the *Got Transition Six Core Elements* designed by the National Health Care Transition Center.

METHODS: A prospective pretest posttest design and a Readiness Ruler was utilized for this pilot along with an interview conducted after the posttest. A group of five healthcare providers (four nurses and one non nurse) participated in this pilot.

RESULTS: The participants scored a mean of 60% on the pretest and 90% on the posttest. The more experienced staff scored lower on the posttest. All reported increased readiness for program initiation after receiving education. Qualitative data revealed a two-sided response from participants in regards to the transition program. All subjects praised the independence provided to patients with the program. They expressed concerns regarding the amount of time needed to provide education to patients as well as hesitancy that may present from patients and caregivers.

CONCLUSION: The results of this pilot verified the learning module provided effective education to staff and could be delivered throughout the entire hospital. Potential barriers should be considered prior to initiation of the program. A more complete readiness tool should be

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incorporated in the program. Once the program is initiated there will need to be follow up across all levels of participating staff.

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Pilot of an Educational Module for an Adolescent Congenital Heart Transition Program in the Pediatric Setting

Introduction

Congenital heart disease is defined as having a defect in the structure or function of the heart or its blood vessels that is present before birth (American Heart Association, 2017). Due to medical advancements and improved surgical care, the population of adult patients with congenital heart disease is on the rise (Anton, 2016). These patients require lifelong medical management that has led to a need for healthcare transition from pediatric to adult cardiac care. This transition involves the process of shifting care from pediatric cardiology to adult cardiology with the goal of improving the ability of adolescents to manage their own healthcare. The purpose of this project was to pilot an educational module on a new congenital heart transition program. The pilot was used to determine whether the education covering the new program was appropriate and adequate before providing it to all hospital staff. The outcome will result in the implementation of a healthcare transition program for pediatric patients within a large Midwest medical system.

Background

According to the Centers for Disease Control and Prevention ([CDC], 2016), congenital heart disease affects one percent of births with nearly 2.2 million individuals currently living with the disorder. More than 85% of children with congenital heart disease will live to be adults (Anton, 2016). Mocerri (2015) found that approximately ten percent of adolescent patients with congenital heart disease are lost during the period of time when transition should ensue. This typically occurs at the age of 18 when the patient stops seeing his or her pediatric cardiologist

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and never starts seeing an adult cardiologist. Further, another 60% of adolescent patients experience a lapse in care after leaving pediatric cardiology (Moceri, 2015).

The American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP) support transition programs for patients with congenital heart disease from pediatric to adult cardiology. The goal of a transition program is to assist youth with assuming responsibility for their own health as they begin to reach adulthood. This transition allows the late adolescents to feel more comfortable and gain confidence with shifting to adult care. The move is made easier through a guided educational and supportive process that is provided by a transition program. There are three steps that healthcare disciplines should address for a transition program: 1) transition planning, 2) transfer of care, and 3) integration into adult care (AAP, 2011).

The first step, transition planning, involves the patient and caregivers assessing the adolescent's healthcare needs, goals, and self-care skills. Patients perform self-assessments using a readiness checklist to determine strengths and weaknesses regarding his or her own healthcare. Healthcare providers can then review this checklist to determine areas of need or education for the patient. This step prepares the patient and caregivers for the transfer to an adult model of care at age eighteen. The transfer is not just about switching to a provider specialized in adult congenital heart defects. It is about helping adolescents develop skills to take the lead in caring for their own healthcare separate from their caregivers. Once independence is gained through a complete readiness checklist, transfer of care can occur by ensuring a smooth handoff with the new provider.

Despite the support from the AAP, AAFP, and ACP, few pediatric to adult cardiology transition programs are in place. There are currently only 21 centers in the United States with

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accredited transition programs, five of which are located in the Midwest (Adult Congenital Heart Association, 2018). As a result of structured transition programs, quality of life for transitioned patients, in terms of perceived health status, overall well-being, and functional status, has been improved (Gabriel, McManus, Rogers, & White, 2017). Positive outcomes have also been noted in self-care skills and knowledge of disease (Gabriel, McManus, Rogers, & White, 2017).

Transition of care for the adolescent with congenital heart disease to adult healthcare is needed to manage the potential complications and associated health conditions attributed to congenital heart disease in adulthood. These health conditions include: arrhythmias, endocarditis, cardiomyopathy, valve dysfunction, and pulmonary hypertension (AAP, 2017). Adult congenital heart patients have a three to four times' higher rate of hospitalizations, intensive care unit stays, and emergency room visits when matched with the overall population (AAP, 2017). Without addressing the need for a healthcare transition within the pediatric cardiology setting, lapses in care and associated complications will continue to go untreated.

A large medical system in the Midwest, which serves over 2,000 patients with congenital heart defects, has identified the need for a transition program. Currently, despite this large population, a transition program for adolescent congenital heart patients does not exist within the system. Patients older than 18 years of age continue to receive care from pediatric providers at the pediatric hospital; however, transitioning to the adult hospital with an age-appropriate model of care at the age of 18 would be optimal. From the standpoint of hospital staffing, non-pediatric patients should be cared for by staff focused on adult issues. The first step in making this physical transition for patients is assisting them in mentally transitioning from a pediatric mindset to an adult focus. This involves understanding his or her own healthcare needs while

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also performing self-care. Therefore, healthcare disciplines must be well educated on the transition program in order to assist patients with their medical transition.

Content of Transitional Program

The National Health Care Transition Center supported by the National Alliance to Advance Adolescent Health created the Got Transition program. This is a resource for healthcare organizations to develop a standard process for the pediatric patient with congenital heart disease to transition to an adult program within their practice setting. The Six Core Elements include: 1) developing a transition policy, 2) tracking and monitoring transition through use of a flow sheet, 3) assessing patient transition readiness, 4) creating individual plans of care for transition, 5) transferring care, and 6) confirming completed transfer. The *Got Transition Six Core Elements of Health Care Transition* template will be used to develop a transition program.

The transition program serves the purpose of preparing adolescents with congenital heart disease and their caregivers to leave the pediatric medical home. Through the transition process they will gain independence before transferring to a provider specialized in adult congenital heart disease. The program developed at this Midwest hospital will be in three phases identified by three adolescent age brackets: 12-15 years of age, 15-16 years of age, and 16-18 years of age. Each phase will have distinct goals based on the developmental tasks within that age group.

In the 12-15 year olds the transition goal will be for the adolescent to gain a basic knowledge of their cardiac diagnosis and treatment plan. For those aged 15-16 years the focus is on increasing their participation in self-care activities such as self-administration of medications. They will be further educated on their cardiac diagnosis and treatment plan and begin discussions of future educational and life goals. Finally, the transition goal for age 16-18 years is for the

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adolescent to independently manage their own cardiac care and actively participate in decision-making regarding transition. After completion of these phases, the adolescent should be ready to transition to adult cardiology at the age of 18. During these phases, the role of the parent also progresses from a care manager to a care consultant when the patient has reached independence.

The pediatric cardiologists will initiate the transition program once the child reaches 12 years of age. In order to meet the goals set out for each transition multiple healthcare disciplines must be involved. For example, a social worker will provide financial and insurance aspects of transitioning care while a nurse will educate the patient on his or her diagnosis and medications. Staff should assess patient readiness through the use of a transition checklist that patients will individually complete with each encounter. This checklist includes topics of health knowledge, lifestyle choices, independent healthcare actions, educational planning, financial needs, and social relationships. Using the checklist, patients assess their current state with each category. For example, one item included is “I can accurately describe what each medicine I take is for. The patient would then check: I do this, I want to do this, or I need to learn this. Staff will then use this information to identify the areas in which the patient needs education or reinforcement. The transition checklist will follow patients to each new encounter because it will be imbedded into the medical record system.

Despite the transition occurring across the entire level of care, the pediatric cardiac center has chosen to initially prepare the inpatient medical staff through the educational module. This was decided because more medical disciplines, including nurses, social workers, respiratory therapists, physical therapists, and occupational therapists, are available to provide education to patients within the inpatient setting. Secondly, hospitalized pediatric patients spend their entire stay on the same unit with the same medical team. Therefore, the institution believes this will

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facilitate opportunities for intensive educational time between medical staff and individual patients to discuss healthcare transition.

Anticipated Positive Outcomes

Many positive outcomes exist from the use of a transition program for adolescent congenital heart patients. Having a transition process in place allows for standardization in care and better access to the specific needs required for their medical condition (National Alliance to Advance Adolescent Health, 2017). New problems can arise as these patients age, making it important to be receiving care from providers who know how to manage adult congenital heart patients. With the education and preparation provided by the transition program, patients gain confidence and independence in regards to his or her health and self-management skills (National Alliance to Advance Adolescent Health, 2017). When caring for themselves they gain the feeling of more control over their lives (National Alliance to Advance Adolescent Health, 2017). Parents are also eased into their new role of care consultant since the program is split into three phases (AAP, 2011).

Challenges

Several challenges are recognized with programs that serve the purpose of transitioning pediatric cardiac patients to adult services. The transition process is complex, requiring not only training for staff but also education for patients and families. The complexity of this process can be potentially emotional for patients and caregivers. The pediatrician has been a constant for these individuals; therefore, they may consider transfer from the known to the unknown to be quite scary and stressful (AAP, 2011).

The engagement of patients and caregivers is necessary for transition to occur; therefore, these individuals may present as a barrier if they choose to remain closed to the process of

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transitioning. The adolescent's developmental and functional abilities may also affect the success of the transition process. Patients with known delays should be given more time to transition if needed. Other barriers may arise from the medical side, such as challenges in the communication of medical records between facilities and an absence of providers capable of caring for patients with these special healthcare needs. Finally, systemic barriers may impede implementation including lack of training for staff and lack of preparation for the patient and caregivers to assimilate into the new adult model of care (AAP, 2011)

Theoretical Framework

The Theory of Interpersonal Relations developed by Hildegard Peplau considers nursing to be a therapeutic and interpersonal process. Peplau emphasizes that the therapeutic nurse-client relationship, made of two components: professional expertise and client need, is the foundation of nursing practice (Gonzalo, 2011). The major feature of this theory embraces the purpose of nursing as helping others identify their felt difficulties through the development of a therapeutic relationship. Peplau identifies different roles assumed by nursing, such as a resource person, teacher, leader, advocate, and counselor, within the therapeutic relationships of her theory (Gonzalo, 2011).

This study has been guided by Peplau's Theory of Interpersonal Relations, and the framework is reflected throughout the educational process. The development of a trusting relationship between healthcare disciplines and pediatric cardiology patients is the foundation for successful education. Through the development of this relationship staff may discover patients' needs and guide them on their journey to independence.

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Purpose

The purpose of this project was to pilot an educational module on a new congenital heart transition program that will be initiated within the children's hospital at a large medical system in the Midwest. The children's hospital has developed a policy and a procedure for the implementation of this transition program. Therefore, the necessary staff must be educated on the new process. This evaluation will be completed with the use of pre and posttests administered before and after education as well as interviews with involved staff members regarding the education provided to them. The pilot will not look at outcomes of the transition program itself but rather the adequacy of the education provided to staff.

Objectives are to:

1. Evaluate the pilot educational module prior to system-wide implementation of the transition program
2. Gain staff insight on the transition program through the conduction of focused interviews

Methods

A prospective pretest posttest design will be utilized for this pilot study along with a qualitative interview conducted after the posttest. The combination of quantitative and qualitative outcome measures is intended to help the primary investigator gain more insight into the education and transition program. This pilot study will serve as an indicator of the appropriateness of the education provided to staff about the new program. A 20-minute, online learning module was provided for a subset of designated cardiac staff, primarily nurses. They were asked to take a pretest before reviewing the educational module and a posttest upon completion of the module. Participation in the pilot was completely voluntary as was the individual interview conducted following the education.

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Setting

The Midwest medical system provides care at more than 250 locations, serving both pediatric and adult patients within a large urban area. The children's hospital operating under this medical system is recognized as a leading pediatric hospital in the Midwest. As part of this children's hospital, the Heart Institute performs around 450 heart surgeries and 12,000 noninvasive diagnostic studies per year. The designated cardiac unit of this children's hospital will serve as the focus of this study.

Sample

The sample consisted of five staff members involved with the care of pediatric cardiac patients, four of which were nurses. Nurses were the focus for the pilot as they are the largest healthcare group involved with the program. The population of interest for this study involved only those inpatient staff that will have interaction with pediatric patients with congenital heart disease requiring transition. Inclusion criteria for pilot participants were any health provider (nurses, social workers, occupational therapists, physical therapists, and respiratory therapists) who would be involved with the transition program and was willing to participate. Exclusion criteria for study participants included any inpatient pediatric staff who were not assigned to cardiac patients involved with the transition program.

Data Collection

Approval was obtained from both the University of Kentucky Institutional Review Board (IRB) and the Norton Healthcare Office of Research and Administration (NHORA) prior to collection of data. Data were obtained from the targeted subjects through the use of a pretest and posttest. These tests were completed prior to and after the learning module. The tests consisted of ten questions with a mixture of true/false, multiple choice, and short answer formats with a

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score that ranged from zero percent to 100 percent (see appendix). These test questions were designed from the learning module. Questions were about the logistics of the transition program, so no congenital heart disease content was included.

Included on both tests was a self-reporting of readiness for transition implementation through the use of the Readiness Ruler. The purpose of this tool is to serve as a quick and easy method for determining the subjects' readiness to change a specific behavior. Participants identify their level of readiness on a scale of zero to ten. Reporting of a lower number indicates less readiness while a higher reported number indicates more readiness (Center for Substance Abuse Treatment, 1999). A score of five on the ruler represents that the person is willing to consider change (American Society on Aging and American Society of Consultant Pharmacists Foundation, 2006). This ruler has been found to be valid in measuring motivation and predicting behavior changes in multiple studies (Heather, Smailes, & Cassidy, 2008; Hesse, 2006; LaBrie, Quinlan, Schiffman, & Earleywine, 2005).

Demographic data was also collected from study participants, including years of experience in their current role, the subject's job title as either a nurse or non-nurse, and their comfort level with caring for pediatric cardiology patients. The participants were initially asked to rank their level of comfort on a scale of zero to five, where zero is very uncomfortable and five is extremely comfortable.

Qualitative data were collected through individual interviews conducted immediately following completion of the posttest. The purpose of the interview was to obtain an understanding of the views held on the proposed transition program. The interviews included questioning about the education provided through the learning module as well as participants' perceptions of the strengths, barriers, and needed improvements of the program.

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Data Analysis

Descriptive statistics, including means, frequencies, and percentages, were used to describe the study participants' demographic characteristics. Means were also calculated to compare pre and posttest scores as well as pre and post Readiness Ruler scores. Themes were drawn from the qualitative data obtained through responses from the individual interviews. Analysis was conducted using Microsoft Excel.

Results

Sample Characteristics

A total of five staff members participated in this pilot study. Four (80%) were nurses while one participant was in a non-nursing role. The number of years of experience reported from all individuals ranged from four to 19 years with a mean of eight years. Participants were asked to describe their comfort level in working with pediatric cardiology patients. A zero to five point Likert scale was used. The majority of participants (n = 4, 80%) gave themselves a score of four, indicating they were mostly comfortable with caring for these patients.

Pretest/Posttest Outcomes

The participants' pretest scores ranged from 50 to 70 percent with a mean score of 60 percent. The staff with more experience performed better on the pretest than those with less experience. All of the study participants had improved posttest scores with a mean score of 90 percent. In contrast to the pretest scores, data showed that staff members with the least experience performed better on the posttest than those with the most experience. Pretest and Posttest scores are presented in Table 1, and a comparison of years of experience to test scores is presented in Table 2.

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Staff Readiness

The Readiness Ruler was utilized to estimate study participants' feelings of readiness to implement the new transition program into everyday practice. Participants were asked to report their level of readiness twice, first on the pretest and once again on the posttest after receiving the education. All study participants reported increased readiness in regards to initiation of the new program after receiving education. The Readiness Ruler scores are presented in Table 1.

Interview Responses

All five study subjects took part in an interview with the primary investigator immediately following the completion of the educational module and posttest. When asked about the test questions, all of the subjects believed that the pretest and posttest were necessary for learning and retention of information. The subjects also felt that the tests were an appropriate degree of difficulty by reporting the questions as not too simple or too complicated (personal communication, September 21, 2018).

The response from study participants was very two-sided in regards to the transition program. All of the subjects had positive comments about the transition program relating to the independence that it provides to patients. Some were also relieved to know that adult cardiac patients would no longer be admitted to their pediatric hospital, which often causes feelings of stress related to lack of experience in adult care. However, all participants were concerned about the amount of time required for educating patients about the program. Participants also expressed worry that patients and caregivers may not be willing or motivated to transition which serves as a huge barrier (personal communication, September 21, 2018).

Additional education. The subjects were asked for suggestions on additional education that would be helpful in order for them to provide better teaching to patients. The majority

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thought that a handout for patients with key information would serve as a reminder about the transition program elements. Several thought it would be helpful to provide the handout to pediatric cardiac patients upon admission to the hospital. In addition, a standard form with important facts should be given to staff members as a resource for what should be taught during patient encounters. One participant stated:

‘In my experience, patients learn best when you give them a visual handout along with your teaching. If we could give them a handout about the transition program it will help us (the staff) remember which topics to cover with the patients as well’ (personal communication, September 21, 2018).

Program highlights. Subjects were asked about their thoughts on the best part of the transition program, and all of them responded with an answer of ‘independence.’ Parents often take the lead when it comes to the child’s healthcare, so this program helps to move the parent-child dyad to a less dependent relationship. One subject added:

‘Patients get to learn what is wrong with them and how to care for themselves’ (personal communication, September 21, 2018).

Another participant stated:

‘The program would give patients a better feeling about themselves because of the independence and knowledge it provides’ (personal communication, September 21, 2018).

Two nurses also responded with feelings of relief that adult patients would no longer be admitted to the children’s hospital. One reflected:

‘This program not only helps the patient but it also helps us nurses. Patients should be receiving the most appropriate care for their age. Sometimes we get these adult heart

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patients, but we have limited experience with adults. We get a little nervous taking care of them since we are used to caring for children. It's nice that this program will get them going to the adult hospital where the nurses are better experienced in caring for them' (personal communication, September 21, 2018).

Suggestions for improvement. When asked for suggestions to improve the educational process for staff, almost all the subjects asked for reinforcement of the education that was provided to them about the transition program. Some recommended an educational flyer to be placed in the break rooms while others recommended an email with key information be sent out before initiation of the program. One participant mentioned the use of a checklist for staff to utilize when educating patients. This would serve as a reminder to the staff on the different subjects that must be discussed with patients and caregivers during the transition process (personal communication, September 21, 2018).

Study participants had few suggestions for improvements of the actual transition program. One participant recommended communication between the pediatric and adult hospitals. This participant said:

'It would be nice to have a resource person from the adult hospital for transitioning patients to go to with questions or concerns about their care once they reach the adult side of the program' (personal communication, September 21, 2018).

Another participant's recommendation was to provide a magnet for patients with information about which hospital to go to for different procedures based on the age of the patient. This person felt that this would be the most confusing information for patients to remember regarding the transition program, so providing them with a reminder would cause less confusion (personal communication, September 21, 2018).

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Barriers. Participants spoke of the barriers that they believed would present with the transition program. All of the subjects expressed concerns about the time required to provide so much education to the transitioning patients. One nurse stated:

‘We already have to do so much during our shift. It will be hard to find time for even more education and charting’ (personal communication, September 21, 2018).

Another commented:

‘We are too busy to go over that much detail with the patients’ (personal communication, September 21, 2018).

Over half of the participants also mentioned the barrier of patient and family willingness to participate in the transition process. While discussing this barrier, one said:

‘If the patients and their families don’t want to transition, they won’t be open to our education’ (personal communication, September 21, 2018).

Participants also expressed concerns about patients with special circumstances such as developmental or physical delays presenting as a barrier. They felt that these patients would be difficult to educate or may require assistance by caregivers due to their delays.

Discussion

This pilot was intended to evaluate the feasibility of an educational approach that will be utilized for the implementation of a new transition program for pediatric cardiac patients to adult care. With the growing population of adult congenital heart patients, it is crucial to transition adolescent patients from a pediatric care model to an adult care model. By implementing a transition program within the pediatric inpatient setting, healthcare providers can assist families in allowing the patient to assume complete responsibility for their own health and hopefully prevent a loss in follow up during adulthood.

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Key Findings

This pilot found that there was a significant difference in posttest scores after participants received education about the transition program. This study also identified that the education had a positive impact on participants' readiness score. The increase in both test scores and readiness scores suggest that the education provided was adequate for staff understanding of the information. During the interview, participants stated that the pre and posttests were necessary and of sufficient difficulty adding further value that education was adequate.

A rather surprising finding was that the three experienced staff members did not do as well on the post test when compared to the two staff with less experience. Research suggests that experienced nurses tend to have greater confidence because of the skills they have inherited from routine practice (Majid et al., 2011; Salam & Alghamdi, 2016). Should these participants believe their experience imitates competence, their confidence could have impeded their learning of the new material. This possibly resulted in the lower test scores. This trend will be further evaluated once implementation of the program occurs hospital-wide, and adjustments to the educational module will be made if needed.

Studies have shown that initial readiness of an individual is an important factor that impacts the successfulness of change; therefore, understanding the environment of readiness within an organization can improve the implementation of a planned change (Hesse, 2006; Holt, Armenakis, Field, & Stanley, 2007; Holt, Helfrich, & Hall, 2010). Readiness is defined as the extent to which an individual is prepared and motivated to implement a change. It is increased when staff has the skills to effectively complete the tasks that are coupled with the change (Holt et al., 2010). For this study, staff reported their readiness to implement the transition program by using the Readiness Ruler.

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The Readiness Ruler is a tool utilized to evaluate an individual's willingness to change on a continuum of zero to ten, with zero being 'not prepared to change' and ten being 'already changing.' Low scores usually predict an absence of change while higher scores predict a likely change. However, the studies for which the Readiness Ruler was utilized measured the likelihood of patients changing their behavior in regards to smoking, drugs, or alcohol (Heather et al., 2008; Hesse, 2006; LaBrie et al., 2005). To better assess the readiness of staff to implement the new change with this program, a different tool could have been utilized. In order to successfully evaluate readiness of staff, four categories should be assessed: 1) the belief that change is appropriate, 2) recognition of management support of the change, 3) capability of successfully making the change, and 4) the belief that benefits will come from the change (Holt et al., 2007; Holt et al., 2010).

A scale that quantitatively measures these areas would be most beneficial in the evaluation of readiness (Holt et al., 2007; Holt et al., 2010). The Readiness for Change Questionnaire and the Organizational Change Recipients' Beliefs Scale are two tools that have evidence of validity and cover the four areas of readiness (Holt et al., 2010). One of these tools will be used for the system wide implementation of the transition program to better evaluate the readiness of staff. However, no matter what tool is used, as many studies have established, an individual's expression of readiness to change a behavior is related to their actual change (Hesse, 2006; Holt et al., 2007; Holt et al., 2010).

Readiness is not the only element that is needed to achieve the goal of practicing with a transition program. The healthcare team must also understand the transition policy and receive training on the program, including how to assess patient readiness for transition and what

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education to provide to patients and caregivers. Educating the healthcare team will provide them with the skills necessary for a successful transition program (AAP, 2011).

Qualitative measures allowed for a deeper investigation into the evaluation of the transition program through the eyes of healthcare staff. Research has demonstrated that these study participants are not alone in their concerns of the barriers of this program. In agreement with study participants, Heery, Sheehan, While, & Coyne (2015) and Paine et al. (2014) found that patients with developmental delays serve as barriers to transitioning. They suggest that these individuals be allowed more time for transitioning to these individuals. Another concern of participants was the potential lack of motivation from patients in regards to transitioning. This concern was supported by Heery et al. (2015) and Paine et al. (2014). Team meetings can be held with these patients or caregivers that are unwilling to learn and participate as a way of increasing motivation. In contrast, Moons et al. (2009) showed that many adolescent patients felt unconcerned about transitioning their care because they perceived the transition to be an expected part of their healthcare needs.

Studies have identified the role that parental involvement can serve as a barrier when parents or caregivers are not able to give up control to their child (Clarizia et al., 2009; Moons et al., 2009; Paine et al., 2014). Parents show more concern than adolescents in regards to transitioning to adult services (Clarizia et al., 2009; Moons et al., 2009). Clarizia et al. (2009) found that parents believed that their child would not be ready to assume full responsibility of their own healthcare by the age of 18. Other studies also discovered that parents felt the transition process was difficult due to the need to give up the attachment to their pediatric cardiologist and establish a trusting relationship with a new adult cardiology provider (Heery et al., 2015; Moons et al., 2009). By assisting caregivers in finding a new adult provider and

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offering an early introduction between families and the provider, these worries can be better managed through the transition program.

Another worry that was expressed by staff involved the anxiety stemming from caring for adult cardiac patients in the pediatric setting. This supports the need for the transition program. Heery et al. (2015) found that nurses from a pediatric unit found it more challenging to care for adults with congenital heart disease because of being less familiar with adult care. Paine et al. (2014) found that inadequate preparation of the patient and insufficient communication from the medical professionals also serve as barriers. However, the purpose of the transition program is to adequately train staff to eliminate these barriers.

Proposed independence as a positive outcome from the transition program was a major theme that emerged from the interview portion of this pilot study. Clarizia et al. (2009) and Heery et al. (2015) found that young patients who were knowledgeable about their health condition and healthcare needs were more likely to express confidence in their ability to care for themselves. These patients also tended to have more independence from their parents (Heery et al., 2015). A parent is more encouraged to give up control when their child expresses confidence and knowledge regarding their diagnosis and medical needs (Clarizia et al., 2009). Patients found it to be an advantage when they had a greater understanding of their care because they could be more involved in the decision making process (Clarizia et al., 2009; Heery et al., 2015).

Participants suggested the need for a resource person from the adult side of healthcare to assist pediatric patients with questions and concerns regarding transition. The desire for this resource was also identified by Heery et al. (2015). Having this resource available and gaining information from them gave the patients a sense of familiarity in the adult world (Heery et al., 2015). The importance of communication between adult and pediatric cardiac providers for a

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successful transition cannot be over stated. Luckily, the transition program serves the purpose of facilitating the development of this relationship as well as an early relationship between families and adult providers.

Limitations

Several limitations were recognized in the design of this pilot study. The study participants were chosen through convenience sampling that resulted in a study population that was essentially all nurses. The least amount of experience from participants was four years. Therefore, no new staff members were included. At the time of the study, mostly nurses agreed to participate; therefore, the sample only consisted of one staff member with a role outside of nursing.

Limitations also exist with the pre and posttests used to analyze the effectiveness of the educational module. The posttest was given immediately following the education. This allowed for analysis of immediate retention of the education; however, it does not evaluate long-term retention of the information. The study would have provided better data if the posttest could have been given to participants after a longer period of time following the education.

Another limitation of this study is the timing of the interviews. Because the interviews were conducted immediately following the posttest, pre-program fears could have been captured from participants. Participants were answering based off of limited experience with the program. Once again, better information could have been obtained if the interviews were conducted with staff after the new transition program had been in place for several weeks. This would give the staff more time to adjust to the new practice and gain a better understanding of what works and what needs improvement.

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Recommendations for changes to the transition program

This pilot study's evaluation of the transition program allows for changes to be made with the program prior to hospital-wide implementation. Instead of the Readiness Ruler, the Readiness for Change Questionnaire should be used to evaluate staff readiness for implementation. This tool has validity and also contains the elements necessary to evaluate readiness for change within the workplace.

Evaluation of the pre and posttests should occur after completion of the module by all necessary staff. This serves the purpose of assessing for a continued trend of more experienced staff performing worse on the posttest than those with less experience. Should this occur, adjustments may need to be made to how the education is provided. As requested by pilot participants, reinforcement of the education will occur through different avenues. Educational handouts will be hung in staff break rooms and an email containing the learning module will be sent to staff as well.

Once the program is initiated there will need to be follow up across all levels of participating staff. A second test should be given to all staff that receives the education in the months following implementation to test retention. A second interview should also be conducted at this time to gain more perspective into the program in practice.

Communication should be made with the adult hospital to create a transition resource person. This individual would be available for transitioning patients to contact with questions and concerns regarding the adult side of the program. Another responsibility of the resource person could be to develop a list of available adult cardiac providers with their office contact information. Caregivers and patients would then be aware of their options making it easier to further research and decide their future care. Finally, this resource could also conduct guided

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tours of the adult facility with pediatric patients and families to familiarize them with the new setting.

Conclusion

The goal of this pilot study was to evaluate a new adolescent congenital heart transition program that will be initiated within the children's hospital of a large Midwest medical system. Findings of this study revealed that the education provided to staff had a positive impact on their knowledge and readiness involving the transition program. This study also contributed to the program highlights, suggestions for improvement, and barriers perceived by medical staff. Based on the results of this pilot study, the learning module provided to staff could be delivered throughout the entire hospital; however, potential barriers and time allotments should be considered prior to initiation of the program. Through implementation of this program, the health of adolescents with congenital heart disease can be better managed by caregivers through a standard in practice.

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Table 1. *Pretest and Posttest Data and Readiness Ruler Scores (N=5)*

<i>Pretest and Posttest Data</i>		
Item	Pretest Mean	Posttest Mean
<i>Knowledge Score</i>	60	90
<i>Readiness Ruler Score</i>	2.4	7.4

Table 2. *Years Experience of Staff Compared to Pretest and Posttest Scores (N=5)*

<i>Experience Compared to Test Scores</i>			
Participant	Years Experience	Pretest Score	Posttest Score
1	4	50	100
2	4.5	50	100
3	8	60	80
4	8	70	90
5	19	70	80

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Appendix Learning Module Pre and Posttest Questions with Readiness Ruler

1. What is healthcare transition?

2. Which providers are responsible for guiding patients through the transition program within the hospital setting?
 - a. RNs only
 - b. MDs or APRNs
 - c. The entire medical team
 - d. Parents or guardians

3. At what age will the process of healthcare transition begin?
 - a. 10
 - b. 12
 - c. 14
 - d. 16

4. What is the goal age for a pediatric patient to be transitioned to the adult healthcare model?
 - a. 17
 - b. 18
 - c. 19
 - d. 20

5. True/False: The transition program will only be implemented within the children's hospital.

6. Which of the following is included in the transition checklist for staff to utilize while educating patients involved in the transition program?
 - a. Independent healthcare actions
 - b. Health knowledge
 - c. Lifestyle choices
 - d. All of the above

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- 7. True/False: Patients with cognitive or developmental delays may continue to have their health care needs managed for them instead of working through independent healthcare transition.

- 8. Which hospital should heart patients 18 years of age and older be directed to for lab draws or x-rays?
 - a. Children's hospital
 - b. Adult hospital
 - c. Either the children's hospital or the adult hospital

- 9. A 20-year-old patient with a cardiac related illness should be admitted for inpatient care to which hospital?
 - a. Children's hospital
 - b. Adult hospital

- 10. How ready are you for the congenital heart transition program to be initiated into practice? (Please circle a number)

0	1	2	3	4	5	6	7	8	9	10
Not ready for change					Ready for change					