2021

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Recommended Citation

Schwaegler, Sarah, "Efficacy of An Adult Congenital Heart Disease Transition Care Program: A Program Evaluation" (2021). *Doctor of Nursing Practice Projects*. 17.
https://scholarworks.seattleu.edu/dnp-projects/17

Efficacy of An Adult Congenital Heart Disease Transition Care Program: A Program Evaluation

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A DNP project submitted in partial fulfillment of the
requirements for the degree of

Doctor of Nursing Practice

Seattle University
College of Nursing

2021

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Abstract

Transition Care Programs (TCPs) were created with the goal to facilitate transfer of care from pediatric care facilities to adult care facilities, as health deterioration is commonly seen in the adult with pediatric disease. University of Washington Medical Center and Seattle Children's Hospital created a TCP for youths with congenital heart disease to aid in their transition to appropriate adult specialized care facilities. This program began in 2014 and had yet to have an evaluation. The purpose of this project is to evaluate the success of the current Transition Care Program from Seattle Children's Hospital's Heart Center to the University of Washington's Adult Congenital Heart Disease clinic. **Findings showed a higher correlation with appropriate transition to adult care when more transitional care educational sessions are attended.** Successful transitions came from meeting the adult provider prior to transitioning care, establishing a relationship, and being educated about the individual's condition and the importance of continued specialized care. Recommendations were made for increased patient satisfaction surveys and continued evaluation of appropriate patient follow-up care.

Keywords: Transition Care Program; Congenital Heart Disease; Adults with Congenital Heart Disease; Transitioning Care; Successful Transitions; Youths with Special Health Care Needs

Efficacy of An Adult Congenital Heart Disease Transition Care Program: A Program Evaluation

Statement of the Problem

Advances over the past several decades in the management of infants and children with congenital heart disease (CHD) has contributed to a decrease in morbidity and mortality and, subsequently, an increase in the number of adults with CHD (ACHD). It is currently estimated that ninety percent of children born with CHD will survive into adulthood (Dolgner et al., 2016), meaning that specialized care is needed for individuals with ACHD. Despite the known long-term risks associated with CHD, many adults have lapses in cardiac follow up. In a multi-center US study of 922 patients, 42% of patients with CHD had a gap in care of at least 3 years and 8% of patient had a gap of at least 10 years. These lapses in care are associated with exaggerated mortality and morbidity. Transition care programs have been hypothesized to improve patient follow-up with appropriate health care providers which, in turn, will improve clinical outcomes.

Unfortunately, there are systemic barriers to care for youths transitioning from pediatric to adult health care. These barriers have proven to have negative effects on the outcomes of those living with chronic conditions. Formalized transition care programs can address these barriers and increase health outcomes for patients living with chronic health conditions.

While there is consensus to have a transition program, however, there is not a standard for this. University of Washington Medical Center (UWMC) and Seattle Children’s Hospital created a Transition Care Program (TCP) in 2014 to aid the transition of patients moving from pediatric CHD care to ACHD-focused care. This program had yet to conduct an evaluation of its success in improving patient transfer to appropriate adult care or with patients’ experience with the program. Therefore, a program evaluation of an existing TCP was performed to see if it was meeting the current hypothesis as well as find potential areas of process improvement.

Background

Adolescence is a pivotal point in the developmental period from childhood to adulthood. With the advances in our healthcare system nationwide, as a country we are seeing a considerable increase in the percentage of youths with chronic health care conditions living into adulthood. There are 25 million youth in the United States between the ages of 12 and 17, of which 5 million have special health care needs (SHCN) (Lebrun-Harris et al., 2018). In 2013, it was calculated that 90% of children and youths diagnosed with SHCN in the United States reach adulthood each year and approximately 750,000 individuals with life-limiting health conditions enter adulthood (Betz, Lobo, Mehring, & Bui, 2013). In 2011, the American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), and American College of Physicians collaborated and reached a consensus regarding specific transition steps for all youth (Lebrun-Harris et al., 2018). These steps created a systematic approach that called for all health care providers to address the following with their patients:

> (1) Transition planning by engaging youth and their parents and/or caregivers in assessing and developing self-care skills for an adult model of care at age 18, (2) Transfer of care by assisting youth in identifying adult HCPs [health care programs] and ensuring a smooth handoff with update[d] medical records, and (3) Integration into adult care by orienting new young adult patients about the practice's approach and offering self-care assessment and skill building (Lebrun-Harris et al., 2018, p. 2).

While this consensus was a milestone in continuing care and multiple reports endorse the standard that pediatric providers should adequately prepare their patients for the transition to adult care (Brindis et al., 2014), there is still no straightforward guideline for assuring appropriate transition of care for youths with special health care needs into adult care. Despite professional consensus and availability of tools to help facilitate successful health care transitions (HCTs), both pediatric and adult providers identify many barriers and seldomly incorporate the recommended transition processes (Jones et al., 2017). When youths transition from pediatric care to adult care they also undergo a transition in assuming primary responsibility for their condition. This assumption of responsibility is a large undertaking for any individual, especially those needing to balance care of very complex conditions. The goal of transition is to "maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate healthcare services that continue uninterrupted as the individual moves from adolescence to adulthood" (Le Roux, 2017, p. 5). Research has shown that repeated patient and family education is one intervention that has been effective in improving follow-up and outcomes of individuals with chronic conditions (Dolgner, 2016). The ideal transition would be one where pediatric patients are educated and taught to become autonomous, understanding the complexity of their condition and the importance of continued diligent care. This, in turn, allows them to assume responsibility for their care, ultimately giving them a stronger foundation to advocate for their health and undergo a seamless transition to adult centered care.

Summary of Transition Care Programs

Transition care programs are in place throughout United States to aid in the transition of care from pediatric-centered care to adult-centered care, mainly focusing on youths with special health care needs. Transitional care is the term that has been used to describe services provided to help bridge the gap seen in transfer of the pediatric patient to adult-oriented care. In order to develop the appropriate services needed for these adolescents, evidence for effective interventions is needed to attenuate the effects of barriers to care.

A Cochrane systematic review of transition of care (2015), noted that preparation needs to start early in adolescence and extend beyond physical transfer of care for effective transitional care. It is imperative that the integration of core principles of adolescent medicine with self-management of chronic conditions, plus appropriate health service structures and professional trainings are incorporated (Campbell, 2016). While each care program varies depending on condition, similar benefits and barriers have been assessed throughout.

Barriers to Transitioning

A multitude of studies and reviews yielded a major theme of lack of personal medical knowledge. Patients who are unaware of the details and requirements to maintain their conditions had significant barriers in their transition of care. Through a systematic review of adolescents' and emerging adults' perspectives, young patients reported feeling inadequately prepared for their health care transitions (Betz, 2013; Porter, 2017). Other patients reported that they felt lost in transferring to adult care, as they were uncertain of the processes and expectations of contacting the adult service program. Crucial to a successful transition is meeting the adult care providers before the transfer (Betz, 2013).

Successful Transitions

A randomized control trial tested an intervention focused on enhancing adherence, based around "transition" (complex set of beliefs, skills, and processes that facilitate the movement from pediatric to adult care) rather than simply "transfer care" (Grady, 2018). In this study, it revealed that transitioning heart transplant patients lack essential knowledge regarding heart transplants and have incomplete self-management and self-advocacy skills (Grady, 2018). These findings reinforce the need for self-management as an essential aspect in a transition program.

The authors of this study also showed that incorporating education and behavioral skills were the most successful in promoting adherence to chronic care regimens (Grady, 2018).

One-on-One Educational Sessions. Lebrun-Harris (2018) and Campbell (2016) found that having a personal doctor or one-on-one nurse-led intervention to prepare young people for transition to an adult care program was associated with improved knowledge of their disease. This led to greater proportions of youths with special health care needs actively working with their health care provider to build skills surrounding care of their condition. In contrast to one-on-one interventions, transition preparation training delivered via a two-day workshop may lead to little or no difference in measures of self-care practices and general health behaviors (Biggs, 2016; Campbell, 2016). This standard of having direct one-on-one interventions between the health care provider and the patient is a pivotal step for a successful transition program.

Collaboration Between Providers. Brindis (2014) found that when adult providers were integrated into the continuum of care and began collaborating with the pediatric patients prior to transition of the pediatric patient to the adult patient setting, the number of unplanned urgent in-hospital transfers for cystic fibrosis patients was cut in half (Brindis, 2014). Collaboration between both pediatric and adult providers during the transition phase is crucial in assuring adequate care for the transitioning patient.

Active Engagement. Betz (2013), Brindis (2014), Lebrun-Harris (2018), and Porter (2017) discuss the importance of active engagement between provider, patient, and family when addressing education, self-advocacy, self-management, and transition surrounding the patient's special health care needs. It has been hypothesized through these that transition strategies that attempts to simply “inform” versus “engage” will not be as useful in helping youth transition. Critical points of all these processes were regular patient-provider engagement to reexamine transition materials and goals. Alone time with patient and provider, recommended by the AAP and AAFP, increases adherence to and engagement in care and likelihood of sharing health risks with HCPs (Lebrun-Harris, 2018). In addition to the one-on-one support and health care provider collaboration, Lebrun-Harris (2018) found that a written receipt of care coordination and written plan was associated with increased transition planning among youths with special health care needs (YSHCN). These results help shape the communication between pediatric and adult care team providers and provides for ongoing feedback between patients, families and providers.

Limitations

Due to poor methodology and systematic review criteria, only four small (N=238) RCTs are available as evidence, of which there is low overall certainty in the body of evidence. Therefore, very few overall conclusions can be made regarding effectiveness of transition care programs (Donkoh, 2009; Campbell 2016). Therefore, more research is needed with a stronger evidence base to inform the development of these transitional care services.

Introduction to An ACHD Transition Care Program

In 2014, the University of Washington Medical Center (UWMC) and Seattle Children's Hospital (SCH) created a formal Transition Care Program (TCP) to facilitate transitioning children with CHD to appropriate centers that provide specialized follow-up care for ACHD (Dolgner et al., 2016). The TCP offers formal one-on-on physician led education sessions for those enrolled in the program prior to graduating pediatric care. The specialized education focuses on their condition and the importance of continued care while fostering patient autonomy. The program supports young adults with their complex medical needs, their families, and their healthcare providers as these young adults move from pediatric-centered to adult-centered medical care; helping to ensure that they have appropriate providers to continue managing and treating their condition. Many of the providers are associated with both SCH and UWMC, giving the TCP a unique advantage in continuing care for their patients as they transition from the pediatric facility to adult facility.

Prior to the TCP, UWMC saw a lapse in recommended follow-up adult care of individuals after they graduated from pediatric care. UWMC identified an especially large gap in the cardiology department. Many young adults were not seen for routine preventive care in clinic, but presented during pregnancy, needing emergent procedures, or in extremis needing urgent hospitalization. It was not determined why this was happening; however, the UW ACHD clinic members hypothesized that it may be due to a lack of knowledge surrounding CHD patients' understanding of their condition and the importance for follow-up care. Thus, they created the transition program. The SCH/UW ACHD TCP addresses barriers to care by promoting one-on-one, physician-led educational sessions that are offered prior to graduating from pediatric care. In addition, many of the adult care providers have dual responsibilities meeting and evaluating patients in pediatric care settings prior to transition.

This program has been in place for six years and has yet to perform a formal evaluation of its success. Thus, a program evaluation was conducted to evaluate the success of the UWMC/SCH ACHD TCP.

Purpose and Aims

The purpose of this program evaluation is to assess whether the TCP between SCH and UW ACHD clinic is achieving its intention to improve quality care and attenuate the effects of transitional barriers for SCH CHD patients establishing care at UW ACHD clinics. The project's objectives are to determine success of the current TCP program as well as to provide recommendations to the program for further quality improvement. This project aims to: 1) determine attendance in the TCP's educational courses (0, 1, 2, or 3 sessions); 2) determine appointment follow-through by initiating care at UWMC within the specified timeframe from leaving care at SCH; and 3) obtain TCP feedback from former CHD patients via a questionnaire on the barriers to continuing care as an adult. Thus, this project will answer the following questions:

1. Do patients who receive TCP formal education establish care with adult care facilities more frequently than those who do not receive TCP formal education?
2. What are patients' impressions of the TCP program?
    a. Did patients feel more adequately prepared to take over autonomy of their cardiac health condition after TCP educational sessions?
    b. What improvements could be made to the current TCP program to improve patient satisfaction with transitioning care from pediatric to adult care facilities?

Theoretical Framework

The project is based on the Champion and Skinner Health Belief Model (2008). This model explains how those suffering with chronic conditions will choose to participate more in their care if they are knowledgeable about what their condition is and how they can reduce negative outcomes, understand that continued care outweighs barriers to care, and believe that they are capable of taking control of their condition.

Additionally, the Practical, Robust Implementation and Sustainability Model, (PRISM) evaluates how the health care program or intervention interacts with the recipients to influence program adoption, implementation, maintenance, reach, and effectiveness (Feldstein & Glasgow, 2008). This will act as an evaluation tool to examine the integration of the TCP into practice.

Methods

Project Type and Setting

This program evaluation used mixed methods, consisting of a retrospective chart review and patient satisfaction survey. Combining data sets can produce a meaningful interpretation of a phenomenon and can strengthen the validity of project findings (Creswell & Plano Clark, 2011). This project was designed to evaluate and improve the transition of care of pediatric CHD patients to the UW ACHD clinic by evaluating rates of establishment of care at UW within each individual's recommended time frame. Additionally, a patient survey was disseminated to past participants in hopes of receiving direct feedback of patient experiences related to the program. Combining qualitative and quantitative data provided a better understanding of a patient's experience and helped identify key characteristics that facilitated or hindered a patient's progression through the TCP.

Participants and Recruitment

Thus, it was exempt from IRB review. A data set was compiled by Seattle Children's Hospital Heart Center nurses with all SCH CHD patients who were eligible for the TCP since 2014 up until 2019. Recruitment of participants for the retrospective chart review (RCR) and patient satisfaction survey had the following inclusion criteria: SCH patients who had a diagnosis of CHD, eligible for TCP formal education sessions, and assigned to transfer to UWMC ACHD clinic. This student researcher then went through all potential participants provided by SCH nurse and selected patients who met the criteria for research purposes and created a new patient dataset. Individuals who did not meet the previously mentioned inclusion criteria were removed from the final patient data set and excluded from RCR.

Available email addresses were pulled from electronic medical records to be used for electronic patient satisfaction survey. Participation in the survey was completely voluntary and informed consent was obtained prior to accessing the survey. All potential survey participants recruited are of adult age. Participants did not receive any gifts or incentives and participation in the program evaluation did not require any monetary cost to the participants.

Data Collection

Quantitative data collection took place over a five-month period, from December 2020 – April 2021. Qualitative data collection took place over a four-month period, from January 2021 – April 2021. Quantitative data consisted of a retrospective chart review (RCR) which evaluated the success of the current Transition Care Programs (TCP) goal of increasing compliance with follow-up care at adult care facilities after graduating from pediatric care. Additionally, quantitative data was also collected in the form of Likert style questions on the patient satisfaction survey which evaluated patient satisfaction and experience with the TCP program. Qualitative data consisted of free response questions on the patient satisfaction survey. Open-ended questions were used to provide subjective information regarding patient experiences. A literature review and consultation with experts from the TCP program guided the development of the patient satisfaction survey.

Data Analysis

Quantitative data for the RCR was organized into a Microsoft Excel spread sheet. Patient establishment of care was analyzed to understand the result formal TCP educational sessions had on patient follow through with adult care. Quantitative and qualitative data from the Patient Satisfaction Survey was recorded and organized in Qualtrics. Responses to free response questions from the survey were analyzed to understand patients’ impression of their experience with the TCP. These patient responses were further organized, linked, and analyzed using MAXQDA2020 software.

Quantitative Analysis

Descriptive statistics were used to analyze all quantitative data in Microsoft Excel and Qualtrics. RCR recorded data in qualitative format which was then coded into quantitative data format and analyzed through Microsoft Excel. Charts were noted if patients were seen in the Emergency Department for cardiac related events prior to being seen in the ACHD clinic at UW. The student researcher used patient names and birthdates to access patient information in the UWMC EHR. Once in the patient's chart, it was recorded whether or not the patient established care with ACHD clinic at UW within the specified timeframe. The student researcher documented the following: (1) whether or not appointment was scheduled, (2) whether or not patient established care, and (3) whether or not patient had initial appointment within the specified timeframe instructed upon final visit at SCH. Once the appointment status was determined, student researcher was provided with the number of TCP sessions each patient had.

Each patient's number of sessions were matched to their patient number and transferred onto the data set with their appointment outcome. This reduced bias when searching for patient follow-up with UW ACHD clinic within the correct timeframe. Each patient was given a six-month leeway phase, meaning if they were recommended to be seen in one year, if they were seen at or before eighteen months, this was categorized as *yes, patient was seen within correct timeframe*. If the patient was seen seven or more months after timeframe, this was categorized as *no, patient was not seen within correct timeframe*. If patient had an appointment scheduled within the correct timeframe, but cancelled or no-showed appointment, this was categorized as *appointment scheduled, but no show*. Each patient was assigned a number with their UW appointment status and number of TCP visits recorded. This information was then moved to a separate document to de-identify the results. The results were then analyzed to look for a correlation between TCP sessions and establishment of care at UW ACHD clinic.

The first nine questions on the patient satisfaction survey were recorded in quantitative format, following Likert scale question format (see Appendix D for questions). These results were recorded and analyzed through Qualtrics.

Qualitative Analysis

Content analysis with inductive reasoning was used for qualitative analysis. The method used for qualitative inquiry was content analysis as this method is used for identifying, analyzing, organizing, describing and reporting themes found in a data set (Nowell, Norris, White, & Moules, 2017). Inductive reasoning was used in addition to content analysis. This approach is used when a project's aim is to describe a phenomenon, in this case the impressions and reactions of patients (Hsieh & Shannon, 2005). Coding categories emerged directly from the raw data during the analysis process. To ensure accuracy in content analysis the qualitative data was guided by five phases: (1) familiarization; (2) coding; (3) generating themes; (4) reviewing and naming themes; and (5) defining themes (Lincoln & Guba, 1985; Nowell et al., 2017, table 1). The application of each phase is presented in tables 1-5.

Phase 1 Familiarization. Patient responses were recorded directly into Qualtrics and reviewed in the report section for initial familiarization with the data. These responses were then exported and directly uploaded to MAXQD2020 where they were cross checked with the original data. Responses were reviewed multiple times on both platforms in order to get a clear overall sense of the information. Potential codes were recorded for each survey response.

Table 1: *Familiarization*

Phase 1: Familiarization

FREE RESPONSE QUESTIONS	1	2	3	4	5
POTENTIAL CODES	Relationship, consistency, prepared, ability, quality care, strengths	More options, collaboration with outside providers, telehealth, maps, improvements	Initial consult, critical, relationship, best interest at heart, seamless, easy	Diet, awareness, appointment awareness, conscious of diet, changes	Explanation, condition, knowledge, participation

Phase 2 coding. MAXQDA's automated in-vivo coding function was used to develop preliminary codes for each free response survey question. Automated codes and potential codes from phase 1 were compiled and refined to create blended phase 1 and MAXQDA codes.

Table 2: *Coding*

Phase 2: Coding					
FREE RESPONSE QUESTIONS	1	2	3	4	5
MAXQDA INVIVO CODES	Worked well, having the same doctor, met me at children's before, up to date on condition, showed no reservations in ability, familiar face, adult provider at Children's	Improve, help navigating parking, way around hospital, telehealth options, felt in a way we didn't, reassuring doctor, more options when transitioning, primary physician out here who knows my history	Your experience, easy, seamless, felt right away UW had best interest at heart, hesitant, initial consult, critical	Changes you've made, being aware of upcoming appointments, trying to conscious of my diet, more focus/awareness of my diet	Changes stem from participating, stem from explaining my condition to me, NA, maybe
BLENDED PHASE 1	Familiarity, relationship, consistency, knowledgeable, more options, collaboration, confidence in patient, initial consult crucial, easy and seamless,				

CODES & MAXQDA CODES	best interest at heart, awareness, diet, appointments, knowledge, explanation of condition

Phase 3 Generating Themes. After analyzing similarities in coding structures, a final set of blended codes were selected and grouped together. These selections were compared to original responses to assure accuracy. Preliminary themes emerged during this phase.

Table 3: *Generating themes*

Phase 3: Generating Themes					
FINAL BLENDED CODE SET	Familiarity, relationship, consistency, knowledgeable, more options, collaboration, confidence in patient, initial consult crucial, easy and seamless, best interest at heart, awareness, diet, appointments, knowledge, explanation of condition				
GROUPED ATTRIBUTES	Familiarity, relationship, consistency, knowledge	More options, collaboration, confidence in patient	Initial consult crucial, easy & seamless, best interest at heart	Awareness, diet, appointments, knowledge	Explanation of condition
PRELIMINARY THEMES	Strengths	Improvements	experience	Take-a-ways	Reason for changes

Phase 4 Reviewing and Naming Themes. Preliminary themes and their grouped attributes were compared back to the raw data to ensure accuracy and relevance. After final review, attributes were condensed and finalized. Themes were finalized into phrases that represented their specific attributes.

Table 4: *Reviewing and naming themes*

Phase 4: Reviewing and Naming Themes			
FINAL THEMES	Strengths	Improvements	Take-A-Ways
FINAL ATTRIBUTES	*Supportive and Trusting relationship, Knowledgeable about condition*	*Increase communication, Collaboration with outside facilities, confidence in patient*	*Knowledgeable of condition, Appointment awareness, importance of diet*

Phase 5 Defining Themes. Definitions for each theme were formulated to encapsulate all aspects from the data.

Table 5: *Defining themes*

Phase 5: Defining Themes	
THEME	DEFINITION
Strengths	Incorporates aspects of Transition Care Program that participants reported worked well through their personal experiences.
Improvements	Aspects of the Transition Care Program that were either missing or could be modified to better the experience for participants according to personal reports.
Take-A-Ways	Reported changes made, experiences with transition, and results that stemmed from the Transition Care Program.

Mixed Methods Analysis

The mixed method analysis consisted of comparing qualitative and quantitative data from the Patient Satisfaction Survey. Independent analysis was completed first, followed by further examination to determine how the findings could be combined. Data triangulation is used to increase the confidence, credibility, and validity of research findings when different methods yield the same results, aiding in a comprehensive understanding of the phenomenon of interest (Heale & Forbes, 2013). Quantitative data was recorded through the first nine questions of the survey and qualitative data came from participant responses to five free-response questions.

Merging independent findings provided a deeper understanding of patients' thoughts and experiences of the program.

Ethical Considerations

The protocols and conduct of this project were submitted to University of Washington's Human Subjects Institutional Review Board (IRB) and Seattle University's IRB. After review of University of Washington Human Subjects Division (HSD) IRB application, the University of Washington HSD determined that the proposed activity "is not research, as defined by federal and state regulations", and waived IRB approval on November 16th, 2020. Concurrently, on December 1st, 2020 Seattle University IRB concurred with the UW IRB and identified this study as Not Human Subjects Research (NHSR). Despite the review board conclusions, steps were still taken to notify patients of pertinent project information. All participants who received the Patient Satisfaction Survey were provided with an explanation of the project's purpose and were required to fill out an Informed Consent (Appendix B) prior to taking the survey. No monetary and/or other incentives were provided. The project investigator, Seattle Children's hospital nurses, and professional mentors all complied with all regulations to maintain participant confidentiality.

Results

Quantitative and qualitative data were collected from multiple sources (See Table 6). Content analysis, descriptive statistics and data triangulation provide a complete evaluation of the TCP's success in patient follow through and patient experience.

Table 6: *Data Sources, Sample and Analysis*

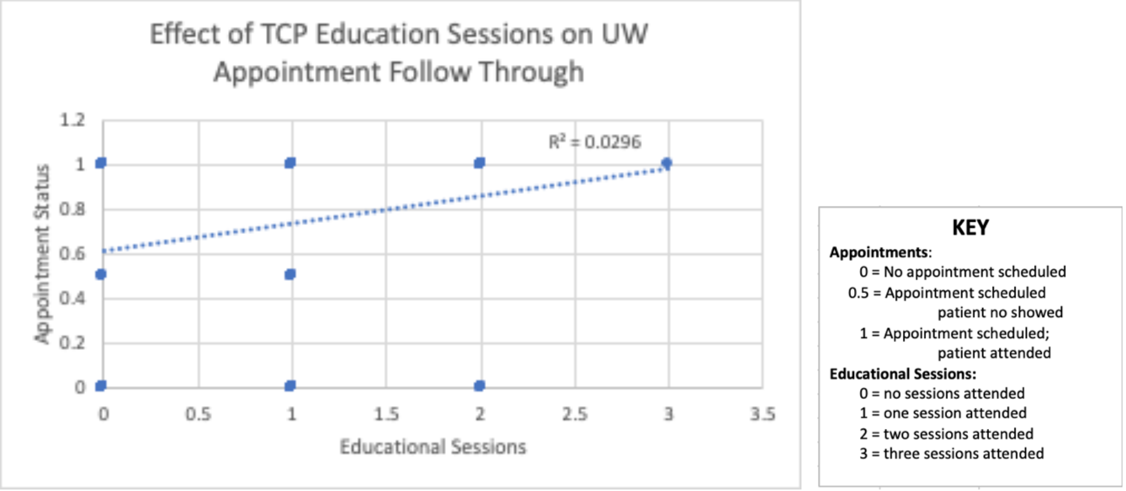
Data Sources	Assessment	Analysis Method	Sample
Retrospective Chart Review (RCR)	Impact of TCP	Descriptive Statistics	N = 335
Patient Satisfaction Survey (PSS)	TCP impression	Content Analysis Descriptive Statistics Data Triangulation	N = 9

Retrospective Chart Review

Quantitative Findings

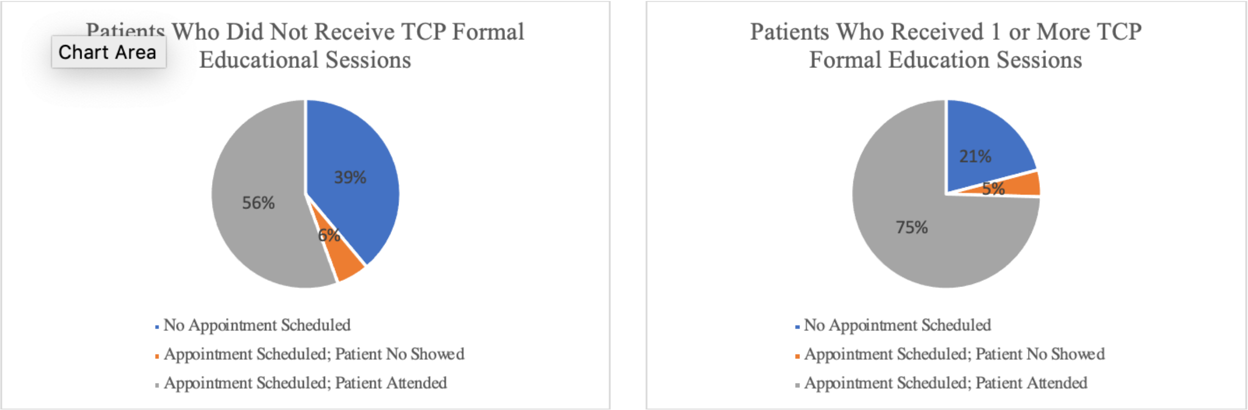
Figure 1 shows the correlation between TCP educational sessions and UW appointment outcomes. R squared calculated in Figure 1 equals 0.0296. This data represents the correlation between TCP educational sessions and establishment of care at UW ACHD clinic within recommended timeframe.

Figure 1. *TCP Educational Sessions and UW Appointment Outcomes*



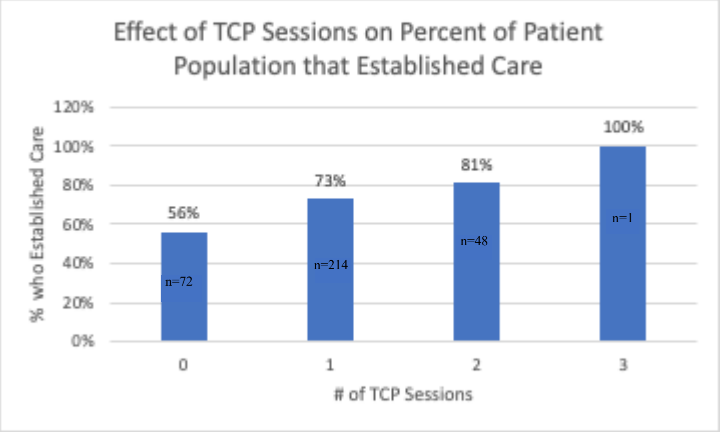
Of patients who did not receive any TCP formal educational sessions and were recommended follow-up care with UW ACHD clinic, 39% did not schedule an appointment, 6% scheduled an appointment but did not attend, and 56% attended their scheduled appointment within the timeframe recommended (Figure 2). Of the patients who received 1 or more TCP formal educational sessions, 21% did not schedule an appointment, 5% scheduled an appointment but did not attend, and 75% attended their scheduled appointment within the timeframe recommended (Figure 2).

Figure 2. *Formal Educational Sessions and Consequent Follow-up Care*



The effect of TCP sessions on percent of patients that established care at UW ACHD clinic separated into individual TCP sessions are shown in Figure 3. Of those who attended one TCP session, 73% established care. Of those who attended two sessions, 81% established care. And 100% of those who attended three sessions established care.

Figure 3. *Effect of TCP Sessions on Establishment of Care*



These findings were used to answer the following project question: Do patients who receive TCP formal education establish care with adult care facilities more frequently than those who do not receive TCP formal education?

Patient Satisfaction Survey

The patient satisfaction survey was sent out electronically to 281 patients. The student researcher obtained emails from the health care facility EHR for those patients that had an email listed. Not all participants in the RCR had emails listed on their chart. The survey was open for a four-month period from January 2021 – April 2021, and three reminder emails were sent asking participants to fill out the survey.

The sample consisted of fifteen recorded responses from past participants. However, of these fifteen, three people signed the consent form but then did not continue the survey. Twelve of the participants filled out the top half of the survey, and six people filled out either partial or all of the free response questions. These findings were used to answer the following project question: What are patient’s impressions of the Transition Care Program?

Quantitative Findings

Fifty percent of participants strongly agreed that the TCP educational session made their transition easier, twenty-five percent somewhat agreed and twenty-five percent neither agreed nor disagreed. Seventy-two percent of participants either strongly agreed or somewhat agreed that they had a better understanding of congenital heart disease after having TCP education, while twenty-seven percent neither agreed nor disagreed. Seventy-five percent of participants agreed that they had a better understanding of how to improve their health and avoid negative outcomes after having TCP education, while twenty-five percent neither agreed nor disagreed. Eighty-four percent of participants agreed that the TCP education enhanced their understanding of the importance of continuing care regardless of barriers to care while sixteen percent of participants neither agreed nor disagreed or disagreed. All twelve participants agreed that they felt their new provider's office was as welcoming as their pediatric provider's office and felt their adult provider had all the information regarding their care they needed. Ninety-two percent of participants agreed that they felt they were easily able to contact their new providers office while one participant neither agreed nor disagreed with this statement. Ninety-two percent of participants felt as though their new provider knew who they were when they called, and one participant neither agreed nor disagreed with this. Fifty percent of participants strongly agreed that they felt more confident in being capable of taking control of their condition after having TCP education; whereas twenty-five percent somewhat agreed, and twenty-five percent neither agreed nor disagreed with the previous statement. These results are shown in Figures 4 and 5.

Figure 4. *Number Breakdown of Participant Responses to Likert Style Questions*

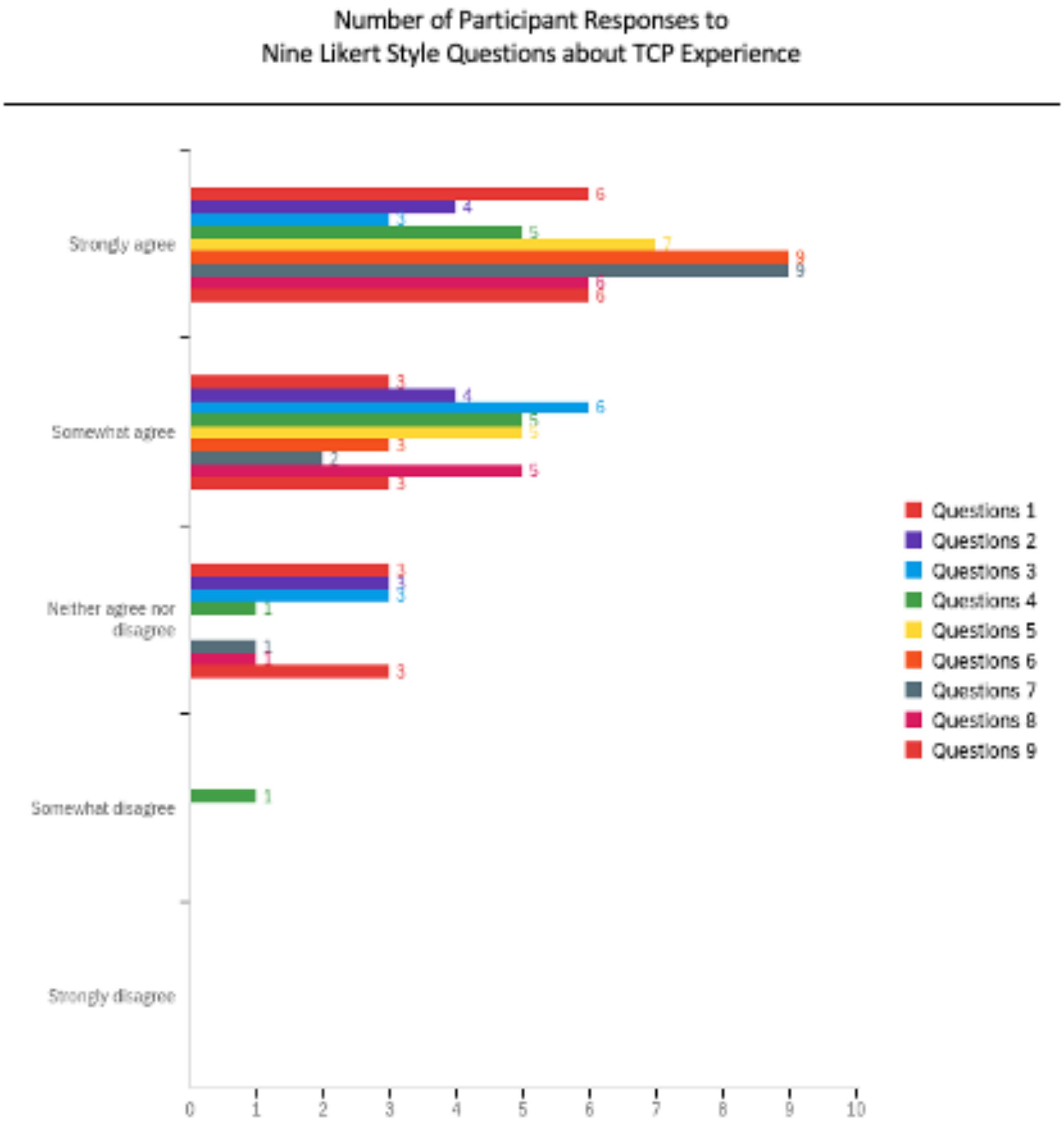
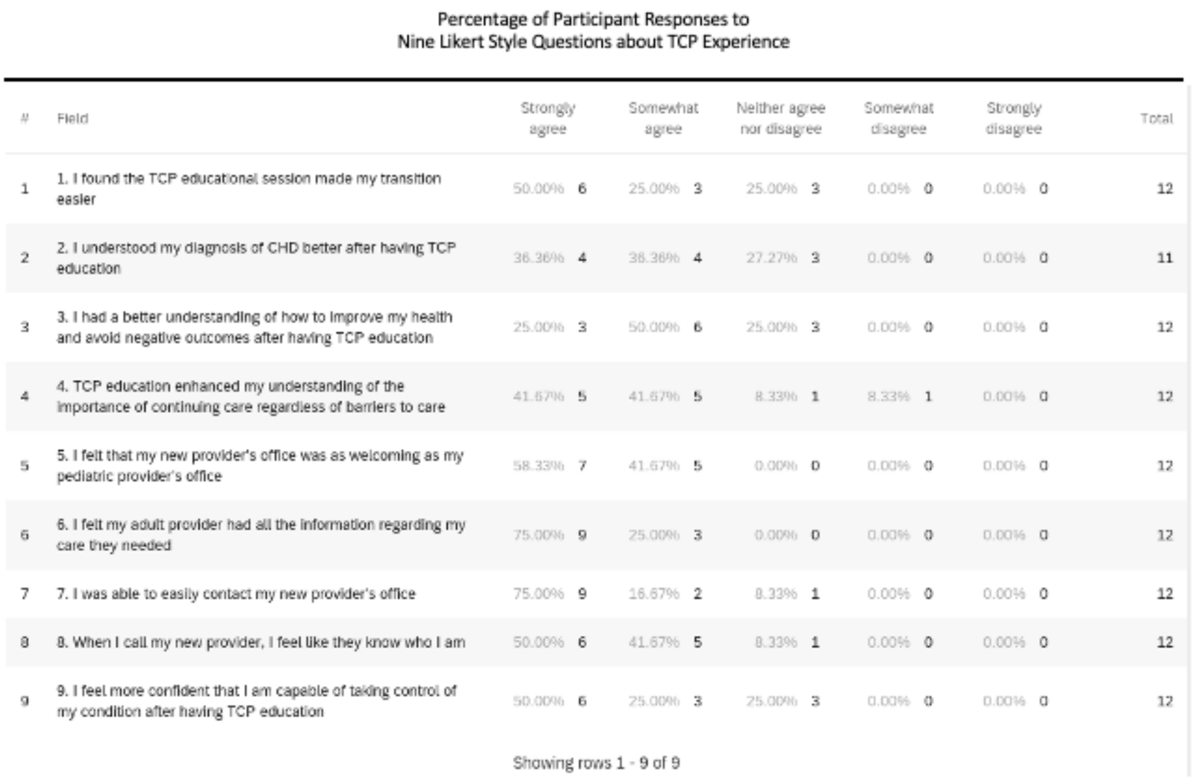


Figure 5. *Percentage Breakdown of Participant Responses to Likert Style Questions*



Percentage of Participant Responses to
Nine Likert Style Questions about TCP Experience

#	Field	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree	Total
1	1. I found the TCP educational session made my transition easier	50.00% 6	25.00% 3	25.00% 3	0.00% 0	0.00% 0	12
2	2. I understood my diagnosis of CHD better after having TCP education	36.36% 4	36.36% 4	27.27% 3	0.00% 0	0.00% 0	11
3	3. I had a better understanding of how to improve my health and avoid negative outcomes after having TCP education	25.00% 3	50.00% 6	25.00% 3	0.00% 0	0.00% 0	12
4	4. TCP education enhanced my understanding of the importance of continuing care regardless of barriers to care	41.67% 5	41.67% 5	8.33% 1	8.33% 1	0.00% 0	12
5	5. I felt that my new provider's office was as welcoming as my pediatric provider's office	58.33% 7	41.67% 5	0.00% 0	0.00% 0	0.00% 0	12
6	6. I felt my adult provider had all the information regarding my care they needed	75.00% 9	25.00% 3	0.00% 0	0.00% 0	0.00% 0	12
7	7. I was able to easily contact my new provider's office	75.00% 9	16.67% 2	8.33% 1	0.00% 0	0.00% 0	12
8	8. When I call my new provider, I feel like they know who I am	50.00% 6	41.67% 5	8.33% 1	0.00% 0	0.00% 0	12
9	9. I feel more confident that I am capable of taking control of my condition after having TCP education	50.00% 6	25.00% 3	25.00% 3	0.00% 0	0.00% 0	12

Showing rows 1 - 9 of 9

Qualitative Findings

Three major themes were found from the online survey responses: Strengths, Improvements, Take-a-Ways. Patient responses are provided below. These findings were used to answer the following project question: What are patients' impressions of the Transition Care Program?

Strengths. Strengths incorporate aspects identified by participants that worked well in their experience with the TCP. The following are some of the participant statements.

> *"Having the same doctor"*
>
> *"I liked that Dr. (medical provider) met me at Children's before I saw him at UW."*

> *“They were up to date on my son's condition, and showed no reservations in their ability to care for a challenging future with my son. I felt they would continue the level of care that children's Hospital provided the prior 20 years.”*
>
> *“Meeting our doctor at Children's and then at UW made the transition easier. It is nice to see a familiar face in a new place.”*
>
> *“I liked getting to see my adult provider at Seattle Children's before I transitioned to UWMC. It was nice to have a familiar face when I transferred over.”*
>
> *“The initial consult with the transition staff was critical. We were hesitant to switch from what we knew (Childrens) and what might be (UW). We felt right away that UW had our best interest at heart.”*
>
> *“...it was easy and seamless.”*

Limitations. Limitations were identified as the following:

> *“More options when transitioning to adult care. I now live in California and do not have a primary physician out here who knows my history and my heart issue”*
>
> *“More Telehealth options would've been helpful as I live so far away from Seattle so it's hard for me to get to appointments.”*
>
> *“Help in navigating parking and finding my way around the hospital. I have autism, and find those things extra difficult.”*
>
> *“It was strange that it was assumed that we would be fearful and would dread the transition to the adult program at UW. Our doctor seemed convinced that we felt in a way that we didn't feel. It took the entire visit of us reassuring our doctor that the transition was not a big deal to us. This makes me feel that it is a big deal to most patients.”*

Take-A-Ways. Take-A-Ways incorporate statements made by participants regarding what they learned and/or changes that came from participation in the TCP.

> What are the changes you've made when it comes to your cardiac care now that you are an adult?
>
> > *"Trying to be conscious of my diet, being aware of my upcoming appointments"*
> >
> > *"More focus/awareness of my diet"*
>
> Do you think that any of these changes stem from participating in the TCP? Please explain.
>
> > *"I think they stem from Dr. (medical provider) explaining my condition to me."*
> >
> > *"NA"*
> >
> > *"Maybe?"*

Discussion

The first aim of this program evaluation was to investigate whether patients who receive TCP formal education establish care with adult care facilities more frequently than those who do not receive TCP formal education. Those who had at least one TCP session were 17% more likely to establish care with the UW ACHD clinic than those who did not receive formal TCP education. Additionally, those who received two TCP sessions were 25% more likely to establish care and those who received three TCP sessions were 44% percent more likely to establish care. There is very high positive correlation that the more TCP sessions, the more likely a patient will establish adult care and as a whole, the transition care program had a positive impact on patient follow up care with the appropriate adult care facilities. With repeated patient and family education, the TCP was successful at improving follow-up transition care with appropriate ACHD medical providers.

Another aim of this program evaluation was to explore patients' impressions of the TCP program. The patient satisfaction survey was sent out electronically to 281 patients. The student researcher obtained emails from the health care facility EHR for those patients that had an email listed. Not all participants in the RCR had emails listed on their chart. Through content analysis, descriptive statistics, and data triangulation, three themes arose from the participant satisfaction survey: Strengths, Limitations, and Take-A-Ways. The success of the TCP program came immensely from supportive and trusting partnerships between patient and provider. Through creating relationships with pediatric CHD patients prior to their transition into adult care, many of the barriers were addressed making the transition more seamless. This is supported by eighty-four percent of participants agreeing that TCP education enhanced their understanding of the importance of continuing care regardless of barriers to care. This relationship provided patients' and patient's families with a sense of security and understanding of what was to come next. Creating this relationship with a specialized ACHD medical provider prior to transitioning was crucial in instilling trust and confidence in the adult system that these patients were about to enter.

The TCP provides a steppingstone for patients transitioning that eases the fear and unknown or transitioning care, in turn improving the rate at which patients establish adult CHD care. All participants agreed that they felt their adult provider had all the information regarding the care that they needed and 75% of participants felt more confident in their capability of taking control of their condition after having TCP education.

Participants stated that the TCP "was easy and seamless", and that changes they have made from having TCP education stem from their medical provider explaining their condition to them. This is also supported by 73% of patients agreeing that they understood their diagnosis of

CHD better after having TCP education. Through one-on-one provider patient educational sessions, patients felt more confident in their CHD understanding, importance in continuing care, and ability to have a seamless transition. These conclusions are in turn supported by the RCR showing the TCP program having a statistically significant impact on patient follow-up with ACHD medical providers at UWMC.

Participants stated that more options when transitioning care would be helpful, such as providing more telehealth options for patients that live far away from UWMC and more collaboration with outside providers for those who move out of state after leaving SCH. Through the RCR it is apparent that the TCP does collaborate and coordinate care between other care facilities but making this clearer to the patients may alleviate feeling uncertain about transitioning out of state or to an outside provider. Another recommendation from the PSS was to assess patient's knowledge base and feelings about transition prior to making assumptions that it is a difficult task. Finding and establishing mutual priorities and goals for both the patient and the provider may aid in the patient feeling more autonomy surrounding their health and more positive outcomes when it comes to transition.

Implications for Clinical Practice

Continuation of the TCP is vital for the health and outcomes of CHD patients. In addition to one-on-one educational sessions, communication from the UW care team reaching out to patients and assuring appointment follow-up was paramount in patients being seen within the recommended timeframe. In addition to the 247 CHD patients from SCH who did establish care at UW ACHD clinic within the recommended timeframe, there were 35 additional patients who still established care but were counted as "no appointment scheduled" since it was not within the allotted timeframe. This is a testament to the Transition Care Program team who continuously follows up with patients to aid in establishing care with adult healthcare facilities. While this project only looked at the transition between SCH CHD patients to UW ACHD clinic, the successful findings can be used to support further research ultimately supporting broadening the scope at which TCPs are utilized in other chronic health conditions. The information gleaned from this project can be very useful in furthering the current pediatric CHD to ACHD TCP.

Limitations

One limitation to this project was that there was no initial pilot study showing baseline follow-up rates prior to implementing the TCP. However, this project was still able to adequately evaluate the programs impact on patient follow-up with adult congenital heart disease specialists. Additionally, there was no documentation to differentiate between when a patient declined versus did not receive TCP education. These patients were all placed into the same category of TCP sessions, zero, and it may be worthwhile to differentiate whether there was a difference in patient follow-up when TCP education was declined versus unavailable. Furthermore, it is important to note that only one patient had three TCP formal educational sessions. That said, there was still a significant increase in patient follow up between those who had one TCP session compared to those who had two sessions.

Another limitation to this project is related to the response rate of 4% and a sample size of 12 participants who responded to the PSS. This high response dropout may lead to nonresponse bias and the survey subsample is not fully representative of the original sample (von der Gracht, 2008). Additionally, the electronic survey was only able to reach those who have access to email on an electronic device, and those who had emails listed in the electronic medical record system which limits the response perspectives and is not inclusive of the entire sample.

Therefore, these results may not represent information that is generalizable to all CHD TCP participants.

Future Considerations and Recommendations

A better way to receive more inclusive patient feedback may be providing patients with a satisfaction survey at their last SCH visit as well as their first UWMC visit. This would potentially increase response rate and be a more accurate portrayal of patient’s experience and provide optimal information for quality improvement. This may provide beneficial information in regard to which aspects of focused intervention and education are the most successful. Additionally, doing a more in-depth chart review looking at demographic information, disease severity, comorbid conditions, patient location, would be helpful in subdividing aspects in which follow-up is common versus where follow-up is lacking for further program improvement. Lastly, with the baseline information found from this project, it would be beneficial to continue tracking patient’s establishment of care to recreate another RCR in a few years to assure programs success is continuing.

Conclusions

In summary, by initiating formal repeated education targeting the patient and the patient’s family, the Transition Care Program successfully improved the follow-up and decreased the frequency in lapse of care in adults with Congenital Heart Disease. Majority of participants who filled out the patient satisfaction survey had positive feelings toward the program and felt the key to their success was creating meaningful relationships with their adult medical providers prior to transitioning care to the adult facility. Future projects should take place to further improve and optimize patient transition to adult care facilities.

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Appendix A

DNP Capstone Timeline

	May 2020	July 2020	December 2020	January 2021	February 2021	March 2021	April 2021	May 2021	June 2021
Refine/Revise Capstone Proposal	■								
IRB Process		■	■						
Retrospective Chart Review			■	■	■				
Create online survey			■						
Disseminate survey and collect data from respondents				■	■	■			
Analyze retrospective chart review						■	■		
Analyze survey responses							■		
Finalize capstone project								■	
Work on oral presentation								■	
Disseminate findings									■

Appendix B

Program Alignment Table

PROJECT ALIGNMENT TABLE

PROJECT QUESTIONS	PROJECT OBJECTIVES	DATA COLLECTION METHOD	OUTCOME EVALUATION
Do patients who receive TCP formal education establish care with adult care facilities more frequently than those who do not receive TCP formal education?	Evaluate the TCP program's goal to improve patient follow-through rate	Retrospective Chart Review	Graph and analyze patient follow-through with establishing care at UW ACHD clinic
What are patients' impressions of the TCP program?	Evaluate the program's strengths and limitations	Patient Satisfaction Survey	Thematic Analysis: Identify major qualitative themes from patient responses

Appendix C

Consent Form

CONSENT TO PARTICIPATE IN RESEARCH

TITLE:
Efficacy of the Adult Congenital Heart Disease Transition Care Program: A Program Evaluation

INVESTIGATOR:
Sarah Schwaegler, schwaeg2@seattleu.edu, (206) 331-0903

ADVISOR:
Therry Eparwa, DNP, MSN, RN, FNP-BC, College of Nursing, Seattle University, (206) 446-3521, eparwat@seattleu.edu

PURPOSE:
You are being asked to participate in a research project that aims to improve the Transition Care Program between Seattle Children's Hospital Congenital Heart Disease pediatric care facility and the University of Washington Medical Center Adult Congenital Heart Disease adult care facility. There is one survey we would like you to fill out to provide feedback of your experience with the program. The survey should take no longer than 15 minutes to complete and is completely anonymous.

SOURCE OF SUPPORT:
This study is being performed as partial fulfillment of the requirements for the doctoral degree in nursing practice at Seattle University.

RISKS:
There are no known risks associated with this study. However, in order to participate in the survey with minimal problems, it is recommended that you have access to a computer with uninterrupted Internet connection, utilizing one of the following web browsers: Internet Explorer 7+, Safari 4+, Firefox 3+, or Chrome.

BENEFITS:
Information provided in this survey will aid in quality improvement efforts with the Transition Care Program. This knowledge will enhance patient outcomes and satisfaction creating a smoother more beneficial transition program. Better education augments opportunities for patients and healthcare providers to engage in conversations about congenital heart disease and enhance transitioning procedures.

INCENTIVES:
You will receive no gifts/incentives for this study. Participation in the project will require no monetary cost to you.

CONFIDENTIALITY:

For purpose of resurvey, your name and email address has been assigned a unique alpha-numeric identifier for this study and is maintained in a separate, password-protected, encrypted document. However, your name will never be used in any public dissemination of these data (publications, presentations, etc.). All research materials will be stored in an electronically encrypted spreadsheet and only the sole researcher will have access to the data. When the research study ends, all identifying information will be removed from the data, or it will be destroyed. All of the information you provide will be confidential. However, if we learn you intend to harm yourself or others, we must notify the authorities.

RIGHT TO WITHDRAW:
Your participation in this study is voluntary. You may withdraw your consent to participate at any time without penalty. Your withdrawal will not influence any other services to which you may be otherwise entitled.

SUMMARY OF RESULTS:
A summary of the results of this research will be supplied to you, at no cost, upon request. Please communicate this request to Sarah Schwaegler at schwaeg2@seattleu.edu or (206) 331-0903.

VOLUNTARY CONSENT:
I have read the above statements and understand what is being asked of me. I also understand that my participation is voluntary and that I am free to withdraw my consent at any time, for any reason, without penalty. On these terms, I certify that I am willing to participate in this research project.

The completion of the online survey(s) implies my consent to participate.

I understand that should I have any concerns about my participation in this study, I may call Sarah Schwaegler, who is asking me to participate, at (206) 331-0903. If I have any concerns that my rights are being violated, I may contact Dr. Michael Spinetta, Chair of the Seattle University Institutional Review Board at (206) 296-2585.

Investigator's Online Signature
Signed: 10/19/2020

Seattle University, 901 12th Ave, P.O. Box 222000 Seattle, WA 98122

Appendix D

Participant Satisfaction Survey

Transition Care Program Satisfaction Survey

The following questions ask about your experience with the Transition Care Program. Please respond to each question using the scale below (for each question select the option that best reflects your response). Please answer open and honestly, there are no right or wrong answers and all responses are anonymous.

	Question	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
1.	I found the TCP educational session made my transition easier	1	2	3	4	5
2.	I understood my diagnosis of CHD better after having TCP education	1	2	3	4	5
3.	I had a better understanding of how to improve my health and avoid negative outcomes after having TCP education	1	2	3	4	5
4.	TCP education enhanced my understanding of the importance of continuing care regardless of barriers to care	1	2	3	4	5

5. I felt that my new provider's office was as welcoming as my pediatric provider's office	1	2	3	4	5
6. I felt my adult provider had all the information regarding my care they needed	1	2	3	4	5

7. I was able to easily contact my new provider's office	1	2	3	4	5
8. When I call my new provider, I feel like they know who I am	1	2	3	4	5
9. I feel more confident that I am capable of taking control of my condition after having TCP education	1	2	3	4	5

FREE RESPONSE QUESTIONS 7-9

The final 5 questions are free response. Please answer open and honestly, there are no right or wrong answers and all responses are anonymous.

7. What worked well with the Transition Care Program for you?

8. What could have made the Transition Care Program better for you?

9. What else would you like the Transition Care Program to know about your experience?

10. What are the changes you've made when it comes to your cardiac care now that you are an adult?

11. Do you think that any of these changes stem from participating in the TCP? Please explain.

Thank you for taking the time to respond to this survey, your participation will enhance the program for those to come. Have a wonderful day!