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A Transition Quick-Guide for Educating Youth with Hemophilia

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This is to certify that the doctoral study by

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Walden University
2018

Abstract

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MSN, Walden University, 2012

BSN, Medical College of Georgia, 2003

Project Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

A 2009-2010 National Assessment Survey of youth with special needs such as hemophilia showed that 40% of youth between the ages of 12 and 17 had a transition plan before transitioning to adult care services. The lack of a transition plan caused youth to fall into a gap of fragmented care when transition services were inadequate. During the gap in care, youth with hemophilia increased use of the emergency room and were hospitalized for complications. The purpose of this project was to prepare youth with hemophilia between the ages of 12 and 17 to transition from pediatric care to the adult hemophilia clinic using a transition quick guide about hemophilia and self-care management. The model used to inform this project was plan-do-study-act. Sources of evidence were taken from 10 youth with hemophilia. Data to assess the project outcomes were collected from the assessment of participants' knowledge before and after educational interventions and review of demographic data from participants' clinic records. Pretest data scores ranged between 19% and 58%. Posttest scores after educational session were between 42% and 95%. The percentage differences between pretest and posttest results showed a 14% increase in knowledge, indicating that knowledge increased using the transition quick guide. The implication for positive social change was that youth who are adequately prepared for the transition to adult care services could avoid unnecessary health complications and enjoy an improved quality of life.

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Dedication

This doctorate of nursing paper is dedicated to my husband and two sons for their continued love, support, and sacrifices that were given on this DNP journey. Both of my parents are deceased, but I would like to dedicate this paper to their memory. They would have been so proud of me. I am very grateful of my siblings for believing in me and motivating me to complete this DNP program. The participants and their families were a blessing for me in sacrificing their time and energy. I am grateful for their time, energy, and belief in me that the project would be essential for their future. In addition, I would like to thank my mentors for their continued guidance and support through this DNP program. It is my hope and prayer that this paper would be effective in making positive social change for the hemophilia population.

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Section 1: Overview of the Evidence-Based Project

Introduction

Hemophilia is a sex-linked genetic disorder that is lifelong which causes bleeding into the deep tissues and joints due to the deficiency or absence of one of the factor proteins (Simmons et al., 2014; Young, 2012). It is important that healthcare providers begin educating families about hemophilia, recognition of bleeds, importance of early treatment, and the importance of prophylaxis therapy to prevent complications. Bleeds that go unrecognized are difficult to treat. Parents or caregivers are taught at the time of the child's diagnosis on how to recognize a bleed, early treatment, and how to manage a difficult bleed. Since hemophilia is a lifelong disorder, it is important that the emphasis of education began to shift from the parent to the youth by the age of 12 years. One of the mainstays of hemophilia education is that the youth have a transition plan that includes learning about the basics of hemophilia, how to recognize an early bleed, how to initiate treatment when a bleed occurs, and how to prevent bleeding episodes before they reach the age of 18 years. According to Young (2012) transition from a pediatric care service to an adult service should be safe and smooth. Systematic reviews showed that youth with hemophilia are at risk for consequences when there is no transition plan for them. Youth were at risk for consequences such as bleeding complications, decreased quality of life resulting from nonadherence to medical therapy, poor access to medical benefits, and poor quality of life (Betz Lobo, Nehring, and Bui, 2013; Findley, Cha, Wong, & Faulkner, 2015). The problem for this DNP quality improvement (QI) project was that the project's site, which is a hemophilia clinic, lacked transitional care services that prepared youth with hemophilia to learn basic knowledge about hemophilia and self-care management skills. With the results from a 2009-2010 National Assessment Survey showing only 40% of youth with special need such as hemophilia have a transition plan, these results showed that 60% were still dependent on parents to manage their hemophilia and provide them with treatment therapy (Simmons et al., 2014). The problem at the project's site was that youth were still dependent on their parents to manage their hemophilia at the age of 17 but the expectation from pediatric and adult care providers was that the youth start transition preparation by 12. It is important to address this issue in a nursing context to show that there is a trend that youth receive fragmented care when transition services are not in place for a safer and lower cost transition to adult care services. Healthy People 2020 set goals for healthcare professionals to increase the percentage of 40% to 85.3% by 2020, thus improving transitional care services for youth with chronic conditions such as hemophilia and preventing fragmented care and decreasing health care costs (Vaks et al., 2016). Unplanned transitions among youth resulted in them falling into a poorly managed care gap, which lead to high healthcare costs and increased morbidity and mortality rates (Aldiss et al., 2015). Early transition planning was the key to improving the care service gap related to transition, thus preventing youth from falling into a poorly managed care gap. Nurses were influential in improving those gaps in practice by exploring literature and gaining knowledge through the translation of evidence into practice.

The goal of the DNP project was to develop a transition quick guide specifically for youth with hemophilia to educate them regarding basic hemophilia and self-care management. The guide will serve as a learning tool to prepare youth to take charge in managing their health and hemophilia. The transition quick guide will also be a checklist that identifies the unmet needs of the emerging young adult population who need final approval from the healthcare team to move from a pediatric to an adult care setting. The implication for positive social change for this DNP project is that strategies to improve transition readiness skills among youth with hemophilia will help them achieve success in decreasing joint bleeds, decrease visits to the ER, and provide them with a good quality of life. Nurses are pivotal in gaining knowledge to improve the transition service gap with an educational approach, thus reducing preventable bleeding complications and high healthcare costs (Ladores, 2015). By exploring the use of the transition quick guide within the hemophilia clinic, the project coordinator who is the author of the DNP project and team members who is the social worker and physician of the local clinic. The DNP project will provide this team with a tool such as the transition quick-guide, that improves the transition health service gap in practice. This transition quick guide will aid the project coordinator in preparing youth to understand basic hemophilia principles and increase self-care and management skills.

Problem Statement

The local nursing practice problem was centered on improving the transition health service gap in practice. The problem was that youth without a standardized transition plan received fragmented care, resulting in frequent joint or muscle bleeds and joint disabilities. The youth within the pediatric hemophilia clinic at the project's site were not transferring adequately to the adult hemophilia clinic. They reported that their transfer to adult care was often abrupt. According to Ladores (2015), there is an emerging need for nurses to function as transition coordinators or become liaisons for QI projects that focus on transition for youth with hemophilia. The project coordinator performed a needs assessment for the Hemophilia Treatment Center (HTC) to address the current method of delivering health services that provide transition preparation to youth. The project coordinator issued 20 needs assessment surveys to the pediatric and adult HTC staff, of which 12 surveys were returned. Some of the responses to the assessment said that the pediatric staff held on to the young adult too long. What this basically meant was that the pediatric staff would transfer youth patients at the age of 22 years. The adult team wanted the pediatric HTC staff to transfer the patients at the age of 18 years. The adult HTC staff also mentioned in the survey that there was no handoff communication between the pediatric and adult HTC at the time of transfer of the youth. The pediatric surveys revealed that the youth and their parents were stressed and fearful of transferring to the adult clinic. Conversely, pediatric providers had concerns about the youth not following up for care after transferring from the pediatric clinic. Youth and their parents have long patient-provider relationships but there were no transition care preparation to get them ready for the transfer to the adult hemophilia clinic. As a result, youth were not following up with care. They made appointments or visited the ER for joint bleeds that was not manageable. A difficult transfer contributed to decreased compliance and deterioration in the youths' overall health (Breakey, Blanchett, & Bolton-Maggs, 2010). The findings from the surveys done by the HTC staff rrevealed that there was a local problem that existed in the pediatric hemophilia clinic. Nurses were in pivotal positions to ensure that youth made a safe and smooth transition to an adult care setting.

Hemophilia is a demanding disorder that requires individuals to begin self-infusions between the ages of 7 and 12. These youth need to show competence in self-infusion skills by the age of 15 years (Berube, Mouillard, Amesse, & Sultan, 2016). Early transition planning is the key to solving this problem that exists within the healthcare system. During a review of charts at the project's local site, young adults between the ages of 18 and 22 were found to have decreased levels of adhering to medical therapy, access to care, and quality of life. Individuals who have problems with adhering to medical therapy, poor access to care are frequently seen in the emergency room and hospitalized for preventable complications. Johnsons and Zhou (2011), found that preventable complications such as joint bleeds, injuries, and increased medication use affects the government budget significantly each year. For this reason, it is critical to address the local nursing practice problem of unplanned transition care within the hemophilia clinic. Transitional care education for youth begins at the age of 12 to promote education and improve service care.

The DNP project held significance in providing nurses the opportunity to broaden the scope of scientific reviews in transitional care not only for the hemophilia clinic but other specialty services. Best practice approaches are important in providing the patient with a high quality of care, preventing morbidity, reducing health care costs, and promoting quality of life (Rehm et al., 2012). The project provided answers to the DNP question regarding whether designing a transition quick guide to use in the hemophilia clinic would enable youth to increase knowledge of hemophilia and self-care management before the age of 18. This DNP project will help nurses identify gaps in practice and continue improving transition planning for better patient interventions.

Purpose

The purpose of this QI project was to assess whether the use of a transition quick guide will improve basic hemophilia knowledge and increase knowledge of self-care skills in hemophilia patients for those under 18 years of age. There remains a meaningful gap in nursing practice related to youth with hemophilia falling into a fragmented care gap due to unplanned transitions. The pediatric hemophilia clinic staff at the project's site were not equipped to design a transition plan with an education and evaluation approach, thus causing a gap in practice. Without a transition plan that educated and assessed transition readiness regarding areas related to youth diagnosis and how to manage it, the youth were predisposed to fragmented care. Transitioning from one life stage to the next is challenging to youth. Youth are challenged with not only learning how to become an adult but also the pressures of day-to-day medical care for their diagnosis. It is important that the pediatric hemophilia clinic acknowledge that transitional care is at an insufficient stage for youth with hemophilia. Without a transition process, education on transitional care, transition tools, and resources, youth continues to be unsuccessful in their transitional care journey. Designing a transition quick guide through a QI approach helped the nurses identify issues related to transition readiness before transferring the young adult to the adult hemophilia clinic.

The DNP project question involves whether designing and implementing a transition quick guide to use in the hemophilia clinic helped the youth increase knowledge of hemophilia and self-care management skills before transferring to an adult hemophilia clinic. Provider's need to improve the transition process within the practice. The problem was that the amount of information found in literature is scant in determining if the youth were adequately prepared to move from pediatric to adult care services without the help of a parent. The transition quick guide was designed for healthcare providers and medical staff to use in a clinic as a checklist for determining if a youth or young adult was ready to take charge of managing their health and condition (Youth Transition Collaborative, 2016). For this QI approach, the project coordinator evaluated the youth's knowledge of hemophilia, skill management, and transitional care using the University of North Carolina (UNC) TRxANSITION scale. The UNC TRxANSITION scale measures health care transition and self-management skills in youth with chronic conditions (Ferris et al., 2012). The major goal of using a QI approach was to provide the project coordinator with an educational tool and a transition readiness scale that is specific in finding measurable improvements among the hemophilia population.

The project has potential to address the gap in the nursing practice regarding transitional care for youth with hemophilia by using the transition quick guide to standardize the education process in transitional care services. A Healthy People 2020 goal was to equip clinicians with the transition resources and services for providing youth with a safe and smooth transition journey towards adult care services (Ciccarelli, Brown, Gladstone, Woodward, & Swignoski (2014). Addressing this gap was relevant to prevent fragmented care and promote a high quality of care for the hemophilia population.

Nature of the Doctoral Project

The sources of evidence that were collected to meet the purposes of this DNP project included literature regarding youth transitioning to hemophilia adult health care services. In particular, the project focused on preparing youth early to manage their hemophilia independently since emerging youth fell into a fragmented care gap after they left the pediatric hemophilia clinic. Guided by the clinical question, a systematic literature search was conducted for this DNP project. Databases searched include MEDLINE, the Cumulative Index of Nursing and Allied Health Literature (CINAHL), PsycINFO, and the Cochrane Database of Systematic Reviews. The search terms and phrases included the following: *Youth*, *young adult*, *transition*, *transfer*, *hemophilia*, *special needs*, *fragmented care*, and *gaps*. The search yielded over 1000 background articles, five systematic reviews, four clinical guidelines, and 62 studies for critical appraisal and synthesis. Finding the right information to answer the clinical question required a search of other sources of evidence. Other types of evidence resources included consulting organizations such as the National Hemophilia Foundation, Worlds Federation of Hemophilia, the National Institutes of Medicine, the Society for Adolescent Medicine, and the American Academy of Pediatrics. Google Scholar was used for searching psychological journals, clinical practice guidelines, and case studies on transition. Collecting and analyzing literature that evaluated patient outcomes was one of the major components in meeting the purpose of this project.

A critical appraisal process was used to organize and analyze the evidence. Critical appraisal is a process used to help the author examine the studies that would be beneficial for the project (Fineout-Overholt, Melnyk, Stillwell, & Williamson, 2015). By using this approach, the DNP project coordinator was able to determine the validity, relevance, and reliability of the literature, as well as whether it applied to the clinical question. The search was limited to studies about youth and young adults in the English language with publication dates between 2005 and 2016 to show if there was evidence to answer the clinical question. The process of collecting literature resulted in finding the best evidence that was significant for exploring this DNP project. The purpose of this DNP project was to address the gap in practice by implementing a transition quick guide into practice as an intervention that will prepare youth with hemophilia to move from the pediatric to the adult clinic. The findings from the research analysis supported that youth who received education sessions with the transition quick guide had an improvement in post-evaluation outcomes.

Significance

The stakeholders making an impact in supporting transition planning within the HTC for the hemophilia population include the National Hemophilia Foundation (NHF), American Pediatric Academy, Centers for Disease and Control (CDC), and Health People 2020. Also, the World Federation of Hemophilia and the Society for Adolescent Medicine are stakeholders that focus on preventing fragmented care among youth within a HTC. The staff members that are necessary in addressing the clinical problem include nurses, a physicians, and social workers in the hemophilia clinic.

This project offered potential contributions to the nursing practice. Nursing contributions to the field of transitional care in the body of literature are limited. The transition quick guide is a tool that will guide nurses in educating and identifying youth who are potentially at risk of falling into a fragmented care gap (The National Alliance to Advance Adolescent Health [NAAAH], 2017). Based on the evidence presented, it is clear that nurses are well positioned to make significant contributions to the nursing practice by ensuring that emerging young adults make a smooth transition to an adult care setting, thus preventing fragmented care.

This project had the potential for transferability to similar practice areas. For example, primary care providers, subspecialists, and other health care professionals in pediatric settings will benefit from using the transition quick guide in preparing youth and young adults for adult care services. Although the transition quick guide could be used in a variety of specialty areas such as sickle Cell, endocrinology, and pulmonology services, the evidence was limited regarding its use for the hemophilia population. For this reason, the project coordinator designed a transition quick guide that was similar to Got Transition's model and implemented it into practice for youth with hemophilia. The Got Transition model is a generic, transition tool for educating youth and young adults on how to manage any disorder. The transition quick-guide in this project is specifically for individuals with hemophilia.

A potential implication for positive social change is the recognition of youth who are unprepared to move safely to the adult hemophilia clinic before they reach 18. Nurses initiate this social change by translating the knowledge gained from literature reviews, the patient's electronic health records (EHRs), and the post data outcome from the transition readiness test. As a result, other disciplines such as general practice staff and specialty services will have access to transition interventions for their practices based on the data collected from this DNP project. In summary, this QI project will show optimal outcomes in using the transition quick guide for youth with hemophilia. Post-test scores from the transition readiness were increased in terms of disease specific knowledge and care management skills by using the transition quick-guide to prepare youth early on transitional care, thus improving healthcare service.

Summary

The absence of a successful transitional healthcare service for youth predisposed youth at a HTC to fragmented care. Fragmented care for individuals with hemophilia is associated with frequent ER and hospital visits, as well as unplanned medical visits due to bleeding complications. As a result, the cost of care related to those preventable visits was high (Johnson & Yi Zhou, 2011). The nurses in the hemophilia practice used the transition quick guide to identify youth who needed transitional care education and resources. The project had a QI design that provided the project coordinator with qualitative data measuring transition readiness among youth with hemophilia for improvement in transitional care. In Section 2, the project coordinator will discuss the background and context of the project, including the model used to inform the project, nursing intervention outcomes, and an introduction of the project.

Section 2: Background and Context

Introduction

The practice problem for this DNP project was that the project site, which is a hemophilia clinic, lacked a transitional care service that prepared youth with hemophilia to learn the basics of hemophilia and improve their self-care management skills. The research question was whether designing and implementing a transition quick guide to use in the hemophilia clinic helped youth increase knowledge of hemophilia and self-care management skills before transferring to an adult hemophilia clinic. The purpose of this project was to address youth with hemophilia falling into a fragmented care gap due to unplanned transition to adult care services. Implementing the transition quick guide into practice will contribute to preparing youth with hemophilia to move from the pediatric to the adult clinic. In this section, the model was discussed and it provided support to the project. The local background and context were reviewed and the project coordinator identified the project team and roles in conducting the project.

Concepts, Models, and Theories

The American Academy of Pediatrics (AAP) recognized that the transitional care process was challenging and time-consuming without a symptomatic approach (McMannus et al., 2015). McEwen and Wills (2011) said that clinical practice guided by theoretical frameworks, models, and theories provides a clear direction for healthcare professionals to test the implementation of interventions. The model chosen for this project is the the plan-do-study-act (PDSA) model. The PDSA model is generally chosen by project coordinator and the medical staff when trying to solve a problem within practice. The PDSA model is a guide to help improve a process. Improving the transition service process for the local hemophilia clinic is small change that the project coordinator is aiming to improve with the PDSA model.

The PDSA Model

Taylor et al., (2013) said that the PDSA model was the systematic series of four steps. Vliet (2009) asserted that the series of steps in the catalyze phase was gaining valuable resources and educational tools for the continuous improvement of a product and process for practice. Today, the PDSA model is widely adopted and used in health care improvements on a global level (Taylor et al., 2013). The project coordinator used the PDSA model to determine whether a small change related to improving transition services for youth, leads to improvement by testing the transition quick guide in the hemophilia clinic. The PDSA model allowed the project coordinator freedom to plan the change of transition services within the hemophilia clinic by identifying the purpose, formulating a hypothesis, collecting data for the hypothesis, analyzing the results, and acting on what was learned. The PDSA allowed the project coordinator, the social worker, and the hematologist to test a change in how they provide transition services to the youth in the real work setting. The purpose of using the PDSA model was to identify if patients were ready to take charge of managing their hemophilia independently before transferring to adult care services.

Definition of Terms

The following terms were defined for this QI project:

Hemophilia: A genetic disorder that causes the individual to have a defective or missing protein needed for the normal clotting process (National Hemophilia Foundation[NHF], 2016).

Antihemophilic Factor Product: A protein agent that is essential in providing normal clotting for individuals with a bleeding disorder (National Hemophilia Foundation, 2016).

Blood Coagulation Cascade: The clotting process of factors (proteins) that control bleeding when a blood vessel is injured or damaged (NHF, 2016)

Spontaneous bleed: Bleeding episodes that occur without a cause (NHF, 2016).

Episodic treatment: Antihemophilic factor product given at the time of a bleeding episode. An episodic treatment is called treatment on demand (World Federation of Hemophilia, 2012).

Prophylaxis: Treating or preventing a bleed before it can occur by infusing factor product two to three times per week (Barry, 2015).

Self-infusion: A process involving infusing factor product by accessing a vein with a butterfly needle (NHF, 2016).

Transitional Care: Healthcare practitioners and staff working collaboratively to maintain the coordination of continuity of healthcare for an individual with hemophilia who moves from one health facility or to another home care model (Joly, 2015).

Relevance to Nursing Practice

Transitional care deals with a broader problem in nursing practice. Osterkamp, Costanzo, Ehrhardt, and Gormley (2013) posited that nurses who work in specialty clinics, there skills were limited in the area of guiding youth through a transition process that prepares youth to gain confidence in hemophilia knowledge and competence in self-care skills. Historically, social workers have the lead role in transitional care because they specialized in the development and psychosocial needs of the youth. However, nurses are needed in the area of transitional care because of their ability to educate patients regarding hemophilia, self-care skills, exploring the literature for best practices and evidence, and writing policies and procedures that are related to the transition process. With advancements in medicine, research, and technology, children with a chronic disorder such as hemophilia, cystic fibrosis, and sickle cell showed that they were living longer; it was essential that nurses have skills in the transition process (Betz, 2012). Youth with hemophilia were expected to independently know about their disorder, demonstrate self-care skills, and show confidence and competence with self-infusion and calculating their factor product (Osterkamp et al., 2013). According to Joly (2015), nurses were pivotal to enhance health and quality of life for the youth; however, they lacked time to effectively educate youth about the transition to adult care. Nurses easily modified it specifically to educate youth with hemophilia (National Center for Health Care Transition [NCHCT], 2017). Nurses have an opportunity and significant role in helping to reduce fragmented care for youth with hemophilia. Using the transition quick guide in this DNP project created a step towards reducing fragmented care through education, thus decreasing ER visits, hospital visits, and reducing healthcare costs in the future.

Based on existing scholarship and research, the current state of nursing practice in the area of transitional care is poor. The influence of nursing as it pertained to transitional care for youth was limited (Betz 2013). Young (2012) highlighted that hemophilia is a lifelong disorder that is typically diagnosed early in life. Existing scholarship and research recommended that patient education and transition tools supported the desired outcome of increasing the youth's confidence in disease specific knowledge and competence in managing their hemophilia. For example, it was important that the individual learn about hemophilia, family history, bleeding symptoms, management of bleeding, and self-infusion skills. Young (2012) argued that physicians in specialty care areas focused primarily on the medical aspect of care and not the developmental, cognitive, and psychodynamics of a youth's health. Young showed that it was imperative that these areas were covered in order to transition the youth safely to an adult care service. Recommendations existed for nursing leaders to provide directions for greater involvement in specialty areas. This was needed to focus on making transition a smoother process for youth and emerging young adults. In summary, the current state of nursing as it pertained to transitional care among youth and emerging young adults was poor. This was largely due to the nurse's lack of participation in transitional care (Betz, 2013; Betz et al., 2013; Joly, 2015; Ladores, 2015). The key to improving the nursing practice in the area of transitional care was for nurses to get involved in exploring the literature, as a result, nurses would find solutions for the problems that still exist in transitional care.

The strategies and standards of practice that were used previously to address this gap-in-practicewere centered on the Got Transition program. Literature showed that the Got Transition program was successful and widely used by various specialty care services for patients with sickle cell, diabetes, and cystic fibrosis (Schwartz et al., 2014). On the other hand, there was limited evidence on Got Transition being used with the hemophilia population. The program was noted being unique because it allowed the healthcare professional to modify the elements to a specific service such as a hemophilia program. Got Transition and the National Center for Health Care Transition developed various tools to help health care providers and staff members promote quality improvement efforts within their clinical practice.

The present DNP project advanced the nursing practice in several ways through the literature. Nurses were found instrumental in implementing evidence in practice and they were meticulously evaluating the outcomes. The DNP project showed potential in advancing the nursing practice. The project provided the project coordinator with the opportunity to explore the evidence of peer-reviewed literature and systematic reviews. Also, the project coordinator was able to find other methods of assessing transition readiness with youth. Evidence-based practice was relevant to nurses because it determined the impact on health care delivery, patient outcome, and cost (Melnyk & Fineout-Overholt, 2015). The ultimate goal of developing the DNP project and showing the evidence was to provide the youth with a safe and successful transfer to the adult hemophilia clinic in the future.

Local Background and Context

The local evidence within the hemophilia clinic provided relevance of the importance of youth being unprepared to transfer from a pediatric to adult care service. The healthcare staff within the hemophilia clinic at the project's site frequently complained that youth were not prepared to transfer to their service. Based on yearly audits for the hemophilia program, evidence obtained from the EHR and ATHN database showed that there was an increased rate of youth ages below the age of 18 years utilizing the ER and were hospitalized for preventable complications such as joint bleeds and joint disabilities. The evidence was relevant and it justified the project-focused question of whether the transition quick-guide enabled youth to increase in basic hemophilia knowledge and self-management skills. A well-planned transition process was shown to have benefited youth with hemophilia and supported that education was needed to provide youth with a quality of life (Breakey et al. 2010; Schwart et al., 2014). Data was collected to determine if implementing the transition quick-guide increased the youth's knowledge in hemophilia and increased the youth skills in managing their care.

The project's local site was the pediatric hemophilia clinic where the DNP project was addressed. The hemophilia clinic was part of a Hemophilia Treatment Center (HTC) located in the Southeast region of the United States. The project coordinator was the author of this DNP project. The project's site was a site that offered comprehensive care to individuals with hemophilia. The project's local site established a hemophilia treatment center (HTC) in 1999, a specialty service for pediatric and adult patients with hemophilia. The DNP project was based on a quality improvement plan that used a systematic approach to assess the health services and to improve the transitional care process within the HTC. The HTC was based on a comprehensive care model because of the complexity and the management focus of the disorder (Bauer, 2015). Literature showed that the health care system was complex and ever changing with discoveries (Melnyk & Fineout-Overholt, 2015). For this reason, the mission of the organization focused on providing leadership, discovery in research, and educational opportunities that were beneficial to support social change and to improve health care for all patients and families. The DNP project was aligned with both the mission and the vision set by the project's local site. The vision of the project's site was to strive for first-class services that individuals would have a destination of choices for education, high quality of care, research discovery, and innovative. With the project's site vision and mission, the project coordinator was given the opportunity to explore discoveries from peer-reviewed and systematic reviews related to health care services in transitional care.

The definitions of the locally used terms that were relevant to understanding the doctoral project included: 1) comprehensive care, and 2) fragmented. Comprehensive was relevant to understanding the DNP project. The primary reason to understand the term comprehensive was that it focused on the individual, which is an important aspect of quality improvement (HRSA, 2011). Fragmented care was a term described in health care when the patient's care was disjointed because the health care system failed the patient. Fragmented care was shown in literature to be associated with high incidence of hospitalization, frequent ER visits, non- adherence to medical therapy, high health care cost, increased morbidity and mortality rates, and poor quality of care among patients.

The DNP project, which was a quality improvement project, aimed to improve the health care system that promoted transitional care services within the HTC, thus, preventing a fragmented care gap.

The federal and state contexts that were applicable to the problem in the DNP project were related to youth being unprepared for transition. Successful transition included having the knowledge and understanding of hemophilia and confidence skills in self-care skills needed to manage hemophilia. National surveys that focused on the patients' needs were done in 2013 by the National Hemophilia Program Coordinating Center (NHPCC), in collaboration with the U.S. Regional Hemophilia Network (RHN). The surveys addressed gaps in needed services for the hemophilia population. Based on the results of the survey, transitioning planning was identified as a national priority for individuals with chronic conditions such as hemophilia. The national survey revealed that only 65% of the youth received the transition outcome. In comparison, there was a 20% increase from the 2009-2010 needs assessment; however, there was room to improve the transition service process within the hemophilia clinics, locally. Identifying gaps in practices provided opportunities for the organization to improve practice by utilizing evidence-based strategies (Melnyk & Fineout-Overholt, 2015). The project conclusions recommended that more information on transition for the hemophilia population was needed for youth to make a smooth and healthy transition to the adult hemophilia clinic (Simmons et al., 2014). The project coordinator implemented the transition quick-guide through the DNP project. As a result, the staff in the hemophilia clinic had a product to guide youth with hemophilia in making a healthy transfer to the adult hemophilia clinic.

Role of the DNP Student

The project coordinator of the DNP project explored the transition quick-guide by educating the youth to see whether there was an increase in their basic hemophilia knowledge and self-care management skills. The professional context of the project coordinator was a Doctoral of Nursing Practice (DNP) student at Walden University. This quality improvement project explored the disease specific knowledge and self-care management skills of youth's with hemophilia by utilizing a modified version of the transition quick-guide by Got Transition. The DNP coordinator implemented and evaluated the project. In the project coordinator's daily practice, viewing yearly audits was part of the nursing responsibilities. The project coordinator witnessed first-hand that youth were lost to following-up care with the hematologist, decreased adherence to treatment therapy, and they lost insurance coverage after transferring to the adult hemophilia clinic. For this project, the project coordinator provided transitional care education and assessments for 10 participants. The project coordinator was enthused about exploring the literature, designing the transition tool, and implementing the project. This project provided the project coordinator with the opportunity to not only educate but to improve a poorly managed care gap related to transitional care for youth with hemophilia. The perspective that affected the motivation of this project was that parents didn't have a full understanding of letting their youth take steps in making health decisions about their care. The bias concerns related to this DNP project were encountered during the implementation of the project. Limiting the project to only participants with hemophilia was a limitation. Also, limiting the project to only 10 participants was a limitation. Including more participants would have provided the coordinator with richer and meaningful data. The future recommendations for the project was to design a full operational transition program for youth with all bleeding disorder.

Role of the Project Team

The process of providing informed information to the team for this DNP project included describing the following: 1) The background information, 2) The evidence from peer-reviewed literature, and 3) The information to the healthcare team. Literature highlighted that health professionals were aware of the problems that existed around health care transition; however, many did not know where to start the process of solving the problem. For example, Luther, Martial, and Barra (2017) explained that care coordination was the best approach to improving the healthcare system. One of the greatest challenges that healthcare leaders faced was ensuring that health professionals and multidisciplinary services worked collaboratively. For this DNP project, the project coordinator formed a team that included a hematologist, social worker, and the project coordinator. The stakeholders that were involved with the DNP project included the vice president for Hemophilia of Georgia, who provided the hemophilia grant to the organization each year. The Regional director was another stakeholder who had the responsibility of monitoring HTCs for quality improvement projects. Finally, the last stakeholder was the administrators of the pediatric department who directed the daily operation of the healthcare services. The coordination of a team was an essential step to start the process of improving transition health care for youth with hemophilia (Luther et al., (2017). The team members received an agenda by email for the first scheduled meeting. The team discussed several agenda items at the first meeting. The items of discussion included: 1) the purpose of a transition QI project, 2) Healthcare service assessment results, 3) team roles, 4) communication methods, 5) cost, 6) project outcome, 7) Times/places for meetings, and 8) the process of reviewing the literature. The project coordinator discussed each item and distributed additional information for the team to understand the purposes. The additional information included providing them with copies of the national assessment articles, utilization reviews of patient's hospital and ER visits, and peer-reviewed articles. The administrators of HRSA explained that this approach allowed the team to address the issues together and to ensure or improve the quality of care (HRSA, 2011). The project coordinator educated the team on the step-by-step process of appraising the evidence. According to Fineout-Overholt, Melnyk, Stillwell, and Willliamson (2010), evaluating the evidence was a problem-solving method that helped healthcare providers gain the best evidence from studies in providing high-quality care. After the first meeting, we met every other Friday at 1 pm in the large conference room in the pediatric hemophilic clinic A group email was developed by the project coordinator to address any questions or concerns before the next meeting. In summary, the DNP project was a quality improvement approach that required the collaboration of a multidisciplinary team and stakeholders. In this section, the project coordinator explained the processes by which communication was disseminated to the team that was involved with the project. The outcome of providing the team with the purpose, review of the evidence, and other informational needs were to provide action plans that lead to measurable improvement in the healthcare services of the hemophilia population.

There were opportunities for team members to share their insight relative to the DNP project in the acknowledgment section of the DNP paper. Also, the team members for the DNP project shared information to the participants for contributing to the evidence in addressing the practice-focused question. The project question asked whether implementing a transition quick-guide for the hemophilia clinic enabled the youth to understand hemophilia and increased self-management skills before transferring to adult care services. The team members had the opportunity to interact with the youth by helping to explain the project. For example, the hematologist had the role of explaining why the project is needed and what the benefits were for the youth to participate in the project. Communication was vital to the champion, multidisciplinary team, and the patients during this time in helping the patient gain trust in the team (Micklos, 2014). The project coordinator described the participant's contribution to answering the clinical question in section 3 of the project.

The timeline and responsibilities of the team members to review and provide feedback at the weekly meetings were important. One of the major challenges that healthcare professionals faced with implementing a quality improvement project was time constraint with team members. Researchers asserted that carving out time to meet each members' schedule was frustrating, but it was achievable when the leader was organized, creative, and flexible (Bissett, Cvach, and White, 2016). The project coordinator as the champion of the project described the timeline and responsibilities to the team members at the first meeting. The review of the evidence was due on Wednesday before each session. After consideration of the assigned literature, each team member was responsible for emailing the team answers to the critical appraisal checklist. Utilizing this approach helped the team manage time with this challenging process. This method usually helped members to elaborate and get engaged in effective communication for scheduled meetings (Fineout-Overholt et al., 2010). Transitioning and transferring of patients was a concern for both pediatric and adult care services, therefore, collecting clinical evidence encompassed a team approach (Micklos, 2016). The physician role was to provide the nurse and the team with 10 patients according to the inclusion criteria. The inclusion criteria include 1) age, 2) diagnosis of hemophilia, 3) assent and consent to participate, and 4) time to attend. The social worker had a significant role in advertising for the project and phoning the participant to advertise the project. In summary, a timeline and the responsibilities of each member were explained to the team member at the initial meeting. The project coordinator allowed each team member to verbalize concerns, barriers, and other ways of receiving feedback on the DNP results.

Summary

There was a broad consensus among scholars that focused on gaps in practice. The gaps in practice were related to the lack of health care transition services for youth in clinic that prepared youth for adult care services, thus, prevented the fragmentation of the healthcare system. The health care system in pediatric settings had not effectively prepared youth with complex conditions such as hemophilia to transfer to adult cares.

Transfer of youth in clinic usually occurred during the time of an ER or hospital visit, which led to poor outcomes. Unplanned transfer of care was related to poor outcomes such as complications, medication adherence issues, and an increasing number of patients lost to follow-up care with a hematologist. The project coordinator utilized the transition quick-guide to educate the youth on how to manage their hemophilia before the age of 18 years. A QI approach was used for this DNP project. The implication of positive social change was related to increasing the recognition of how youth were unprepared to transition due to the lack of a health care transition service. The lack of a health care transition service was the impacting contributor to fragmented care that was related to an increase in ER visits, hospital visits, and high healthcare cost and from that, the nursing practice gained knowledge in the combat against fragmented care. In Section 3, the DNP project coordinator provided evidence for the project by providing the collection and analysis of evidence. The section showed the findings related to systematic reviews, surveys, briefings, and classic articles. This section provided the reader with the literature review, information on participants, sources of evidences, models, and procedures used to collect the evidence.

Section 3: Collection and Analysis of Evidence

Introduction

The problem of the lack of transition services for youth with chronic conditions such as hemophilia, cystic fibrosis, and sickle cell continues to be a challenge for health care staff in specialty areas. The practice problem was that the local site lacked transitional care services for youth with hemophilia preparing them to understand basic hemophilia knowledge and self-care management skills before transferring them to an adult hemophilia clinic. Based on a review of EHR and the American Thrombosis and Hemostasis Network (ATHN) database at the project's practice site, there was a trend associated with youth seen in the ER or hospitalized for care after they were transferred to the adult hemophilia clinic. The pediatric hemophilia providers usually transferred youth by the age of 18 to the adult clinic. Vaks et al. (2016) recommended initiating transition programs early at the age of 12 to diminish the gap in transition care services for youth with hemophilia.

Youth who are less than 18 lack competency and confidence in managing their disorder on a daily basis (Vaks et al., 2016). According to Vaks et al. (2016), most youth depend on their parent or caregiver to manage their disorder after transferring to an adult hemophilia clinic. As a result, parents or caregivers are not able to continue supporting youth after the age of 18 in managing their disorder, providing guidance in adhering to medication therapy, and maintaining insurance coverage. In Section 3, the project coordinator will provide evidence for the DNP project by identifying sources of evidence needed to show the problems that exist with transitional care among participants with hemophilia. The section will also explore the foundational evidence for this project through a systematic review of relevant journals and professional organizations to provide an analysis and synthesis of the literature related to youth transitioning to adult care services.

Practice-focused Question

The local practice problem was youth with hemophilia lacks knowledge in hemophilia and there is a deficit in self-care management skills. The practice- focused question concerned whether using a transition quick guide with hemophilia participants who are less than 18 years old increase their knowledge of hemophilia and self-care management skills as evidenced by increased post-test scores in transition readiness outcomes. The purpose of DNP project was to improve the transitional care service gap in practice by exploring the use of the transition quick guide in the hemophilia clinic. This project focused on improving the youth's quality of life and meeting their unmet needs related to transitional care. The project proposed to implement the transition quick guide as a QI approach in preparing youth on transition readiness before transferring them to the adult hemophilia clinic, thus increasing their knowledge regarding basic hemophilia and self-care management skills.

Sources of Evidence

The project coordinator obtained approval from the International Review Board (IRB) and consent from parents before any sources of evidence were collected from participants. The sources of evidence on which the project coordinator relied on to address the practice-focused question were the data from pre and posttest. The project coordinator collected demographic data from the EHRs and data such as age, diagnosis, education related to diagnosis, transition readiness assessment, bleeding episodes, and follow-up of care appointments between 2015 and 2017. The project coordinator used the ATHN database to collect data from the participants on education related to diagnosis, transition readiness assessments, and bleeding episodes. The rationale for collecting data from the ATHN database was to retrieve information that may have been missed in EHRs. The ATHN database was the backup system for obtaining the data. The local site of the project was authorized to use the database for patient care through a grant and contract for the hemophilia program. The project coordinator obtained permission through IRB and the site administrator to obtain data from the ATHN database.

Quality data was significant in addressing the problem that existed with the hemophilia clinic and the practice-focused question. Collecting and performing an analysis of the data provided supportive evidence for the need of the project coordinator, social worker, and the hematologist to implement interventions for improving transitional care services in the hemophilia clinic. The project coordinator obtained documentation that related to what was being taught, how often, and the results of the education. Transition readiness assessment data provided evidence on the specific assessment tool such as the UNC TRxANSITION used, how often it was used, and the results from using UNC TRxANSITION tool. The documentation on bleeding episodes showed how many bleeds per year and who managed them. Information on follow-up care provided evidence regarding how often the youth with hemophilia was seen in clinic to ensure adherence to care.

Collecting and analyzing data was the appropriate way to address the practice-focused question. Data provided the future direction in improving the transitional care service for individuals with hemophilia. Healthcare organizations that were without a transition process that promoted education in hemophilia or chronic conditions such as sickle cell or cystic fibrosis caused an abrupt transfer of the youth to adult care services. Youth who are abruptly transferred to an adult service are at risk for fragmented care (Quon et al., 2015). The project coordinator linked the significances of the problem to nursing and the clinical practice, thus addressing the practice-focused question. Also, the collection and analysis were essential in providing the appropriate way to address the practice-focused question while preventing bias and examine the meaning and validity of the study findings and whether the theoretical knowledge found in the literature (Burns & Grove, 2009). The collection and analysis of evidence is essential for healthcare providers, researchers, and nurses to continue providing knowledge and interventions that are evidence-based, as well as the implementation of future interventions.

Published Outcomes and Research

The databases and search engines used to find outcomes and research related to the practice problem included: Cochrane Database of Systematic Reviews (CINAHL), Ovid, MEDLINE Simultaneous Search, ProQuest, and Health and Psychosocial Instruments. Other databases and search engines included Goggle Scholar to identify government agencies and foundations that reported data from needs assessments surveys, briefings, and healthcare updates. The agencies and foundations that were included in the search were: NHF, CDC, ASH, GOT Transition Initiative, the National Alliance to Advance Adolescent Health (NAAAH), and the National Institute for Health (NIH). These databases provided educational materials, resources, guides, and tools related to the impact of unprepared adolescents and young adults transitioning to adult healthcare practices. The information that was retrieved from those sources also provided the project coordinator with the limitations of various studies related to transitioning youth. Also, the reports from the NHF and the CDC provided data related to decreased satisfaction in transition youth due to unmet needs in transition, strategies, and recommendations for future research in the testing of existing measures, developing new measures to establish evidence-based tools and the development of educational tools specific for the hemophilia population.

The key search terms and combinations of search terms to be used included transition, transfer, adolescent, youth, healthcare, hemophilia, bleeding disorder, adherence, problems, readiness, measures, and psychosocial. Combinations of search terms used included Healthy People 2020, self-determination, quality healthcare, self-care, and transition to adult healthcare. The scope of this review in terms of years, types of literature, and the sources searched were guided by the practice-focused question. The search was limited to 7 years, the types of literature were peer reviewed, historical, scholarly journals, and systematic reviews that recognized transitional care in youth with hemophilia. The search yielded over 1200 background articles with over 40 selected for the inclusion criteria, 5 systematic reviews, 3 major guidelines, and 15 studies for rapid appraisal and synthesis.

The search of the literature and sources were exhaustive and comprehensive by using the rapid appraisal and synthesis approach. The project coordinator used an evidence-based model to rapidly appraise and synthesis the literature (Melnyk & Fineout-Overholt, 2013). The project coordinator determined which studies to keep, the level of evidence in each study, whether the studies were conducted, and how valid were the studies in answering the practice-focused question. The body of evidence revealed various transition process and programs, readiness assessment tools, recommendations for future research, and strategies for implementing successful transition programs.

Literature Review

Introduction

Youth with chronic conditions such as hemophilia presented unique needs and challenges. A need that was essential as the youth moved through the life span was their ability to transition from a pediatric to adult healthcare services (Ladores, 2015). The practice problem for the project's local site was that there was a lack of transitional care service that prepared youth who are less than 18 years of age to understand the basic knowledge of hemophilia, and competency in self-care management skills. These skills and knowledge were proven through literature to be needed before the youth moved from a pediatric hemophilia clinic to and adult hemophilia clinic. The project question asked, "Did using a transition quick-guide with hemophilia participants who are less than 18 years old increased their knowledge of basic hemophilia and increased their knowledge of self-care management skills as evidenced by increased post-test outcome?" Evidence suggested that early education in transitional care was key to improving the transition service gap in practice (Vaks et al., 2016). Evidence from the project's local site in yearly audits showed that youth who were transferred to the adult hemophilia clinic at the age of 18 years were frequently seen in the ER. They were seen for preventable joint bleed complications as a result of lacking specific education related to hemophilia. The audits also showed that there was no focused education on transitional care relating to youth learning basic hemophilia, how to manage a bleed independently, and the skill demonstration of self-infusing with a factor product. Providing knowledge and resources to the youth for their transition journey would not only improve the gap in practice but also they decreased the risk of fragmented care in youth. Nurses had an integral part in improving the gap in practice for this DNP project. Nurses were found to be essential in addressing this problem in practice by providing youth with an educational intervention such as the transition quick-guide. As a result, care was improved, self-care interventions improved, and the cost for care will be managed in the future. The literature review presented in this next section analyzed the evidence from the various articles. The evidence for this literature review covered the main focus of the DNP project, which included: 1) Hemophilia statistics and the overall effects on youth, 2) the unmet needs in transitional care among youth, and 3) a nursing intervention such as the transition quick-guide for educational purposes in transitional care.

Hemophilia Statistics and the Overall Effects on Youth

Approximately 750,000 youth in the United States were found being diagnosed with chronic disorders such as hemophilia. They reached adulthood because of the advancement in technology and medicine each year (Betz, Labo, Nehring, Bui, 2013). Yet, with the upward trend of life expectancy of the youth, formalized systems of transitional care were found lacking in order to move pediatrics to adult care services (Betz, 2013). For decades, this growing dilemma has provoked widespread calls from federal and medical services such as the National Hemophilia Foundation (NHF), Centers for Disease Control and Prevention (CDC), Healthy People 2020, and Got Transition, which urged healthcare providers to develop a transition process that would facilitate education and skills. Ultimately, transition processes aided youth with hemophilia in moving from parent centered to independence (Betz, 2013). Hemophilia is a life-long bleeding disorder that exposed the individual to major complications such as joint disability, organ failure, and even death (Breakley, Blanchette, Bolton-Maggs, 2010). Breakey et al. (2010) argued that ineffective transition results in deterioration of the overall health and quality of life (QOL) for the youth with hemophilia. Recurrent joint bleeds was a major debilitative problem found in literature, which had a life-long impact on function and QOL for an individual with hemophilia. Additionally, poor access to care, poor compliance, and knowledge gap lead to recurrent joint bleeding that decreased the youth's function and quality of life (QOL) (Aldiss, Ellis, Cass, Pettigrew, Rose, & Gibson, 2015). Factor replacement therapy was used and was the preferred treatment for individuals with hemophilia. Skipping treatments or not adhering to the prescribed plan resulted in frequent and severe pain with probable bleeding episodes. Since hemophilia is a lifelong disorder, youth must learn early to manage their disorder with confidence and competency. The optimal outcomes were assured as a good quality of life and the prevention of costly ER or hospital visits. Health People 2020 issued healthcare provided a goal to increase the percentage from 40% to 85.3% in transitional care service for youth by 2020. The DNP project provided the project coordinator with an opportunity to implement the transition quick-guide for other nurses to influence quality outcomes, increase knowledge on basic hemophilia, and self-care skills by increasing the transitional care needs for youth with hemophilia.

Unmet Needs in Transitional Care among Youth

Youth with hemophilia faced unique needs and challenges as they underwent rapid changes in social, emotional, and cognitive capabilities that were associated with the unmet needs in transitional care (Quon et al., 2015). Even for healthy youth, the transition to independence was complicated. Often youth with hemophilia had far-reaching consequences than healthy youth because hemophilia was treated in a continuous process of changes. Those changes required an approach that dealt with how the individual manage hemophilia, which was called a transitional approach (Chesshir, Brown, Byerley, & Ward-Begnoche, 2013; Guy, 2012; Quon et al., 2015). Breakey et al., (2010) highlighted three significant issues that affected youth with hemophilia. The issues included accepting the need for self-management, maintaining adherence to therapy, and coping with the impact that hemophilia had on their physical and social life. Challenges such as overbearing parents had a negative effect on the youth's self-care needs. For example, almost 25% of youth 17.5 years still required parents to assist in their hemophilia-related care. The negative outcome was that the youth became inexperienced in how to identify and properly manage a bleeding episode. This example showed that parents often played a huge role in the youth's day-to-day treatment routine, even after they reached the age of 18 years. Breakley et al., 2010 suggested that healthcare providers educated youth to take over the responsibility of self-care management by the age of 12 years, thus, improving the youth's unmet need in transition. Quon et al., (2015) argued that there was comprehensive care, extensive childhood prophylaxis, and safer factor products for the hemophilia population; however, transitional care related to understanding hemophilia, education on confidence and competency in self-management skills was needed. The importance of adhering to treatment was low in the hemophilia population. Adhering to a treatment regimen required that the youth prioritized their therapy around family, school, work, or social gatherings. Evidence showed that an unplanned transition and difficult transition led to decreased compliance, deterioration of overall health, and poor QOL in youth with hemophilia (Breakey et al., 2010). In a Scandinavian study, the findings showed that 40% of youth with hemophilia reported that they did not follow their treatment plan as prescribed. In addition, an international survey of nurses from several hemophilia treatment centers reported that there was a significant decrease in adherence to treatment plans from 90% in age 0-12 years down to 54% in the 13-18 years age group, and a further decrease to 36% in the 19 -28 year age group. The surveys showed that the need to educate youth early on transition preparation was high (Breakey et al., 2010). Breakey et al., (2010) also showed in another survey that youth were challenged in their social life. Living with hemophilia hindered them from participating in various sports, going to parties, having relationships, and gaining employment. As a result, poor compliance with their treatment led to recurrent joint bleeds, ER visits, or hospitalization, and a life-long impact on QOL. The transition quick-guide was a tool that nurses utilized in the hemophilia clinic to educate youth on their transitional care needs before the age of 18 years, thus, resulting in improved intervention outcomes and improved quality of life.

Chesshir et al., (2013) argued that issues associated with transition affected all patients; however, only 17% patients with special needs such as hemophilia reported a planned transition to adult health care. Transition was challenging for youth and their parents, however, proper planning and education made transition less problematic. McManus et al., (2013) reported that in a National Survey, only 40% of sample size of 17,000 youth with special healthcare needs such hemophilia, their transitional care needs was met by their provider. This survey showed that youth with special needs such as hemophilia was not receiving adequate education on transition preparation for an adult care setting. In Sharma, O'Hare, Antonelli, and Sawicki (2014), they revealed that it was important for health care providers to educate youth on self-management skills; however, it was equally important to educate them on a specific disorder such as hemophilia. It was also revealed that providers needed to help youth understand the rationale of transition from child-oriented to adult-oriented healthcare. This DNP project provided the project coordinator with the opportunity to educate the youth using the transition quick-guide and to assess their readiness to transition with the TRxANSITION scale. The data analysis showed an increased in post-test outcome.

Nursing Invention in Transitional Care for Youth

Over the past decade, the nursing profession was found in literature to play vital role in coordinating the care of hemophilia, educating, writing policy, and providing advocacy for patients at hemophilia treatment centers (HTC) (Butler et al., 2015). Kelly (2014) highlighted that transitional care nurses were found over a decade ago. There were increased amounts of demands from health care organizations such as the NHF, CDC, and the IHI for providers to implement transition services and programs into practice. Health care organizations reported that youth were experiencing abrupt and unplanned transition from pediatric care to adult care services that caused healthcare consequences such as frequent ER and hospital visits for complicated bleeding episodes for youth with hemophilia. Kelly (2014) argued that healthcare providers were not held accountable for the responsibility of developing a transition process,a process that led youth to become confident and competent in taking charge of their hemophilia before the age of 18 years. Kelly (2014) posited that nurses were essential disciplines that improved the youth's transition service needs before the age of 18 years. Betz (2013) asserted that with the increased life expectancy in youth, new services such as healthcare transition were needed to address the youth's long-term health service needs and support. Healthcare disciplines such as physicians have provided the implementation of healthcare transition in a medical, policy and research approach. In contrast, nurses had the opportunity to influence transitional care services for youth with hemophilia by using an educational, advocacy, and support approach; however, the translation of evidence in transitional care service for the nursing practice was found limited. According to Sharma (2013) nurses had a better approach of sustaining contact with youth because they were able to assess the needs of the youth and communicate the youth's needs effectively. Similarly, Davidson et al., (2015) reported the findings from a web-based survey that assessed the provider-reported utilization of 11Essential Steps for transitioning youth. The survey was distributed to 376 disciplines such as physicians, nurses, social workers, and residents. The survey showed that respondents identified nurses were more likely to meet transition needs of youth, scoring >7 compared to other disciplines. The demand to implement transition processes within HTC across the country was high. The project's local site was a HTC that was without a transition process. Education was the main focus of the comprehensive care model at a HTC; however, educating youth who are less than 18 years was found low. With an understanding that part of the nurse's role in the HTC was enhancing health, promoting a good quality of life, educating, and providing advocacy for youth, the project's coordinator proposed the development and implementation of the transition quick-guide. McLaughlin et al., (2016) utilized the transition quick-guide and other resources from Got Transition to illustrate best practices in transition for youth with special needs. The study used a case study approach at a Rhode Island hospital. A panel discussion on transitioning youth to adult care health services was part of the learning collaborative. The study introduced various transition resources for healthcare providers to use in educating and guiding youth and their families. The resources included a variety of resources from Got Transition. For example, the transition quick-guide tool, readiness assessment tools, and a tip sheet to start the transition process were utilized in the study. The validity of the transition quick-guide was not noted in the study; however, the outcome of the study was providing essential transition resources to health care providers that showed improvement in transition at several healthcare organizations. Healthcare organizations such as academic clinics, HTC's, and specialty clinics were among a few (McLaughlin et al., 2016). The transition quick-guide was an educational tool that could be modified to meet specific needs of the individual. The modification was discussed in the procedure section of this paper. In conclusion, the current state of transitional care for youth with hemophilia was found disjointed and unplanned (Bryant & Walsh, 2009). Nurses could have used this opportunity to influence translation of evidence into practice by improving the unmet needs of youth with hemophilia. Educating youth in transitional care should have begun early. One way to influence the translation of evidence included the development and the implementation of the transition quick-guide into practice for youth with hemophilia. The use of nursing interventions had the capability to help youth have a successful and safe transfer, and to improve healthcare cost. For this DNP project, the focus remained on educating the youth with the transition quick-guide and an increased post-intervention outcome.

Archival and Operational Data

The project coordinator obtained approval from Walden University and the project site's IRB. Data was collected from the power chart office information system at the project's local site to provide information on the 10 participants that met the inclusion criteria. Parental consent and the participant's assent were obtained prior to data collection. A copy of the consent and assent forms was provided to Walden's IRB during the application process. Participants completed a pretest before the project coordinator initiated the education by using the transition quick-guide. Each participant completed a post-test after the education session. The percent of change between pre and posttest was used to answer the project's question. Demographics including race, age, and diagnosis were collected. Additional data that was relevant to archival and operational collection included historical data related to education in transition readiness assessments, the number of bleeding episodes within the last year, and follow-up of care appointments dating 2015- 2017. The justification of the relevance of the data collection was to support answering the question of whether designing and implementing a transition quick-guide increased knowledge on basic hemophilia and self-care management skills in youth with hemophilia as evidenced by increased post-test scores.

Evidence Generated for the Doctoral Project

Participants

The individuals who contributed evidence to address the practice-focused question were youth who had a diagnosis of hemophilia. A convenience sample size of 10 participants was included in the DNP project. The pediatric hemophilia clinic was the location for the DNP QI project. The participants were selected through an inclusion approach. Youth who met the following criteria were eligible for project participation: 1) Age 12 to 17 years, 2) English speaking, 4) the ability to read and write, 5) confirmed diagnosis of Hemophilia (documented labs), 6) patient of the hemophilia clinic, and 7) Parents' consent and child assent. The relevance of choosing the participants for answering the practice-focused question was to utilize a QI project on a small scale in exploring the use of transition quick-guide in the hemophilia clinic. The approach used was to see if educating the youth with the transition quick-guide increased the youth's knowledge in basic hemophilia and self-care management skills. The outcome for youth learning this information was an increased post-test. Youth who contributed evidence to this DNP project increased their scores in youth's transition readiness skills and an increase in knowledge of hemophilia, thus, preventing fragmented care in the future.

Procedures

In this proposed DNP quality improvement project, the project coordinator obtained IRB approval from Walden University and the project's local site to conduct the project. Potential participants were recruited to participate in the project by issuing fliers to them in clinic. The project coordinator and social worker issued the fliers out to the participants and the parents. The fliers provided an overview of the project, inclusion and exclusion criteria, and an honorarium supplement of $10 gift care to Target. Clinical health records were reviewed at the project's local site for 1 week on youth 12- 17 years that would participant in the project. Information that was reviewed is the age, diagnosis, and education on hemophilia and transition readiness, follow-up care visits, and the number of bleeding episodes. The project coordinator assessed and evaluated the participants by using the transition quick-guide. The data was collected from the pre/posttest scores using the UNC TRxANSITION assessment tool (HRSA, 2011). By using various methods of collecting evidence, the data analysis demonstrates how the results aligned with project constructs.

Instruments

In the next section, the DNP project coordinator provided a description of each model and the tools that were used for the project. The following model and tools were used for this DNP project: the Plan-Do-Study-Act cycle (PDSA), the Transition Quick-Guide, UNC TRxANSITION assessment tool for the pre-posttest. Before utilizing the tools or instruments with the participants, the project coordinator obtained consent from the parents and assent from the participants.

PDSA Cycle

A PDSA cycle was the model used to test the changes on a small and flexible scale (Marcellus & Harrison, 2012; HRSA, 2011). The PDSA was a systematic process for gaining information and knowledge on how to continue improving a process, service, or product. Dr. Shewart introduced the cycle to Dr. W. Edwards Deming, who later developed the PDSA (Vliet, 2009). The PDSA cycle was one of the most common methodologies used by healthcare organizations, businesses, and the industrial world. In literature, the PDSA was deemed as a tool with reliability in improving quality of care, safety, and patient satisfaction. The procedure in using the PDSA allowed rapid cycles, the flexibility to do a pilot test, see what happened when the test was run, see what problems were encountered that you can learn from to improve on the process or service. The project coordinator plans to test pilot 2 of the 10 youth with hemophilia using the transition quick-guide. Finally, the last cycle allowed the project coordinator and the team to act on the results or abandon the pilot efforts (Taylor et al., 2013). In Marcellus & Harrison (2012), the PDSA cycles were used to demonstrate the reliability in improving how they transitioned premature infants from a feeding tube to oral feeds. The project authors concluded by showing that the PDSA cycles improved parent and care provider satisfaction in transition, and they were able to evaluate and implement a stepwise oral infant feeding guide for parents and the care providers in a neonatal setting. The PDSA cycle was a reliable model that has been used for centuries. The project coordinator utilized the PDSA for this quality improvement project to explore the use of the transition quick-guide for improving the transition readiness process in the pediatric hemophilia clinic, for youth 12- 17 years of age.

Transition Quick-Guide

The transition quick-guide was found to be a resourceful guide for youth and young adults, to include those with chronic conditions or disabilities. The transition quick-guide was created through an Alliance with the Youth Transitions Collaborative, Got Transition/Center for Health Care Transition Improvement. According to Harwood, McManus, & White (2017), they suggested that adopting Got transition quick-guide and other resources from Got Transition showed reliable results. It was also used to improve education and address the transitional care needs of youth with chronic conditions such as hemophilia. The transition quick-guide was used to help individuals learn to gain knowledge on their condition, self-care and decision making skills for taking charge of their health before the age of 18 years. The project coordinator used the transition quick-guide tool in a semi-structured interview. The project coordinator explored whether the transition quick-guide was effective in educating youth on basic hemophilia knowledge and self-management skills. The transition quick-guide was used and modified with permission through an Alliance with the Youth Transitions Collaborative, Got Transition/Center for Health Care Transition Improvement group (Got Transition, 2016). For this DNP project, the modifications included the exclusion of the education on insurance and communication skills. The project coordinator used the guide for youth 12 to 17 year olds in this DNP project. Modifications changed the reliability and validity for this DNP; therefore, documentation was outlined in the limitation section. The transition quick guide will be found in **(Appendix C).**

UNC TRxANSITION Scale

The UNC TRxANSITION was a transition readiness scale used by many healthcare providers to screen the youth ability to move from a pediatric to an adult setting. Dr. Ferris created the UNC TRxANSITION with the assistants of several colleagues at the University of North Carolina (UNC), Chapel Hill. The UNC TRxANSITION was a 10-domain, 32 item questionnaire that health professionals could modify. Dr. Ferris gave permission to use and modify the UNC TRxANSITION scale for this DNP project (See Appendix A). The 10 domains includes: the type of Illness, medication, Adherence, Nutrition, self-management, reproduction effects (genetics), career, insurance, support system/communication, and new healthcare provider. Domains such as nutrition, career, insurance, and support/communication were not part of the youth's testing process. Administering the instrument took 8 minutes for the participant to complete. The UNC TRxANSITION instrument was used as the pre/posttest in measuring 6 of the 10 domains of transition readiness before and after using the transition quick-guide with the participants in the DNP project (Zhang, Ho, & Kennedy, 2014). UNC TRxANSITION was one of the leading readiness tools used by Got Transition because it could be modified and scored. According to Zhang (2014), if the participant didn't give enough information for a particular question, the project coordinator could prompt the participant to give additional information. Based on literature reviews, the construct validity and reliability for the UNC TRxANSITION was promising in measuring overall transition readiness (Schwart et., 2014; Zhang et al., 2014). Systematic reviews also showed that the UNC TRxANSITION was recognized as a valid and reliable instrument for measuring health care transition, self-management skills and communication skills in youth, young adults with chronic conditions (Ferris et al., 2012). For this DNP project, the project coordinator explored the use of the UNC TRxANSITION scale in improving transition readiness for youth with hemophilia in the pediatric hemophilia clinic.

Procedure Steps for the Project

After receiving approval from the site administrators, IRB, and faculty at Walden University, the project coordinator and team members conducted the project in steps. The steps for this project included obtaining data from the participants through the hemophilia clinic and the participant's school. The schools that were included were middle and high schools within 25 miles of the local area. The informed consent from parents and assent from the participants were explained, reviewed, and signed by the parent and youth before the sessions started. The following procedure steps included:

Step 1. Obtained approval from site administrators, IRB, the faculty at Walden University, and the local middle or high schools of the participants.

Step 2. Fliers were mailed and issued to the parent and participant interested in the project. The fliers provided the description of project, purpose, and objective, location, and an honorary supplement of a $10 gift card from Target.

Step 3. The project coordinator accessed the participants EHR to collect demographic data, which was de-identified for the use in this project.

Step 4. Data was entered into an Excel database and stored on a password-protected computer in the project coordinator office who would only have access. The office was locked when the project coordinator was not there in the office.

Step 5. The interested participants were scheduled through the hemophilia clinic. The project was explained to the parent and the participant.

Step 6. The project coordinator discussed the consent, assent, and signature process with the parents and participants. There was a question and answer session regarding the project, consent, and assent process before moving to the testing process.

Step 7. A pilot test of the first 2 participants was done to initiate the PDSA cycle. The results of the test showed a positive outcome. The 2 post-test scores increased based on the results from the UNC TxANSITION scale. This was after the education session of the transition quick-guide.

Step 8. The social worker, physician, and the project coordinator met the following week in the hematology conference room to discuss the results of the PDSA cycle and whether to abandon or pursue the project. The team discussed the results, and agreed to go forward with the project.

Step 9. The additional 8 participants were scheduled through the hemophilia clinic or participants school.

Step 10. The participant used a DE -identified code for protection. An ID with 4 numbers was created for the participant. This ID was written on the pre/posttest by the project coordinator.

Step 11. The project coordinator explained the testing process to the participant. The project coordinator asked participant the pre- test questions from the UNC TRxANSITION scale. The pre-test took about 8 minutes.

Step 13. The project coordinator started the education process using the transition quick-guide after the pre-test session. This session took 20 minutes to complete. The participant had the opportunity to be engaged in the education session.

Step 14. The project coordinator issued the post-test after the education session. This session took 8 minutes to complete.

Step 15. The project coordinator issued the participant a $10 gift card to Target and gave gratitude to the participant's for participating in the project.

Step 16. The project coordinator scored the test on return to the coordinator office.

Step 17. All documents were filed in a file folder under the participant's ID code. The file folder was taken back to the project coordinator's office to be locked. The results were documented on an Excel spread sheet within a secure computer system at the local site.

Step 18. The final step in the project included the final results of the PDSA cycle, team discussion and the post project data analysis. This information is documented in section 5 of this paper.

Step 19. The entire conduction of the project took 15 days from the date of IRB approval.

Protections

The procedure used in the DNP project to ensure ethical protection of the participants included following the guidelines of Walden University and the local project's site IRB. The project coordinator took action to protect and maintain the participant's privacy, which included informing the parent and participant about the Health Insurance Portability and Accountability Act (HIPAA). The parent signed a HIPPAA form after the project coordinator explained that the participant's health records, data developed from the project, and that the project information would only be disclosed to the project team. The project coordinator also explained to the parent and participant that the health information related to the project would be de-identified by removing information such as name, home address, telephone number, and social security number from the documents used in the project. De-identifying the participant's information was part of the data retention plan for this DNP project. The participant was given a unique ID for the project that included 4 numbers to maintain privacy and confidentiality. The parent and the participant were assured that the information and data retrieved for this DNP project would only be used for the time frame of 28 days to conduct the project after receiving approval from IRB.

According to Burns (2009), reimbursement measures were beneficial in motivating and compensating the participant for their time to participate in the project. The project coordinator posted on the fliers that an honorarium gift card of $10 to Target would be issued. The project coordinator purchased the incentive with personal funds. Incentives for this DNP project documented within the IRB application.

Analysis and Synthesis

The systems used for recording, tracking, organizing and analyzing the evidence were through the participant's EHR, ATHN database, secure drive, and an Excel Spreadsheet. The EHR included the use of powerchart office. Powerchart office was the electronic means of viewing the participant's diagnosis of hemophilia, age, date of visits, race, and education documentation. Other important information included the factor products, pharmacy, clinic visits, hospital and ER visits for each participant. ATHN database was a system used by all of the HTCs in the United States. The project coordinator was able to pull demographic data, transition status, number of joint bleeds, and history of bleeding, follow-up clinic visits, ER and hospital visit from the data base. The various sources of evidence were recorded on an Excel spreadsheet for tracking and analyzing the evidence. The demographic data collected for the DNP project were evaluated by calculating the frequency, means, and percentages from the findings of the hemophilia population. Share drive was a secure system developed by the organization to manage, store, and save files for this project. The Excel spreadsheet was saved into the share drive. In order to assure the integrity and accuracy of the evidence, planning and organization of the procedures was essential (Barns & Grove, 2009). The project coordinator implemented data quality control in each phase of the project to manage outliers and missing information (Needhan et al., 2009). For example, designing the Excel spread sheet to track, organize, and manage the data was a unique method to prevent outliners and missing information. Analysis showing that the participants had extreme scores that were widely separated from the rest of the subjects was not identified to report (Barns & Grove, 2009). Calculating the percent differences and averages from the findings was done and the Excel system analyzed the results of the pre/post data.

Summary

Life expectancy has increased for youth with special needs and chronic conditions such as hemophilia. Youth with hemophilia were surviving to adulthood due to advancement in therapy and research. The transition period from pediatric to adulthood presented unique needs and challenges for the hemophilia populations (Ladores, 2015). Challenges and needs such as learning to keep up with the daily demands of managing hemophilia, and learning to move from dependent role to an independent role were devastating. The site of the DNP project lacked a transition service to prepare youth early on how to transition safely to an adult hemophilia clinic. Based on yearly audits for the hemophilia program at the project's local site, youth who are 18 to 22 years of age used the ER for care frequently, and there were increased hospitalization rates for bleeding complications. As a result, the patient often experienced increased health services utilization and costs associated with the emergency and hospital visits due to gaps in care (Speller-Brown et al., 2015). The yearly audits at the project's local site also showed that youth 18 -22 years of age were lost to follow-up care within a hemophilia clinic, lose insurance coverage, and adherence to factor therapy was low. The evidence showed that there were gaps in care in the hemophilia clinic at the project's local site. According to a National Survey of Children with Special Health Care Needs (NS-CSHCN), only 40% of youth age 12 to 17 years with special needs such as hemophilia received pediatric to adult-care health transitioning planning in 2009- 2010 (Butler et al., 2016). Health People 2020 had set the goal to increase that percentage by 85.3%. Section 3 provided the collection and analysis of evidence for this DNP project (Healthy People 2020, 2017). The practice question asked whether the transition quick-guide was effective in preparing youth with hemophilia the basic knowledge of hemophilia and self-management skills. The project coordinator explored this question by collecting and analyzing data that correlates with the problem. In section 4, the project coordinator presented those findings, implications, and the recommendations for future projects. The ultimate goal for implementing the DNP was to support quality improvement and the benefits of promoting positive social change for youth with hemophilia.

Section 4: Findings and Recommendations

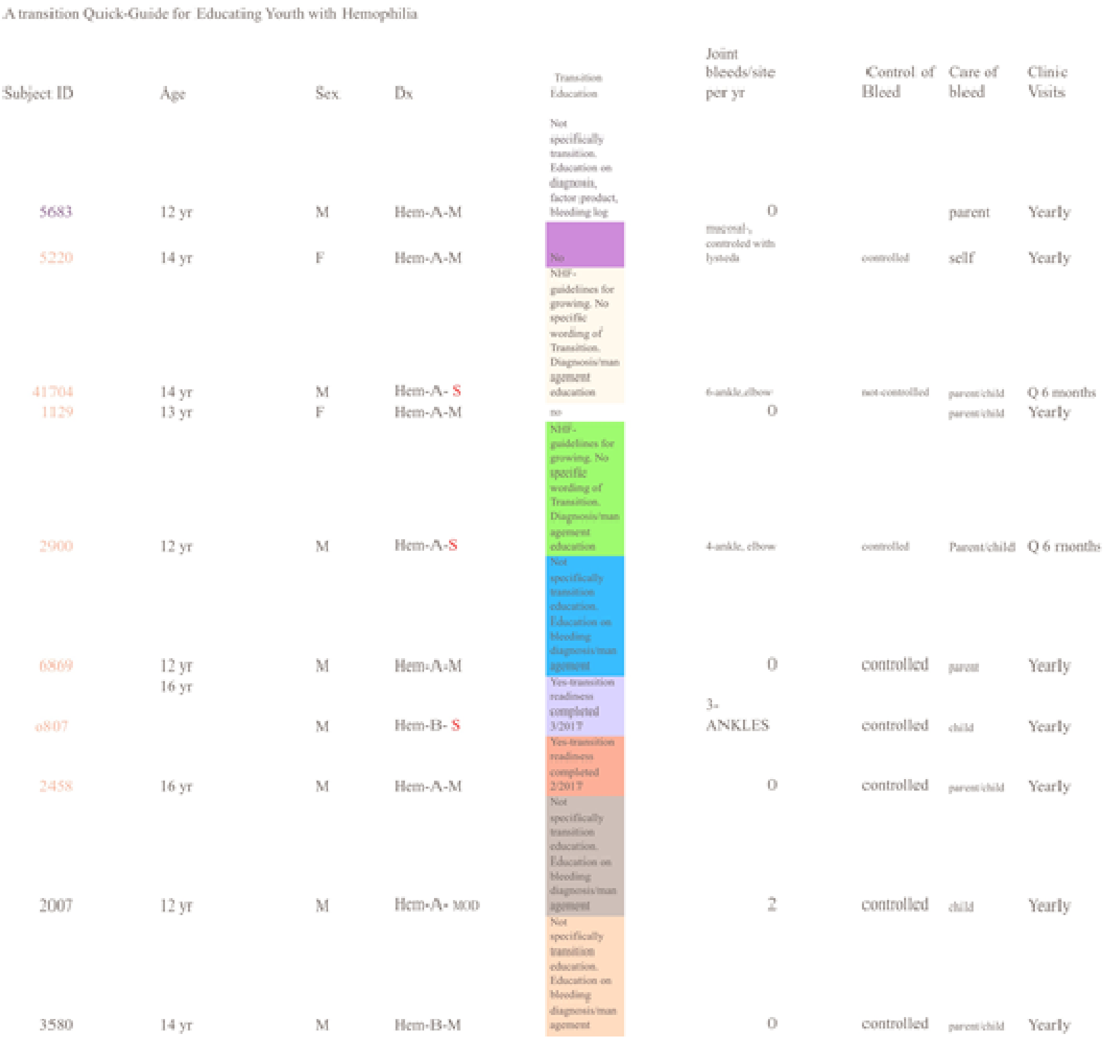
Introduction

The local problem was the need for transition education and planning for youth who are diagnosed with hemophilia. Youth with hemophilia fall into a fragmented care gap when transition services are not adequate. Youth who fall into a fragmented care gap are seen frequently in the ER and hospitalized for complicated joint bleeds. As a result, youth have increased joint disabilities, muscle bleeds, and healthcare cost escalation (Johnsons & Zhou, 2011). The gap in practice was a lack of transition services in the local hemophilia clinic for youth between 12 and 17. There is a need for transition services that are designed to educate and evaluate transition readiness for youth with hemophilia. Without a transition plan, youth are predisposed to care that is fragmented (Breakey et al., 2010). The practice-focused question asked whether a transition quick guide for youth between the ages of 12 and 17 with hemophilia enabled them to increase their knowledge of self-care management skills as evidenced by increased post-test scores in transition readiness. The purpose of the project was to prepare youth with hemophilia who are 12 to 17 years of age to transition to the adult hemophilia clinic and care.

The sources of evidence used for this project included the participants' electronic medical records (e-MRs) after IRB approval from the local site and Walden University. The project coordinator used the e-MRs to obtained diagnoses, education in transition, frequency of doctor visits, the number of joint bleeds per year, and who manages participant care. The purpose of obtaining this information from e-MRs was to verify responses to the pre/posttest of transition readiness from the participants. Also, viewing e-MRs provides evidence that is consistent with information found from past studies that were relevant to this QI project. Only two of the 10 participants had information related to transition education documented in their charts. Although education about specific disorders was mentioned in e-MRs, there were no details about what was being taught about the disorder. An analytical strategy that was used for this project was descriptive statistics to evaluate education levels regarding transition readiness before and after education. Data was analyzed using Microsoft Excel to obtain percentage differences and means for pre and posttest scores.

Table 1

Demographic Table



A transition Quick-Guide for Educating Youth with Hemophilia

Subject ID	Age	Sex	Dx	Transition Education	Joint bleeds/site per yr	Control of Bleed	Care of bleed	Clinic Visits
5683	12 yr	M	Hem-A-M	Not specifically transition. Education on diagnosis, factor product, bleeding log	0		parent	Yearly
5220	14 yr	F	Hem-A-M	No	mucosal-, controled with lysteda	controlled	self	Yearly
41704	14 yr	M	Hem-A- S	NHF-guidelines for growing. No specific wording of Transition. Diagnosis/management education	6-ankle,elbow	not-controlled	parent/child	Q 6 months
1129	13 yr	F	Hem-A-M	no	0		parent/child	Yearly
2900	12 yr	M	Hem-A-S	NHF-guidelines for growing. No specific wording of Transition. Diagnosis/management education	4-ankle, elbow	controlled	Parent/child	Q 6 months
6869	12 yr	M	Hem-A-M	Not specifically transition education. Education on bleeding diagnosis/management	0	controlled	parent	Yearly
6807	16 yr	M	Hem-B- S	Yes-transition readiness completed 3/2017	3-ANKLES	controlled	child	Yearly
2458	16 yr	M	Hem-A-M	Yes-transition readiness completed 2/2017	0	controlled	parent/child	Yearly
2007	12 yr	M	Hem-A- MOD	Not specifically transition education. Education on bleeding diagnosis/management	2	controlled	child	Yearly
3580	14 yr	M	Hem-B-M	Not specifically transition education. Education on bleeding diagnosis/management	0	controlled	parent/child	Yearly

Findings and Implications

The main purpose of this project was to investigate youth knowledge regarding hemophilia and self-care management skills using a transition quick guide as an educational tool within the hemophilia clinic. Pre and post transition readiness was evaluated using the 10-point UNC TRxANSITION scale. The project included 10 participants who were diagnosed with hemophilia and 12 to 17 years of age. There were a total of 8 male participants, partly because hemophilia was inherited in an X-linked recessive way. There were only two females who participated in the project. Although hemophilia is X-linked, some of the females were symptomatic carriers; therefore, females were included in the project. Symptomatic carriers had symptoms such as menorrhagia, joint bleeds, and frequent nosebleeds; therefore, it was important that females learned self-care management skills. The youngest of the participants was 12, and the oldest was 16. The scores of pretest data on a 10-point scale ranged from 19% (lowest score for pretest) to 58% (highest score for pretest). The mean total for transition education pretest scores was 40%. An education session on hemophilia knowledge and self-care management was performed immediately after the pretest. The posttest scores obtained after educational session ranged from 42% (lowest score for posttest scores) to 95% (highest posttest score). The mean total education score for the posttest was 54%. The percentage differences between pretests and posttests showed a 14% increase in knowledge, and therefore the findings showed that knowledge after the pretesting session increased. Dr. Ferris and colleagues suggested that the UNC TRxANSITION scale and the transition quick guide were reliable and valid tools that had potential to measure healthcare transition skills and disease knowledge among youth and young adults. It is important that youth and young adults learn disease-specific knowledge and master self-care skills prior to transferring to an adult clinic (Ferris et al., 2012). It is also important that the healthcare team begin documenting specifically what transition education was being taught to patients. It is also important to scan this information into medical records to monitor progress. This project provided results that had the potential to help improve transition services for youth with hemophilia. During the pre and posttest sessions, participants were fully engaged and enthused about answering the questions. They were able to show that the youth concur with the use of the transition service, independence, and confidence in their knowledge about hemophilia. They were able to communicate with the social worker, hematologist, and the project coordinator without the help of parents or caregivers. The results showed that it was important to document transition readiness. Documentation provided the healthcare team with methods to track and translate evidence into practice.

Table 2

Transition Readiness Outcome

Pt. ID	Transition Quick-Guide-Education	Pre- Test Score (10 Point Scale)	Pre-Test Percentage	Post- Test Score (10 Point Scale)	Post- Test Percentage	Difference in Percentage Increase
5683	Yes	5.77	58%	9.5	95%	**37%**
5220	Yes	2.71	27%	5.03	50%	**23%**
41704	Yes	5.11	51%	5.19	52%	**1%**
1129	Yes	2.66	27%	4.21	42%	**16%**
2900	Yes	4.79	48%	5.42	54%	**6%**
6869	Yes	1.92	19%	4.42	44%	**25%**
807	Yes	4.96	50%	5.36	54%	**4%**
2458	Yes	4.25	43%	5.08	51%	**8%**
2007	Yes	3.68	37%	5.43	54%	**18%**
3580	Yes	4.08	41%	4.33	43%	**3%**

Posttest scores 42% (lowest score for posttest scores), and 95% (highest posttest score). The mean total education score for posttest was 54%. The percent difference from pretest to posttest showed a 14% increase in knowledge.

Limitations

The unanticipated limitations for this QI project were the small sample of 10 participants, limitation of only hemophilia participants, and the age limits. Although the project was a pilot study to make a change within clinic practice, the potential impact of these limitations was an alteration in viewing trends within practice. A greater sample of at least 20 participants had the potential of identifying a relationship among the variables in order to see a trend within practice (Burns & Grove, 2009). Limiting the project to only participants with hemophilia had an impact on improving the transition service for patients with other bleeding disorders. The hemophilia clinic served patients who were not only diagnosed with hemophilia, but also included other bleeding disorders such as Von Willebrand, platelet defects, and other rare bleeding disorders. The project coordinator only measured specific areas with the TRxANSITION scale. The tool could be modified based on disease-specifics and age. The DNP project only assessed the youth's disease-specific knowledge and self-management skills. The scale was a 10-scale domain but, it had a 32-question scale. Many of the questions were irrelevant for the project but relevant for the transition journey of the youth. As a result, this could have had a potential impact on the results of the project.

Another insight gained from this DNP project experience was the need to expand the age. The age criteria for the QI project were 12 to 17 year olds with hemophilia. Literature showed controversy with the age range of starting transition for youth with a chronic condition due to medical and psychosocial aspects. Breakey et al., (2010), defined the transition period at the ages of 10- 19 years. Feinstein, Rabey, and Pilapil (2017) defined starting the transition period at the age of 12- 13 years. The hemophilia clinic at the local site had many youth who were 11 years of age, interested in beginning the transition journey. As a result, the project was limited to participants who had benefited from learning transition care early. On the other hand, there were many young adults who were 18 years of age, who depended on their parents to provide their care. Young (2012) argued that ages13 to 18 were the most challenging periods of life for youth with a chronic disorder such as hemophilia when it comes to transitional care. Youth with severe hemophilia were on a prophylaxis regimen of factor product. This means that they infused their factor product 2- 3 times per week. The major challenge for this age group was non-compliance issues with the prophylaxis regimen, thus, increasing the risk for bleeding complications. Continued investigations on the precise time for starting transition education and planning provided a better understanding on the youth's developmental and psychosocial readiness.

Implementation of Findings

The findings imply that the lack of transition readiness among youth with hemophilia can affect youth between ages 12 years to 17 years, various races, and genders. The sample of 10 participants was limited to a small population; however, a 14% increase in post-test scores showed that opportunities to educate youth about their transitional care were possible. Using a larger sample size had the potential to increase the knowledge of the participants and show a stronger correlation for the body of knowledge, theory, and practice in transitional care knowledge for youth with hemophilia. The education sessions took place in the hemophilia clinic or the participant's school. Opening the education sessions to the school settings had positive impact on the participant and the school staff. The participants and parents had the convenience of taking part of the project without traveling a distance to the project site. Also, the participant had the opportunity to participate in a project without the parent being present. Participants were engaged and asked questions during the education sessions. In past education sessions with the hemophilia clinic, youth were not attentive or engaged in the education sessions, and the parent did the communication for the youth. The implementation of the findings provided an opportunity for the hemophilia clinic staff and school staffs to form a partnership within the community in improving transitional care among youth and young adults.

The potential implications to positive social change were to increase the youth's health outcomes by joining other health care providers, private entities, communities, in heightening the awareness of developing transition programs that promote independence, and to improve the quality of life for youth. Implementing positive social change through the implementation of this DNP project helped strengthen relationships among the youth with chronic disorders, their families, and the health care community (Feinstein et al., 2017). The project coordinator of this DNP project was an advanced practice nurse (APN). This experience demonstrated that nurses could assume the role of coordinating the transition team for youth within subspecialty settings. Nurses were pivotal in assessing health care needs of patients. Nurses were also pivotal in understanding the comprehensive care involved in a youth's developmental, social, and psychosocial aspect of the lifespan (Betz & Redcay, 2003). Nurses should consider including a transition quick-guide within the clinic's transition procedure or program. A transition quick-guide was a quick but structured way to educate and evaluate transition readiness among youth.

Transition quick-guides were reliable and valid in evaluating transition readiness among youth with chronic conditions.

Recommendations

The recommended solutions that will potentially address the gap-in-practice that cause youth to face costly and dangerous gaps as they transition from pediatric to adult care services focused on redesigning education and evaluation tools that would improve the value of care for youth with hemophilia and other chronic disorders. The UNC TRxANSITION scale was utilized and implemented in this DNP project. The youth showed a 14% increase in disease-specific knowledge and self-management skills after the education session. This was a one-time education session; however, the youth were engaged during the time the scale and guide were being used. The UNC TRxANSITION and transition quick-guide had shown reliability and was a valid tool. Based on the post-data results, the tools were recommended for future studies or projects. Nurses were pivotal in building and supporting policy and practice standards for the tools to be used in practice. The tools were beneficial in improving the quality of care that shapes the youth's biological, developmental, behavioral and psychological domains. This helped improve the youth's outcome for self-management during the critical transition period. Engaging the youth in receiving care by initiating contracts for the youth to have buy-in and to maintain retention was another recommendation for future projects. Buy-in and retention were important for the retention of the transition project. Finally, providing a checklist or transition quick-guide during the youth's transition journey was found to be important in the transition process. Pilot testing the transition checklist or transition guide with larger sample sizes to assess the clinical effects and the ease of implementation was suggested. The transition quick-guide and UNC TRxANSITION scale is shown in (appendices 1 and 2).

Contribution of the Doctoral Project Team

The foundation of the project was based on using the Plan-Do-Study-Act (PDSA) cycle, originally developed by Dr. Walter Shewhart, and later Dr. W. Demings, who modified the PDSA cycle. The PDSA included four steps. Setting aims, establishing measures and indicators, selecting changes, and testing the changes within the project were the four steps. Another key step in utilizing the PDSA cycle was developing a team. The doctoral project team included a hematologist, social worker, and the project coordinator. The team had weekly meetings to discuss resources, and literature related to the project, and the progress of the project. After IRB approval, the team met to decide on the 2 participants to pilot test for the project. The 2 participants met the project criteria. One of the participants agreed to have the session done at the school setting, and the other came to the hemophilia clinic. Based on the results of the pre and posttest scores, the team chose the UNC TRxANSITION scale to evaluate readiness along with the Transition Quick-Guide tool. The hematologist contributions of the doctoral project team included being the champion and the referring participant's physician to the project coordinator or social worker. The hematologist provided the team with insights from a business perspective in keeping the stakeholders informed about the direction of the transition process. The hematologist also helped the team stay motivated during the IRB process. The wait period for IRB approval was long and tedious. The social worker contributions were initially to help with the consenting process. The social worker contributed time viewing literature, evaluation tools, and other valuable transition resources from the Got Transition website. The social worker also contributed time in advertising for participants to participate in the project. The social worker passed out fliers in clinic, and informed the parents about the project. The project coordinator contributed time and synthesis skills to research the literature and write about the findings in other studies. The project coordinator also coordinated the team, and helped formulate a plan to implement the project. After IRB approval, the project coordinator help scheduled the education sessions for the participants within the clinic or school setting. The project coordinator also educated the parent and participant on the consenting process, and obtained signatures. The project coordinator had the responsibilities of managing the data, and the analyzing the scores for the findings. The team discussed and made plans together for future recommendations. The team decided that the transition quick-guide and the UNC TRxANSITION would improve the transition service for patients with hemophilia and other bleeding disorders. The recommendations were discussed earlier in the section.

Based on the results and the feedback from the participants, the team discussed designing a poster for other medical services to view the results at the various hemophilia meetings in the United States. The project coordinator planned to publish the findings with the Hemophilia Journal, which is the official Journal of the World Federation of Hemophilia.

Strength and Limitations of the Project

The purpose of the DNP project was to explore using the Transition Quick-guide among youth 12- 17 years of age to educate and plan a transition journey. The strength of the DNP project was that the youth's post-scores from the UNC TRxANSITION scale increased after educating them with the transition quick-guide. Overall, there was an increase with the n=10 patients, based on a 10 point domain UNC TRxANSITION scale. The limitations of the project were the weaknesses in the study design that limited the credibility of the findings. Limitations such as small sample size and the restriction to only the hemophilia population were identified in exploring the project. These limitations had the potential to decrease the generalizability of the findings (Burns & Grove, 2009).

Clearly, there was more work to be done with the transitional care process. The recommendations for future projects that should address similar topics and using similar methods were transition projects that studied the young adult after transferring to the adult health care service. The solution was to address the key unmet needs of the young adult by initiating local and national surveys of patients with hemophilia and other bleeding disorders. Hemophilia was a lifelong disorder. Transition planning included plans that move with the youth throughout their lifespan.

Section 5: Dissemination Plan

Youth with hemophilia are faced with many challenges during the transition period to adulthood. Pediatric healthcare facilities need to have transition services available to prevent youth from falling into a fragmented care gap. This DNP project provided me with the opportunity to design an educational tool and explore using it with youth who are diagnosed with hemophilia. The findings from the project showed that the youth's scores in transition readiness in regards to specific disease knowledge and self-management skills increased after using the transition quick guide. The project coordinator, hematologist, and the social worker, made plans to continue using the transition quick guide and the UNC TRxANSITION scale in the hemophilia clinic. A plan to disseminate this work was to present the information in the form of an abstract to the local hemophilia team. Those who benefit from the findings will include nurses within ambulatory care, school, community health, and in-patient settings. Hemophilia is a rare disorder; however, it is important to increase the awareness of the transitional care problem that exists among youth for nurses, thus, using the evidence presented from the project to improve practice, processes, and outcomes.

Analysis of Self

Advancing my knowledge gave me the experience to operate within the healthcare system to effect change. As a practitioner, I believed that the PDSA model chosen for the DNP project helped me to understand the participants and their issues regarding unplanned transitional care. I chose the PDSA model to guide me through the project. After choosing the PDSA model, I was able to set goals, implement a team, communicate about the local problem, establish measures and indicators, and select and make changes throughout the project. The PDSA model provided me as a practitioner with a framework to improve the clinical practice. This DNP project provided me with opportunities as a practitioner to set long-term professional goals. One professional goal was to expand this project into a transition program for youth and young adults with bleeding disorders.

As a scholar and project manager, I was able to design a scholarly project such as the transition quick-guide and to utilize a reliable transition scale for transition readiness to show a positive outcome of youths readiness in understanding hemophilia knowledge and competence in self-care skill through this DNP project. As a scholar, I was able to implement and evaluate the value and outcomes of the intervention, and through the UNC TRxANSITION scale discovered through literature reviews. Implementing my project and sharing findings from the implementation portion of the project will provide other nurses with information that will help transitional care for patients with chronic conditions. The nurse who is the project coordinator of this DNP project is in a pivotal position to formulate healthcare policies and standards pertaining to their role. My project gave me the opportunity to help shape best practices to improve quality of care and practice. My plan was to share the findings of this project and other future projects. As a result, other nurse practitioners in specialty areas will discover, replicate, and develop similar projects regarding healthcare transition.

Major challenges in completing my project involved the IRB process through the local site. Walden University provided me with information that I needed to get clearance from my local IRB before starting my project. The local IRB wanted the authority to approve the project since it took place at the local site. After submitting various forms such as the various participant waiver forms, advertisement forms from the local IRB, and score analysis form from the local IRB. It took 2 months before getting approval to begin the implementation process of the project. Transitional care is simple, but time is essential to address the needs of the patients and families. In addition, to have a successful transition program, it took money to operate programs of such magnitude. Many researchers from the literature reviews recommended applying for grants through the NIH to help design successful transition programs.

Summary

The overall rates for transition planning for youth with chronic disorders were low based on national surveys. A National survey showed that 40% of youth between the ages of 12 and 17 had a transition plan before transitioning to adult care services. Unplanned transition for youth with hemophilia predisposed them to be to risk for fragmented care. The doctoral project provided me with the opportunity to explore the evidence through peer-reviewed, systematic, and scholarly papers related to youth and transitional care. Healthcare settings in specialty areas that cared for youth with chronic disorders lacked transition services to move them safely from a pediatric service to an adult care service. Evidence showed that youth with hemophilia were frequently seen in the ER or hospitalized for complications related to hemophilia. Complications such as uncontrolled bleeding, joint disabilities, chronic pain, and muscle and internal bleeding causes poor quality of life for individuals with hemophilia as well as increased healthcare costs. The local hemophilia clinic lacked transition services that start as early as 12. The DNP project provided me with the knowledge to synthesize the literature, professional guidance in choosing a model such as the PDSA as a framework, and the resources to create an evidence-based tool such as the transition quick-guide to implement in the clinical practice. The transition quick guide and UNC TRxANSITION scale were explored in this DNP project to improve transition outcomes by increasing the youth's disease-based knowledge and self-care management skills. This project provided data and findings from the pre and post scores of the youths transition readiness that showed how data could be translated into practice. Translating the findings into practice will bring effective change by providing the youth with hemophilia confidence in understanding hemophilia, and competence in their skills to manage hemophilia. Youth who are adequately educated for the transition to adult care services avoid unnecessary health complications and enjoy an improved quality of life.

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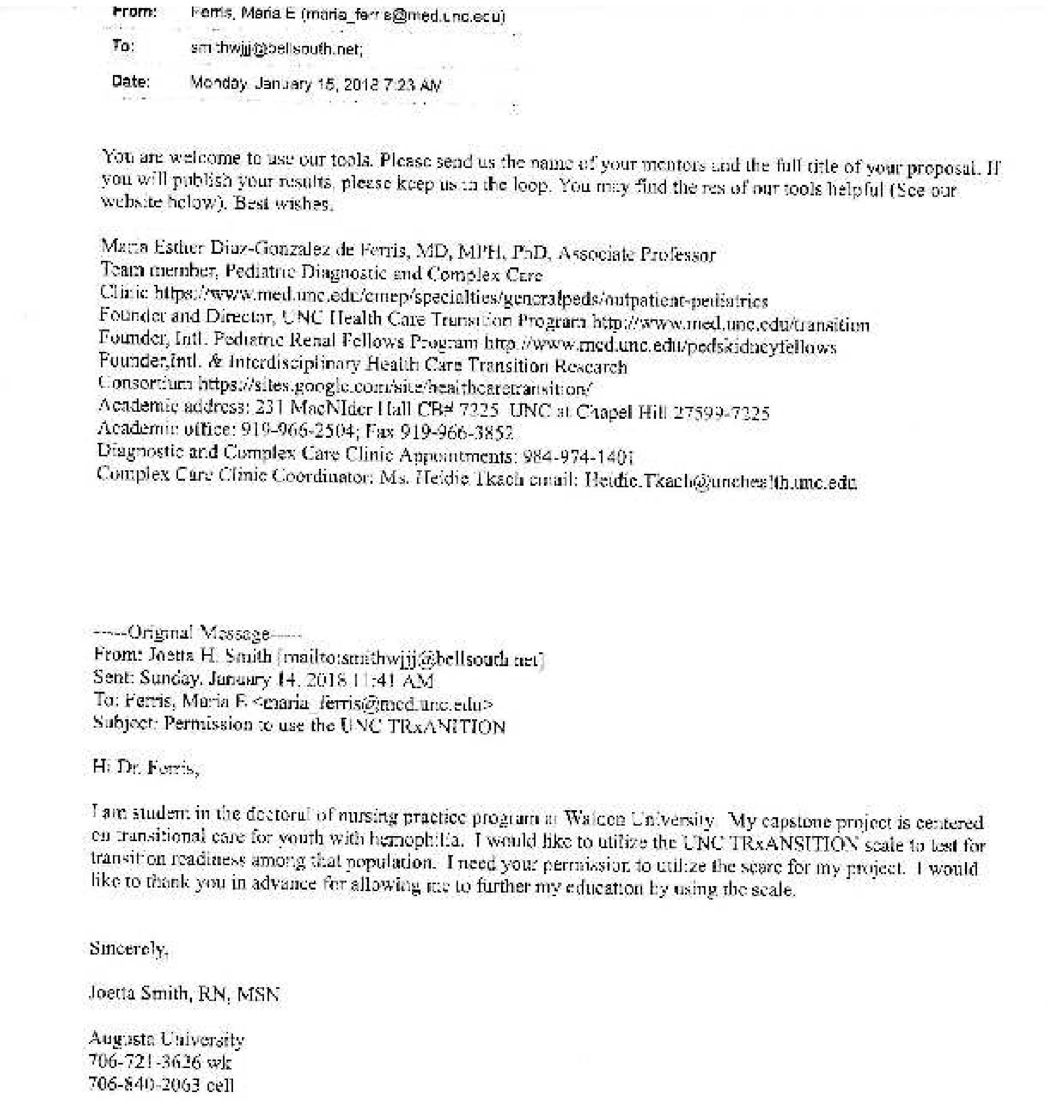
Appendix A: Permission Letter



From: Ferris, Maria E (maria_ferris@med.unc.edu)
To: smithwjjj@bellsouth.net;
Date: Monday, January 15, 2018 7:23 AM

You are welcome to use our tools. Please send us the name of your mentors and the full title of your proposal. If you will publish your results, please keep us in the loop. You may find the res of our tools helpful (See our website below). Best wishes.

Maria Esther Diaz-Gonzalez de Ferris, MD, MPH, PhD, Associate Professor
Team member, Pediatric Diagnostic and Complex Care
Clinic https://www.med.unc.edu/cmep/specialties/generalpeds/outpatient-pediatrics
Founder and Director, UNC Health Care Transition Program http://www.med.unc.edu/transition
Founder, Intl. Pediatric Renal Fellows Program http://www.med.unc.edu/pedskidneyfellows
Founder,Intl. & Interdisciplinary Health Care Transition Research
Consortium https://sites.google.com/site/healthcaretransition/
Academic address: 231 MacNider Hall CB# 7225 UNC at Chapel Hill 27599-7225
Academic office: 919-966-2504; Fax 919-966-3852
Diagnostic and Complex Care Clinic Appointments: 984-974-1401
Complex Care Clinic Coordinator: Ms. Heidie Tkach email: Heidie.Tkach@unchealth.unc.edu

-----Original Message-----
From: Joetta H. Smith [mailto:smithwjjj@bellsouth.net]
Sent: Sunday, January 14, 2018 11:41 AM
To: Ferris, Maria E <maria_ferris@med.unc.edu>
Subject: Permission to use the UNC TRxANITION

Hi Dr. Ferris,

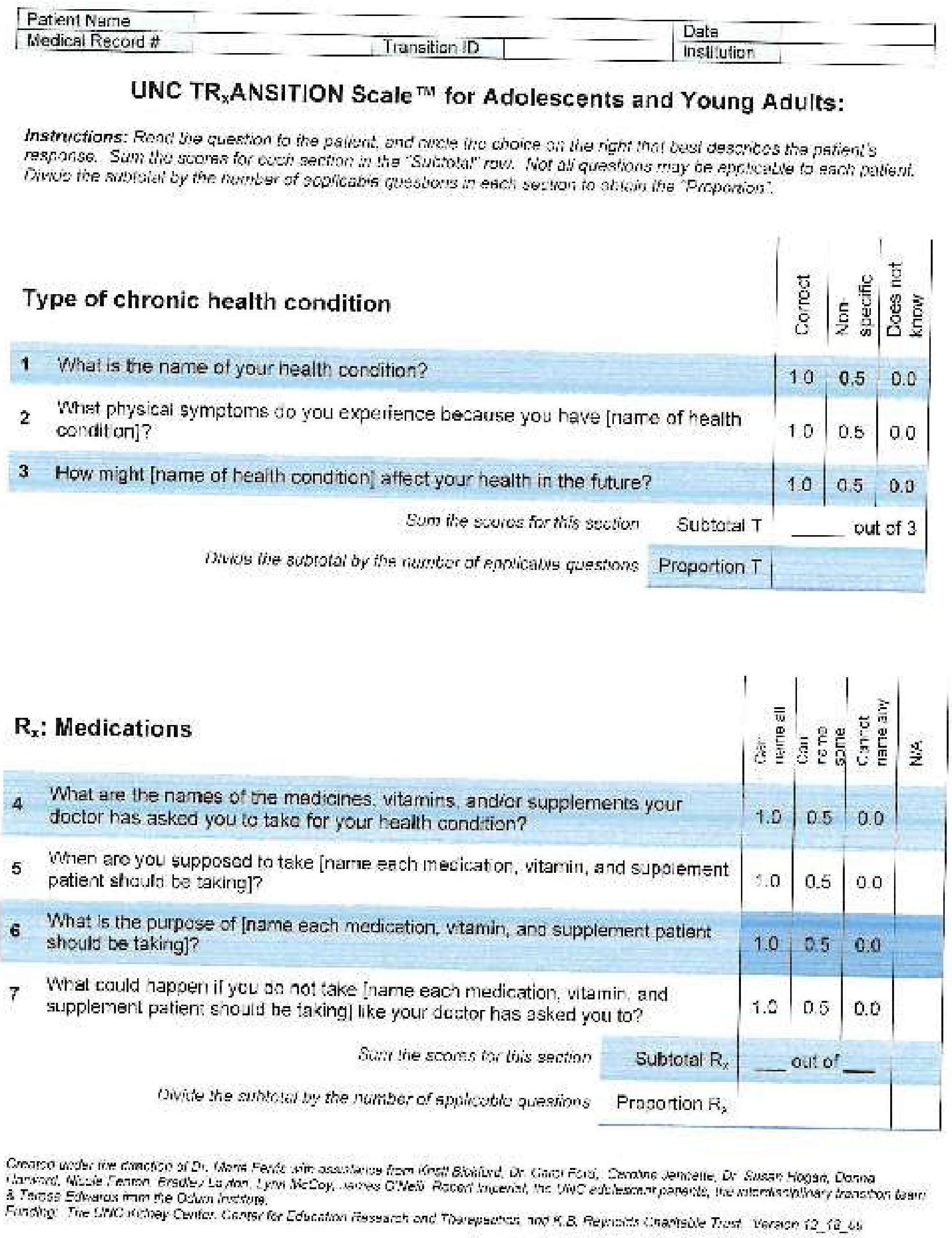
I am student in the doctoral of nursing practice program at Walden University. My capstone project is centered on transitional care for youth with hemophilia. I would like to utilize the UNC TRxANSITION scale to test for transition readiness among that population. I need your permission to utilize the scale for my project. I would like to thank you in advance for allowing me to further my education by using the scale.

Sincerely,

Joetta Smith, RN, MSN

Augusta University
706-721-3626 wk
706-840-2063 cell

Appendix B: UNC TRxANSITION Scale



Patient Name
Medical Record #
Transition ID
Date
Institution

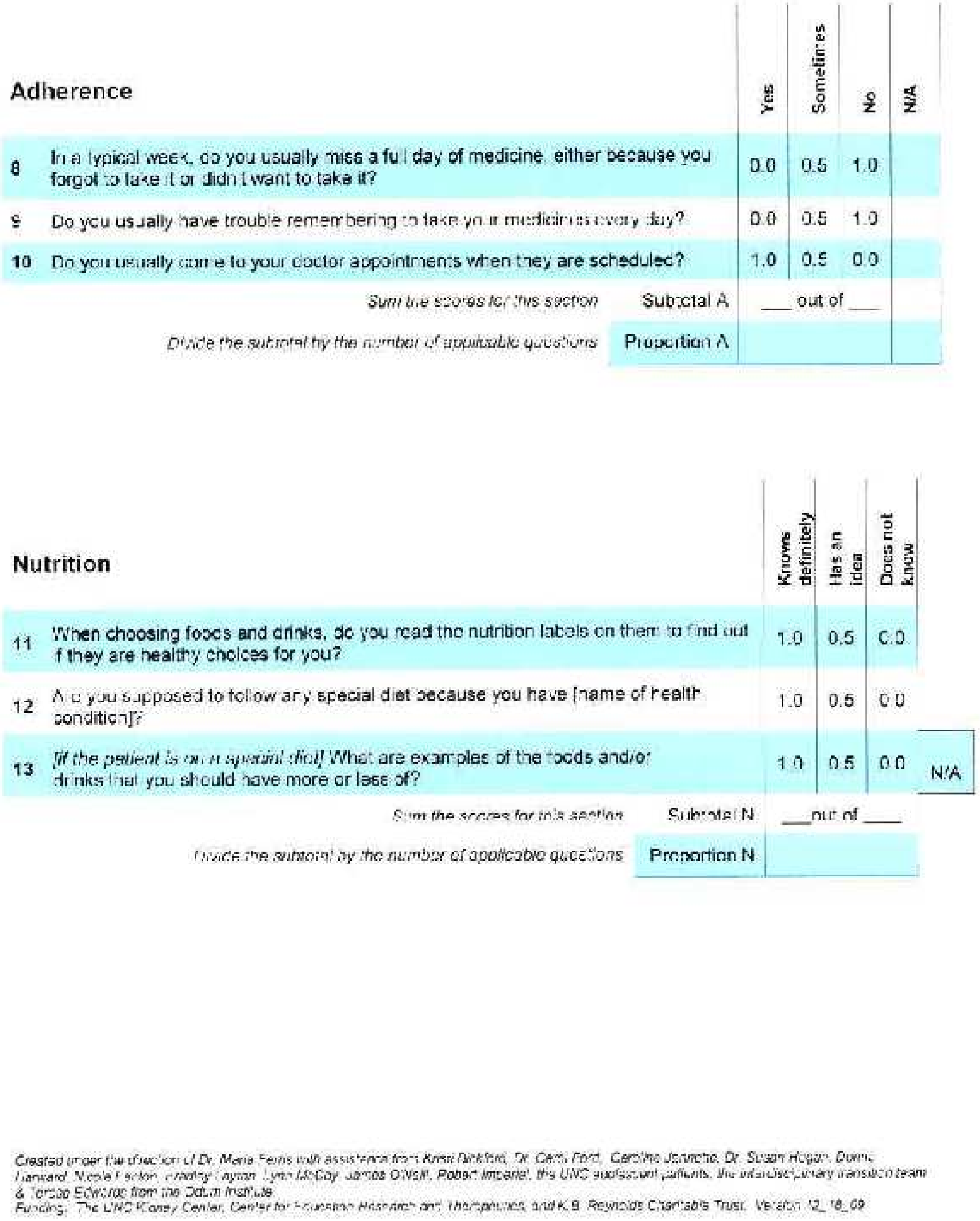
UNC TR$_x$ANSITION Scale™ for Adolescents and Young Adults:

Instructions: *Read the question to the patient, and circle the choice on the right that best describes the patient's response. Sum the scores for each section in the "Subtotal" row. Not all questions may be applicable to each patient. Divide the subtotal by the number of applicable questions in each section to obtain the "Proportion".*

Type of chronic health condition		Correct	Non-specific	Does not know
1	What is the name of your health condition?	1.0	0.5	0.0
2	What physical symptoms do you experience because you have [name of health condition]?	1.0	0.5	0.0
3	How might [name of health condition] affect your health in the future?	1.0	0.5	0.0
	Sum the scores for this section Subtotal T	___ out of 3		
	Divide the subtotal by the number of applicable questions Proportion T			

R$_x$: Medications		Can name all	Can name some	Cannot name any	N/A
4	What are the names of the medicines, vitamins, and/or supplements your doctor has asked you to take for your health condition?	1.0	0.5	0.0	
5	When are you supposed to take [name each medication, vitamin, and supplement patient should be taking]?	1.0	0.5	0.0	
6	What is the purpose of [name each medication, vitamin, and supplement patient should be taking]?	1.0	0.5	0.0	
7	What could happen if you do not take [name each medication, vitamin, and supplement patient should be taking] like your doctor has asked you to?	1.0	0.5	0.0	
	Sum the scores for this section Subtotal R$_x$	___ out of ___			
	Divide the subtotal by the number of applicable questions Proportion R$_x$				

Created under the direction of Dr. Maria Ferris with assistance from Kristi Bickford, Dr. Carol Ford, Caroline Jennette, Dr. Susan Hogan, Donna Harward, Nicole Fenton, Bradley Layton, Lynn McCoy, James O'Neill, Robert Imperial, the UNC adolescent patients, the interdisciplinary transition team & Teresa Edwards from the Odum Institute.
Funding: The UNC Kidney Center, Center for Education Research and Therapeutics, and K.B. Reynolds Charitable Trust. Version 12_12_08



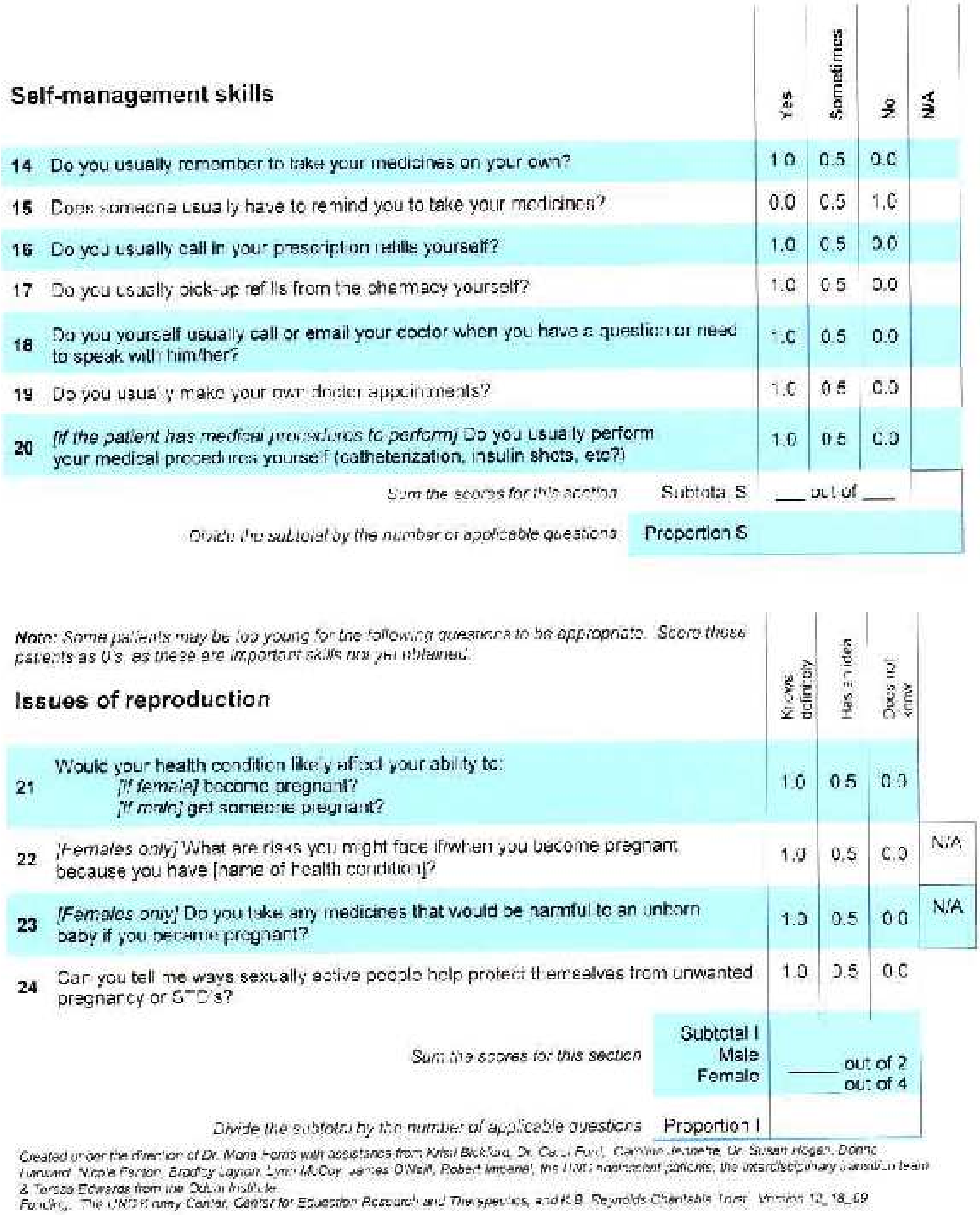
Adherence

		Yes	Sometimes	No	N/A
8	In a typical week, do you usually miss a full day of medicine, either because you forgot to take it or didn't want to take it?	0.0	0.5	1.0	
9	Do you usually have trouble remembering to take your medicines every day?	0.0	0.5	1.0	
10	Do you usually come to your doctor appointments when they are scheduled?	1.0	0.5	0.0	
	Sum the scores for this section Subtotal A	___ out of ___			
	Divide the subtotal by the number of applicable questions Proportion A				

Nutrition

		Knows definitely	Has an idea	Does not know	
11	When choosing foods and drinks, do you read the nutrition labels on them to find out if they are healthy choices for you?	1.0	0.5	0.0	
12	Are you supposed to follow any special diet because you have [name of health condition]?	1.0	0.5	0.0	
13	*[If the patient is on a special diet]* What are examples of the foods and/or drinks that you should have more or less of?	1.0	0.5	0.0	N/A
	Sum the scores for this section Subtotal N	___ out of ___			
	Divide the subtotal by the number of applicable questions Proportion N				

Created under the direction of Dr. Maria Ferris with assistance from Kristi Bickford, Dr. Cerri Ford, Caroline Jennette, Dr. Susan Hogan, Donna Harward, Nicole Fenton, Bradley Layton, Lynn McCoy, James O'Neill, Robert Imperial, the UNC adolescent patients, the interdisciplinary transition team & Teresa Edwards from the Odum Institute.
Funding: The UNC Kidney Center, Center for Education Research and Therapeutics, and K.B. Reynolds Charitable Trust. Version 12_18_09



Self-management skills

		Yes	Sometimes	No	N/A
14	Do you usually remember to take your medicines on your own?	1.0	0.5	0.0	
15	Does someone usually have to remind you to take your medicines?	0.0	0.5	1.0	
16	Do you usually call in your prescription refills yourself?	1.0	0.5	0.0	
17	Do you usually pick-up refills from the pharmacy yourself?	1.0	0.5	0.0	
18	Do you yourself usually call or email your doctor when you have a question or need to speak with him/her?	1.0	0.5	0.0	
19	Do you usually make your own doctor appointments?	1.0	0.5	0.0	
20	*[If the patient has medical procedures to perform]* Do you usually perform your medical procedures yourself (catheterization, insulin shots, etc?)	1.0	0.5	0.0	
	Sum the scores for this section	Subtotal S	___ out of ___		
	Divide the subtotal by the number of applicable questions	Proportion S			

Note: Some patients may be too young for the following questions to be appropriate. Score these patients as 0's, as these are important skills not yet obtained.

Issues of reproduction

		Knows definitely	Has an idea	Does not know	
21	Would your health condition likely affect your ability to: *[If female]* become pregnant? *[If male]* get someone pregnant?	1.0	0.5	0.0	
22	*[Females only]* What are risks you might face if/when you become pregnant because you have [name of health condition]?	1.0	0.5	0.0	N/A
23	*[Females only]* Do you take any medicines that would be harmful to an unborn baby if you became pregnant?	1.0	0.5	0.0	N/A
24	Can you tell me ways sexually active people help protect themselves from unwanted pregnancy or STD's?	1.0	0.5	0.0	
	Sum the scores for this section	Subtotal I Male Female	___ out of 2 out of 4		
	Divide the subtotal by the number of applicable questions	Proportion I			

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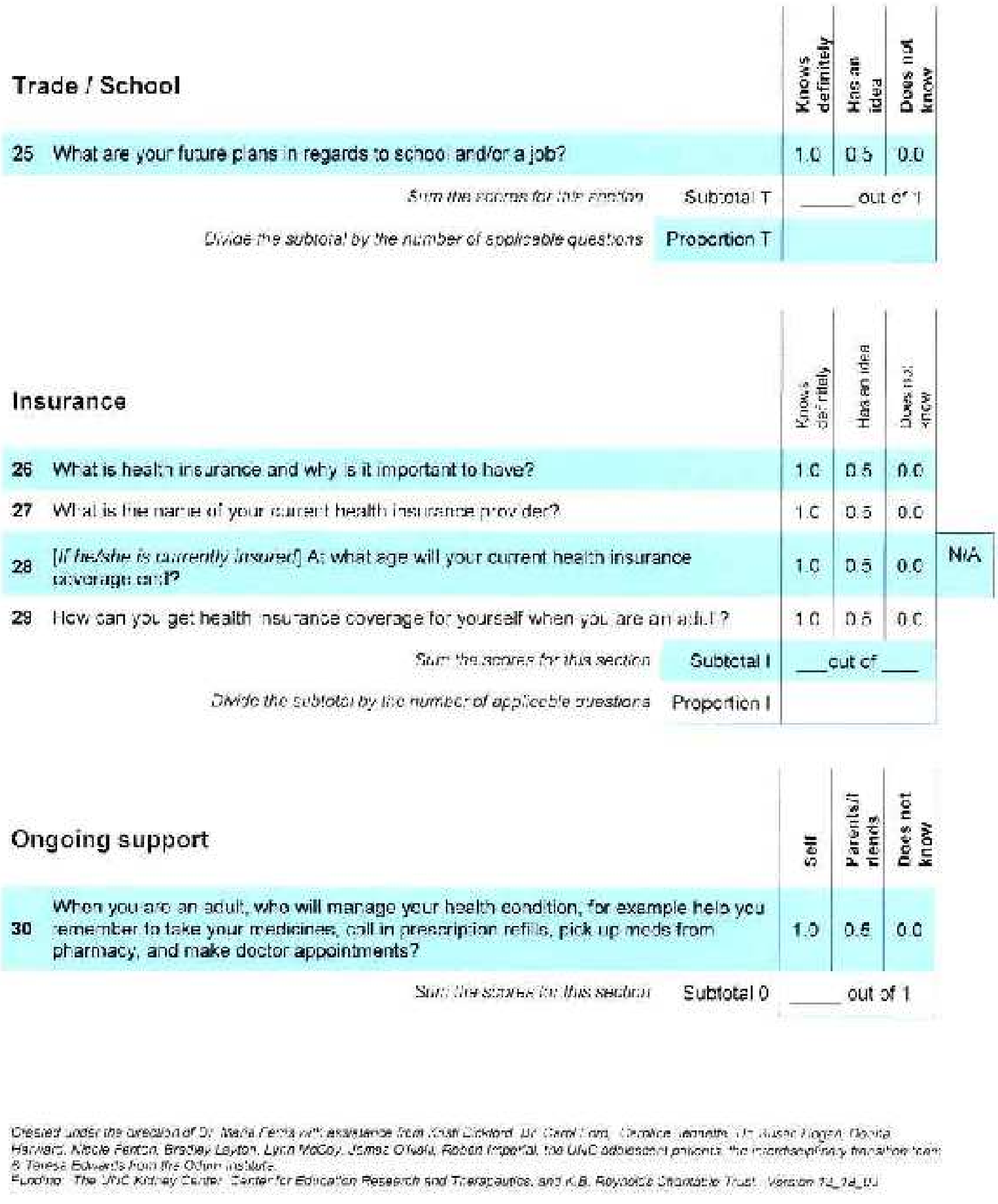

Trade / School

		Knows definitely	Has an idea	Does not know
25	What are your future plans in regards to school and/or a job?	1.0	0.5	0.0
	Sum the scores for this section Subtotal T	____ out of 1		
	Divide the subtotal by the number of applicable questions Proportion T			

Insurance

		Knows definitely	Has an idea	Does not know	
26	What is health insurance and why is it important to have?	1.0	0.5	0.0	
27	What is the name of your current health insurance provider?	1.0	0.5	0.0	
28	*[If he/she is currently insured]* At what age will your current health insurance coverage end?	1.0	0.5	0.0	N/A
29	How can you get health insurance coverage for yourself when you are an adult?	1.0	0.5	0.0	
	Sum the scores for this section Subtotal I	___out of ___			
	Divide the subtotal by the number of applicable questions Proportion I				

Ongoing support

		Self	Parents/friends	Does not know
30	When you are an adult, who will manage your health condition, for example help you remember to take your medicines, call in prescription refills, pick up meds from pharmacy, and make doctor appointments?	1.0	0.5	0.0
	Sum the scores for this section Subtotal O	____ out of 1		

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New health care providers		Knows definitely	Has an idea	Does not know
31	When it comes time for you to switch to an adult doctor, how will you find one?	1.0	0.5	0.0
32	In order to get your medical records transferred to another doctor, what is required to make this happen?	1.0	0.5	0.0
	Sum the scores for this section Subtotal N			out of 2
	Divide the subtotal by the number of applicable questions Proportion N			

Raw total score	*Sum all section subtotals here (max 32)*	
T.R$_x$.A.N.S.I.T.I.O.N Score™	*Sum all section proportions, or divide the raw total score by the total number of eligible questions (max 10)*	

http://unckidneycenter.org/hcprofessionals/transition.html

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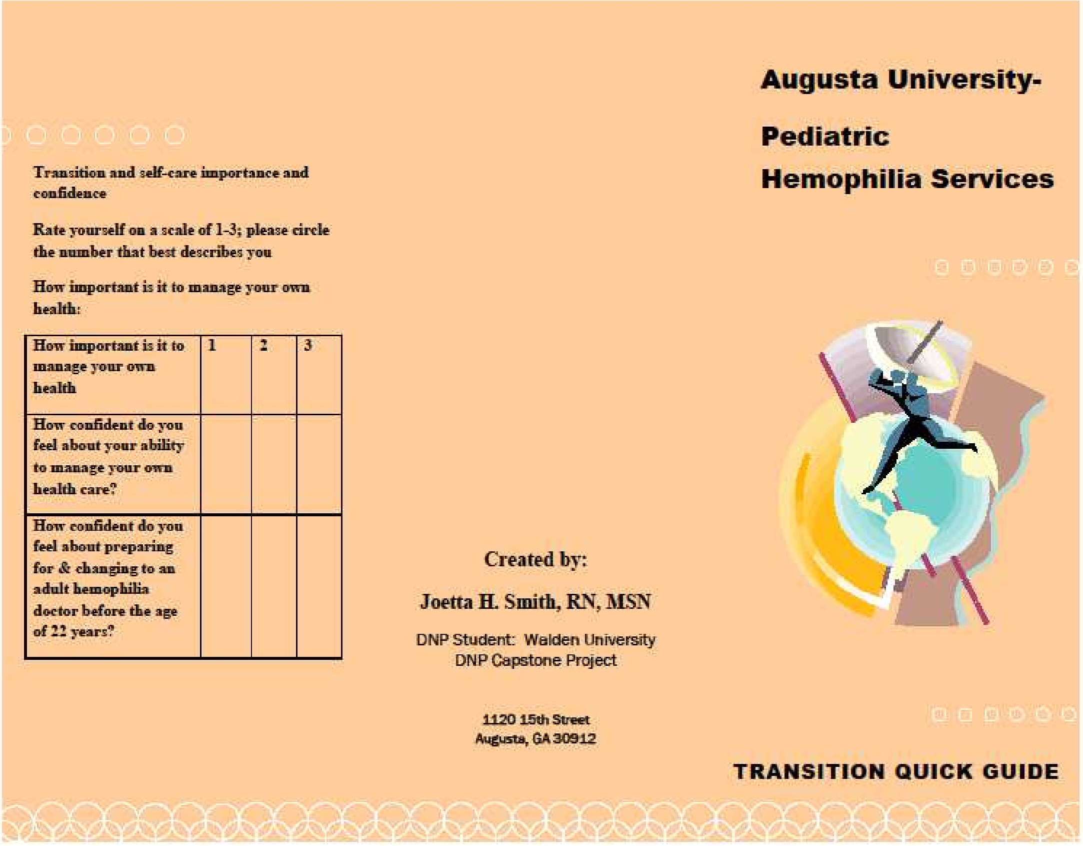
Appendix C: Transition Quick Guide



Transition and self-care importance and confidence

Rate yourself on a scale of 1-3; please circle the number that best describes you

How important is it to manage your own health:

How important is it to manage your own health	1	2	3
How confident do you feel about your ability to manage your own health care?			
How confident do you feel about preparing for & changing to an adult hemophilia doctor before the age of 22 years?			

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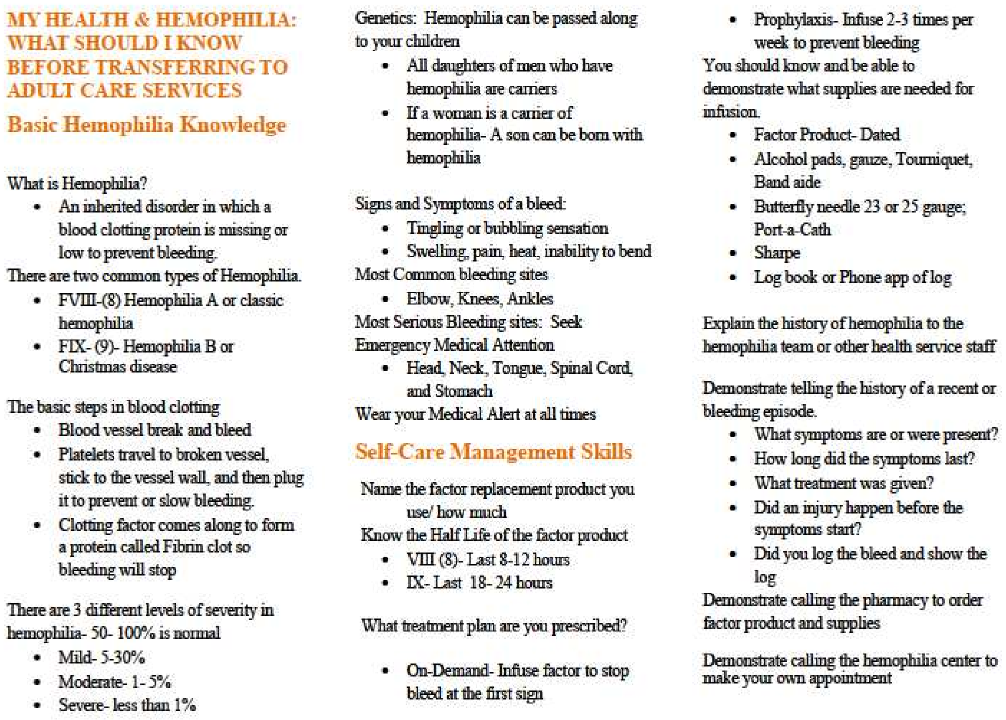
Pediatric Hemophilia Services

TRANSITION QUICK GUIDE



MY HEALTH & HEMOPHILIA: WHAT SHOULD I KNOW BEFORE TRANSFERRING TO ADULT CARE SERVICES

Basic Hemophilia Knowledge

What is Hemophilia?
- An inherited disorder in which a blood clotting protein is missing or low to prevent bleeding.

There are two common types of Hemophilia.
- FVIII-(8) Hemophilia A or classic hemophilia
- FIX- (9)- Hemophilia B or Christmas disease

The basic steps in blood clotting
- Blood vessel break and bleed
- Platelets travel to broken vessel, stick to the vessel wall, and then plug it to prevent or slow bleeding.
- Clotting factor comes along to form a protein called Fibrin clot so bleeding will stop

There are 3 different levels of severity in hemophilia- 50- 100% is normal
- Mild- 5-30%
- Moderate- 1- 5%
- Severe- less than 1%

Genetics: Hemophilia can be passed along to your children
- All daughters of men who have hemophilia are carriers
- If a woman is a carrier of hemophilia- A son can be born with hemophilia

Signs and Symptoms of a bleed:
- Tingling or bubbling sensation
- Swelling, pain, heat, inability to bend

Most Common bleeding sites
- Elbow, Knees, Ankles

Most Serious Bleeding sites: Seek Emergency Medical Attention
- Head, Neck, Tongue, Spinal Cord, and Stomach

Wear your Medical Alert at all times

Self-Care Management Skills

Name the factor replacement product you use/ how much

Know the Half Life of the factor product
- VIII (8)- Last 8-12 hours
- IX- Last 18- 24 hours

What treatment plan are you prescribed?

- On-Demand- Infuse factor to stop bleed at the first sign
- Prophylaxis- Infuse 2-3 times per week to prevent bleeding

You should know and be able to demonstrate what supplies are needed for infusion.
- Factor Product- Dated
- Alcohol pads, gauze, Tourniquet, Band aide
- Butterfly needle 23 or 25 gauge; Port-a-Cath
- Sharpe
- Log book or Phone app of log

Explain the history of hemophilia to the hemophilia team or other health service staff

Demonstrate telling the history of a recent or bleeding episode.
- What symptoms are or were present?
- How long did the symptoms last?
- What treatment was given?
- Did an injury happen before the symptoms start?
- Did you log the bleed and show the log

Demonstrate calling the pharmacy to order factor product and supplies

Demonstrate calling the hemophilia center to make your own appointment