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Enhance Transition Care for Medically Complex Adolescents

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Abstract

Medically complex adolescents with spina bifida and shunted hydrocephalus are living into adulthood and requiring healthcare as adults. For effective neurosurgical care to continue from a pediatric practice to an adult practice, a transition process is necessary and supported by evidence-based practice to minimize risks for discontinuing care, patient dissatisfaction, death, and increased hospitalizations and emergency room visits. Studies reveal effective transition care will lessen patient dissatisfaction and prevent death. Evidence reveals mobile applications improve patient satisfaction, knowledge of patient education, improve medication adherence, and improve disease management with follow-up visits. A quality, improvement project assessed transition importance and transition confidence with utilization of a Transition Readiness Assessment tool and the HydroAssist® Mobile Application for adolescents with spina bifida and shunted hydrocephalus. A one cohort project was conducted with seven adolescent participants at an outpatient pediatric clinical setting. Results revealed an increase in the transition importance and transition confidence scores. Development of a transition program for adolescents with complex medical conditions can improve the adolescent's confidence and importance to successful transition process within adult practices.

Keywords: complex medical health adolescents, medically complex pediatrics, pediatric transition and adult care, transition competence, transition importance, transition care pediatric neurosurgery, transition assessment, transition preparation, transition spina bifida and hydrocephalus, mobile applications with hydrocephalus, and technology apps in healthcare

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Enhance Transition Care for Medically Complex Adolescents

Spina bifida is a medically complex condition resulting in a neural tube defect from incomplete closure of the spinal cord during the twenty-eighth day of development in the embryonic period (Le & Mukherjee, 2015). Adolescents with spina bifida can function at various degrees related to the level of the spinal cord defect. Adolescents with lower spinal cord defects are high functioning with minimal neurological deficits (Bellin et al., 2011). Higher spinal cord defects can result in low functioning with developmental delays, sensory and motor disabilities, and bowel, and bladder dysfunction (Bellin et al., 2011). Adolescents with spina bifida are at risk of developing hydrocephalus, an accumulation of excessive cerebrospinal fluid in the ventricles, which leads to increased intracranial pressure and eventually death when not surgically treated (Sepulveda et al., 2017). Pediatric neurosurgeons treat, manage, and diagnosis disorders of the head, spine, and nervous system from the age of newborns to the teenage years. Due to the pediatric neurosurgeons' narrow scope of practice, they are unable to provide medical care for adults (Rothstein & Li, 2015).

With a complex pediatric medical history, pediatric and adult healthcare providers must play a pivotal role in communicating, educating, and participating with the adolescents during a vital transition process from a pediatric practice to an adult practice. As adolescents commonly carry cell phones, the free HydroAssist® Mobile Application permits the adolescents to keep track of the plan of care (see Definition of Terms, Appendix A; Hydrocephalus Association, 2019). The mobile application permits the adolescent to insert prior hydrocephalus surgeries, shunt type, programmable valve setting, providers contact information, and screenshots of previous radiographic images from a head ultrasound (US), head computed tomography (CT), or head magnetic resonance imaging (MRI) (Hydrocephalus Association, 2019). The transition process is critical to health care by preventing medical errors, identifying early intervention, decreasing readmissions while reducing hospital stays, and fostering early communication with the adolescents, their families, and the healthcare teams (Centers for Medicare & Medicaid Services, 2018; Lebrun-Harris et al., 2018; Thibadeau, Alriksson-Schmidt, & Zabel, 2010). Medically complex adolescents need early preparation and discussion to transition care from the pediatric providers to adult providers (Lestishock, Daley, & White, 2018). Timely transitioning grants the adolescents and families the ability to be prepared with their questions answered and confidence to transfer care (Oswald et al., 2013).

Significance

Roughly five million adolescents live in the United States with complex medical health (Lebrun-Harris et al., 2018). In the 2000s, healthcare organizations revealed the importance of transition planning for adolescents with complex medical health. During 2011, several organizations such as the Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), and American College of Physicians (ACP) determined the transition process steps for providers to discuss and implement with adolescents and families (American Academy of Pediatrics, 2019; Lebrun-Harris et al., 2018). Literature reveals an increased need for transition planning as poor transitioning to adult health care leads to discontinuity of care, decreased adherence to medical management, increased morbidity, and frequent hospitalizations (Corkins, Miller, Whitworth, & McGinnis, 2018; Lebrun-Harris et al., 2018).

The 2016 National Survey of Children's Health (NSCH) published data addressing transition planning from 20,708 participants (Lebrun-Harris et al., 2018). The NSCH revealed a low percentage of transition planning with 17% of adolescents with complex medical health (Lebrun-Harris et al., 2018). Transition planning is improved with care coordination and engaging the adolescents during the transition discussions to prevent confusion, dissatisfaction, and unnecessary hospital visits (Lemke, Kappel, McCarter, D'Angelo, & Tuchman, 2018).

Local Issue

Transitioning care for medically complex adolescents is a national and local issue. From a national standpoint, studies have revealed transitioning care discussions should start at twelve to fourteen years of age (Berkowitz, 2009; Lemke et al., 2018). The 2016 National Survey of Children's Health (NSCH) addressed the limited transition process occurring in the United States which results in patient dissatisfaction, increased hospitalizations, and discontinuing care (Lebrun-Harris et al., 2018). Nationally, there are 1,645 neonates born with spina bifida (Centers for Disease Control and Prevention [CDC], 2018a). The CDC has a National Spina Bifida Patient Registry that includes multiple types of spina bifida (myelomeningocele, lipomyelomeningocele, meningocele, split cord malformation, and terminal myelocystocele) and various patient outcomes related to mobility, skin breakdown, and bowel and bladder function (CDC, 2018b). Unfortunately, a patient registry does not exist for several states including Missouri and Kansas (CDC, 2018b). A total of 7,924 participants are enrolled within the twenty institutional registries in the United States (CDC, 2018b).

Diversity Considerations

Adolescents with spina bifida are a diverse population with multiple ethnicities and various levels of cognitive and physical function. Spina bifida occurs in all ethnicities with Hispanic women having the highest rate of occurrence at 3.3%, non-Hispanic Caucasian women at 3.1%, non-Hispanic African American women at 2.8%, and non-Hispanic Asian-Pacific Islander women with the lowest rate at 1% (Kirby et al., 2019). Geographically, spina bifida is included as one of the highest rated birth defects of the twenty-seven most common birth defects

(Kirby et al., 2019). From the data collected in 1999-2007, babies born with spina bifida were more often in New Jersey and North Carolina in comparison to the other nine states (Arizona, Colorado, Florida, Illinois, Massachusetts, Michigan, Nebraska, New York, and Texas) reviewed in the study (Kirby et al., 2019).

Problem Statement

Medically complex adolescents transitioning care from a pediatric practice to an adult practice are at risk for discontinuing care, increased hospitalizations and emergency room visits, patient dissatisfaction, and deaths.

Intended Improvement and Purpose

The transition process is improved with early preparation and interventions with the adolescent and their families. The ideal age to start the transition process is at twelve to fourteen with completion of the transition process by twenty-two years of age (Berkowitz, 2009; Lemke et al., 2018; McManus et al., 2015; Rothstein & Li, 2015; Sawicki et al., 2017). The project site currently discusses the transition process at seventeen years old which is later than the evidence supports. As a result, a trigger for change existed for improvement of transition importance, transition confidence, and transition readiness with utilization of the Transition Readiness Assessment tool and the HydroAssist® Mobile Application. In the project, the adolescents completed the Transition importance and transition confidence. After the Transition Readiness Assessment tool was completed, the clinic nurse helped the adolescents download the HydroAssist® Mobile Application and insert the medical history consisting of hydrocephalus treatments, radiographic images, and providers' contact information. The primary purpose of the project was to improve transition importance and transition confidence in medically complex

adolescents with spina bifida and shunted hydrocephalus with utilization of the intervention of HydroAssist® Mobile Application. Adolescents were predicted to feel empowered and confident after using the mobile application to enhance understanding of the plan of care and the transition process.

Facilitators and Barriers

The pediatric neurosurgeons supported the project to advance transitioning care for adolescents with spina bifida and shunted hydrocephalus. Additional facilitators were the clinic nurse managers in the Neurosurgery clinic and Spinal Differences clinic, the Transition Program Manager, and the clinic nurses who work in the Neurosurgery clinic and Spinal Differences clinic. Minimal costs were utilized to implement the project. Grant funding was not available to assist with the cost of providing gift cards for participants who complete the post-intervention test. Therefore, an incentive to complete the post-test was not available which may have negatively affected the post-test response rates (see Project Cost, Appendix B). Change was a barrier as the clinic nurses had difficulty pre-screening participants that met inclusion criteria in a timely fashion prior to their clinic visit which led to several missed opportunities for adolescent involvement in the improvement opportunity. During the project, the HydroAssist® Mobile Application was unable to be downloaded for three weeks as the Hydrocephalus Association was making several upgrades to the mobile application which also prevented applicants for enrolling in the project. The mobile application was only in English which presents a barrier to Spanish speaking only participants.

Review of the Evidence

Inquiry

In the medically complex adolescents with spina bifida and shunted hydrocephalus

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greater than fifteen years old, does utilization of the Transition Readiness Assessment tool and the HydroAssist® Mobile Application improve transition importance and transition confidence with transitioning from a pediatric neurosurgery practice to an adult neurosurgery practice during six months at an outpatient pediatric clinic setting?

Search Strategies

Several databases were reviewed to identify literature related to the inquiry of transitioning care for medically complex adolescents with spina bifida and shunted hydrocephalus. Databases were searched through the University of Missouri-Kansas City Health Science Library and included PubMed, CINAHL, and Cochrane. In addition, the search engine Google Scholar was used to identify literature. The keywords were complex medical health adolescents, medically complex pediatrics, pediatric transition and adult care, transition competence, transition importance, transition care pediatric neurosurgery, transition assessment, transition preparation, transition spina bifida and hydrocephalus, mobile applications with hydrocephalus, and technology apps in healthcare.

A total of one hundred and ten studies were reviewed in relation to the inquiry. The exclusion criteria consisted of studies greater than ten years old unless a pertinent study, adults transitioning care, English not as the primary language, and unpublished manuscripts. After detailed review of the studies, twenty-two studies met the inclusion criteria while multiple studies were excluded for various reasons (see PRISMA diagram, Appendix C). The twenty-two studies provided evidence regarding preparation with transitioning care, components of a transition model, and education of medically complex adolescents. The levels of evidence for the twenty-two studies were two level 1 systematic reviews, five level 2 quantitative systematic reviews, two level 3 quasi-experimental, four level 4 cohort studies and cross-sectional, one level

5 quantitative systematic review, one level 6 descriptive study, and four integrative reviews (see Evidence Rating System, Appendix D; Melnyk & Overholt, 2015, adapted; see Synthesis of Evidence Table, Appendix E).

Synthesis of Evidence: Topics and Themes

The evidence of literature found studies composed of three topics: preparation with transitioning care, components of a transition model, and education of medically complex adolescents. Within these three topics, nine themes were revealed from the literature. Evidence from the topic preparation with transitioning care developed three themes: increased autonomy for the adolescent, improved preparation with utilization of technology to manage medical conditions, and utilization of transition readiness tools to help with preparation to transfer care. Components of a transition model resulted in three themes: effective transition process assesses the needs of the adolescents, increased patient satisfaction results from using a transition tool to help enhance the communication between the adolescents and the providers, and improved patient outcomes while reducing barriers to transition care. Education of medically complex adolescents is a topic that displayed three themes: reviewing the medical conditions with the adolescent enhances awareness of the medical condition, education empowers self-care and increases quality improvement, and knowledge improves patient satisfaction and trust.

Preparation with Transitioning Care

Preparation with transitioning care from a pediatric practice to an adult practice is a process that requires ongoing teaching and not a one-time discussion (Lestishock et al., 2018). Studies showed that early discussion of transition encourages the adolescent to feel comfortable answering the providers' questions independently without the use of a parent or guardian. When young adolescents are taught about their care and interested in their health, they are likely to seek

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medical attention when experiencing abnormal symptoms related to their chronic medical health (Oswald et al., 2013). When a designated multidisciplinary team is formed and includes case managers, social workers, and group leaders, increased autonomy will develop to ease the transition process. To improve transition education, an assessment is conducted for feedback from adolescents and families on ways to enhance the autonomy with transitioning care (Lestishock et al., 2018). Advanced practice providers are not used effectively to support and educate adolescents with chronic medical illnesses to achieve the goal of independency while transitioning care (Lestishock et al., 2018). To minimize delays with transitioning care, the adolescents should receive adequate information and feel confident relaying the information back to the health care staff or provider prior to transitioning care (Oswald et al., 2013).

Technology is on the rise in health care with mobile applications to help manage medical conditions. Studies revealed that technology improves and promotes knowledge for adolescents while preparing to transition care to an adult provider (Campbell et al., 2016; Lestishock et al., 2018). One study mentioned technology as a low-cost yield for a medically complex adolescent to communicate with the providers (Huang et al., 2014). Increased patient satisfaction was noted with the use of technology to manage Type 1 diabetes for individuals with access to technology and engaged in self-care management (Waite, Martin, Franklin, Duce, & Harrison, 2018). Huang et al. (2014) measured the use of technology in adolescents with chronic disease preparing to transition care and revealed 79% compliance with the utilization of the MD2Me mobile application. The mobile application was noted to improved disease management, self-efficacy, and provider communication (Huang et al., 2014).

Several studies were reviewed with multiple transition tools noted to assess readiness to transition care from a pediatric practice to an adult practice (Betz, Smith, & Macias, 2010;

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Campbell et al., 2016; Huang et al., 2014; Sawicki et al., 2017). Adolescent Assessment of Preparation for Transition (ADAPT) is a 26-item survey developed to assess youth with chronic health conditions and preparation to transition care from a pediatric practice to an adult practice (Sawicki et al., 2017). The results from the ADAPT tool prompted thoughts with a transition coordinator, utilization of transition tools, and training in the clinic to help discuss and review a thorough transition process (Sawicki et al., 2017). Transition Readiness Assessment Questionnaire (TRAQ) 4.1 measures readiness to transition care while assessing completion of self-management skills (Huang et al., 2014). Transition Preparation Training (TPT) involves workshops for adolescents with spina bifida to improve well-being, role mastery, and self-care practice (Betz, Smith, & Macias, 2010). Campbell et al. (2016) revealed knowledge of chronic diseases were improved with one-on-one workshops, but higher drop-out rates.

Components of a Transition Model

Multiple transition tools are available for implementation in health care institutions. According to the 2016 National Survey Children's Health, adolescents without special health care needs are receiving transition planning roughly 14% of the time in comparison to 17% in adolescents with special health care needs (Lebrun-Harris et al., 2018). An inadequate transition process leads to adolescents with increased rates of morbidity and mortality (Lemke et al., 2018). Transition care coordinators are beneficial in the transition process for adolescents with complex medical health (Lemke et al., 2018). At 6-months post intervention, adolescents had increased patient satisfaction while receiving less conflicting advice from the providers. After 12-months post-intervention, adolescents reported increased discussions about the transition process and decreased confusion with the provider in comparison to the peers that did not have a transition coordinator (Lemke et al., 2018). Seeley and Lindeke (2017) also studied the use of transition

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care coordinators to assist with the development and readiness to transition care for adolescents with spina bifida. The transition care coordinators communicated with the adolescents and families to facilitate completion of transitioning goals which were determined by the adolescents from the Transition Readiness Assessment Questionnaire. Seeley and Lindeke (2017) revealed the importance of utilizing nurses in the transition process.

The recommended steps toward transition planning from the Six Core Elements of Health Care Transition algorithm were developed by the American Association of Pediatrics (AAP)/ American Academy of Family Physicians (AAFP)/ American College of Physicians (ACP) (American Academy of Pediatrics, 2019). The Six Core Elements of Health Care Transition includes policy in transition, transition registry, transition preparation, transition planning, transfer of care, and transfer completion (McManus et al., 2015). The Six Core Elements of Health Care Transition resulted in positive outcomes on satisfaction with transition care, assistance with transition tools and resources, and autonomy of the adolescent due to excess time with the provider to fully assess transitioning care (Gabriel et al., 2017; McManus et al., 2015; McPheeters et al., 2014.

Education of Medically Complex Adolescents

During transitioning of care, adolescents benefit from education of their medical condition, hospital fees, and insurance coverage options. Adolescents with spina bifida were interviewed to assess their experiences with transitioning care, recent visits in the pediatric practices, and support (Lindsay, Fellin, Cruickshank, McPherson, & Maxwell, 2016). While transitioning care, the adolescents need to learn about their medical condition and feel confident describing their health care history and plan of care with future providers. With an organized

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transition model, adolescents are educated and prepared toward transitioning which leads to adolescents and parents feeling support during the transition process (Lindsay et al., 2016).

Hospital and emergency department charges are helpful to discuss during the transition process, then adolescents are aware of the costs per visit (Inouye et al., 2019). Data was studied from 2006 to 2014 and revealed one-third of inpatient admissions were preventable with a median cost of \$31,000 (Inouye et al., 2019). The average cost of inpatient and emergency department visits for the spina bifida population in 2014 was two billion dollars (Inouye et al., 2019). Additional quality improvement projects are needed to educate adolescents on the cost of frequent hospitalizations, emergency department visits, and actions to decrease these preventable visits (Inouye et al., 2019).

Transition providers are responsible for educating adolescents on the morbidity and mortality of spina bifida to increase quality improvement and self-care (Vinchon, Baroncini, & Delestret, 2012). Vinchon et al. (2012) assessed treatment and follow-up plans for adults with hydrocephalus. By 20 years of age, an eighteen percent mortality rate was revealed (Vinchon et al., 2012). Educating medically complex adolescents is essential during each clinic visit to assess social needs, well-being, and health (Liptak et al., 2010). Self-care was studied by Bellin et al. (2011) and assessed the level of spina bifida and quality of life. Poor functional outcome was reported for individuals with hydrocephalus related to congenital malformations, posthemorrhagic, or spina bifida (Vinchon et al., 2012). Bellin et al. (2011) revealed sacral level spina bifida are higher functioning with increased quality of life and self-care in comparison to thoracolumbar levels of spina bifida.

Mobile applications improve patient satisfaction, knowledge of patient education, medication adherence, and disease management with follow-up visits (Radbron, Wilson, McCance, & Middleton, 2019; Yu, Parmanto, Dicianno, & Pramana, 2015). Yu et al. (2015) studied utilization of the iMHere application in individuals with spina bifida. The iMHere application intrigues the adolescent to insert medical information pertaining to bowel, bladder, medications, mood, and skin breakdown (Yu et al., 2015). The iMHere assesses other spina bifida concerns while the HydroAssist® Mobile Application focuses on treatment of hydrocephalus and radiographic images (Hydrocephalus Association, 2019).

Theory

Middle range theories were evaluated to assess the transition process children further experience while transitioning care from a pediatric practice to adult practice. The middle range theory that applies to the inquiry is the Transitions Theory, while implementing the concepts of preparation, transition care, and medically complex health.

Transitions Theory

The Transitions Theory was developed by Dr. Afaf I. Meleis and utilized to provide vulnerable families the framework needed to promote healthy responses to transition (Meleis et al., 2000). Dr. Meleis first experienced interest in the transition process in the 1960s through support groups for nurses and various individuals in the community (Meleis, 2010). Dr. Meleis determined that role insufficiency was related to unhealthy transitions with difficulty assuming a new role in the transition process (Meleis, 2010).

Concepts

The Transitions Theory is multifactorial and includes five concepts: process, awareness, disconnectedness, time span, and critical points (see Theory to Application, Appendix F, Meleis et al., 2000; Meleis, 2010). The process consists of informing and educating the families about the transition process (Meleis, 2010). Awareness consists of evaluating the adolescent and

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families while making them aware of the reason to transition (Meleis, 2010). Disconnectedness focuses on any doubt or worries the adolescent may experience during the transition process (Meleis, 2010). The time span for transition to begin is as early as twelve years old with final transitioning at twenty-one years old (Meleis, 2010). Critical points evaluate events and change during the transition process (Meleis, 2010).

The concepts apply to the inquiry while assessing the process of transition with utilization of the Transition Readiness Assessment tool and the HydroAssist® Mobile Application. The Transition Readiness Assessment tool assesses awareness by evaluating the adolescent's transition progress. The clinic nurses helped the adolescent insert the health information into the HydroAssist® Mobile Application to decrease doubts or worries and minimize errors during the transition process. Transition training began at fifteen years of age and was limited to adolescents with spina bifida and shunted hydrocephalus. Critical points were assessed with discussions during the clinic visit.

Methods

Institutional Review Board

Institutional Review Board (IRB) at the study site deemed the project as quality improvement (see IRB Approval Letter, Appendix G). A formal process was conducted which included utilization of the Office of Research Integrity Leadership and the Human Research Protection Program (HRPP) at the study institution. An IRB coordinator was assigned to the project. Faculty at University of Missouri-Kansas City approved the project proposal (see Faculty DNP Project Letter, Appendix H).

Ethical Issues

As a quality improvement study, signed informed consent was not required. Participation in this study was voluntary for the adolescents, without any harm or risks. Completing the Transition Readiness Assessment tool was the preferred assessment tool at the institution site. The adolescents had the ability to refuse to complete the Transition Readiness Assessment tool and enrollment in the project. The transition assessment was completed as a baseline pre-test intervention prior to downloading the HydroAssist® Mobile Application and inserting the participant's medical history. At two weeks post-intervention, the participants received an email to complete a two question post-test to assess transition importance and transition confidence. Privacy and confidentiality were protected as the participants received the survey through the institution site Research Electronic Data Capture (REDCap). The project team leader had no conflicts of interest. The HydroAssist® Mobile Application does not store or transmit personal information in the cloud as the personal data resides on the participant's mobile device (Hydrocephalus Association, 2019).

Funding

The cost of the project was minimal which eases the flexibility of others to duplicate this project in the future. In the initial phase of the project, breakfast was provided at a meeting of the project leader with ten clinic nurses to discuss the project, provide handouts, review the Transition Readiness Assessment tool, conduct practice sessions in downloading the free HydroAssist® Mobile Application, and review project forms (see Project Cost, Appendix B). There were no fees to utilize the Transition Readiness Assessment tool and the HydroAssist® Mobile Application. At the end of the project, the nurses were provided a small gift of appreciation (see Project Cost, Appendix B).

Setting, Participants, and Sampling Method

The project was completed at a pediatric hospital in the Midwest during and outpatient clinical setting. Inclusion criteria consisted of a convenience sample of adolescents greater than fifteen years old with spina bifida and shunted hydrocephalus, English or Spanish speaking, and developmentally appropriate. Exclusion criteria included other languages spoken besides English and Spanish, less than fifteen years old, adolescents with hydrocephalus for other medical reasons, or cognitive and physical delays without the ability to use the mobile application or complete the Transition Readiness Assessment tool. At the project site, all adolescents greater than fifteen years of age were encouraged to complete the Transition Readiness Assessment tool.

EBP Intervention

A total of four phases were included in this project to assess transition importance and transition confidence. The first phase started in summer 2019 while collecting the sample size of adolescents with spina bifida and shunted hydrocephalus. The project team leader educated the clinic nurses on the project and the project forms, reviewed the Transition Readiness Assessment tool, and outlined detailed instructions about the HydroAssist® Mobile Application with handouts. To prevent from meeting outside work time, a mandatory breakfast meeting was offered to the clinic nurses to review the project guidelines and the time frame for the project. The second phase involved the nurses and project team leader informing the adolescents of the project which consist of completing the pre-test Transition Readiness Assessment tool while in the clinic. Participants also provided an email address for REDCap to complete the post-test questionnaire two weeks after enrolling in the project. The nurses helped the participants medical information on the mobile application. In February 2020, the third phase occurred with completion of enrolling participants. The final phase reviewed the statistical data with

conclusions of the project and dissemination of the results in April 2020 (see Intervention Flow Diagram, Appendix I).

Organizational Change Process and Evidence-based Practice Models

Roger's Diffusion of Innovation (DOI) is an organizational change model that implements new practices in clinical settings (Pashaeypoor et al., 2017). DOI consists of a bell-curve with five categories of adopters which are innovators, early adopters, early majority, late majority, and laggards (Rizan, Phee, Boardman, & Khera, 2017). DOI change model fits well with the project while implementing change in an outpatient clinical setting. Sustainability after completion of this project is important but also supported by the clinic nurses and providers to enhance the transition process.

The Iowa Model assists clinicians evaluation and implementation of quality improvement studies in patient care (Buckwalter et al., 2017). The Iowa model was established from the organizational change model, Roger's Diffusion of Innovation (Buckwalter et al., 2017). The Iowa model was developed by nurses and widely used in studies (Buckwalter et al., 2017). Advancement of quality improvement studies and patient engagement occurred with the revision of the Iowa Model. The model of evidence-based practice change is beneficial with this project as it fosters utilization of quality improvement, change theory, clinical expertise, and a combination of data collection procedures (Rosswurm & Larrabee, 1999).

Study Design

The quality improvement study used a one cohort, quasi-experimental design to assess the transition importance and transition confidence scores with use of the Transition Readiness Assessment tool. The HydroAssist® Mobile Application was the intervention in the project (see Logic Model, Appendix J; see Project Timeline Flow Diagram, Appendix K).

Internal and External Validity

Internal validity consists of strengthening the interventions by obtaining a sample size of forty adolescents with spina bifida and shunted hydrocephalus using convenience sampling with inclusion and exclusion criteria. The Transition Readiness Assessment tool is a pre-intervention test completed upon initial enrollment into the project by each adolescent to establish a baseline of transition importance and transition confidence scores for adolescents greater than fifteen years old with spina bifida and shunted hydrocephalus. After two weeks, a post-intervention test was completed to assess transition importance and transition confidence scores after utilization of the HydroAssist® Mobile Application. The project team leader bias was limited as the clinic nurses spoke to many of the participants about the project, set-up the Transition Readiness Assessment tool on a hospital computer, and educated the adolescents on the use of the HydroAssist® Mobile Application. A threat to internal validity occur with the selection of the sample and selection bias as the project was limited to a non-randomized selection of adolescents greater than fifteen years old with spina bifida and shunted hydrocephalus.

The project consisted of a small sample size, and a larger sample size was needed to establish validity in generalizing the results and determining an increase in transition importance and transition confidence. External validity is less likely to be a threat to the transferability of the intervention as replication can occur in other populations and settings.

Primary Outcome

The primary outcome includesd improvement in the transition importance and transition confidence scores with the Transition Readiness Assessment tool and the HydroAssist® Mobile Application. With support, adolescents may achieve a better understanding of their complex medical history, grasp the importance of transition care, and establish confidence to transition

from the pediatric practice to the adult practice successfully. Adolescents with improved transition readiness decrease the risk of unnecessary hospitalizations, discontinuity of care, and death (Campbell et al., 2016; Vinchon & Dhellemmes, 2007).

Measurement Instruments

The measurement tool used in this project is the Transition Readiness Assessment tool developed nine years ago for clinical care at the project site (see Measurement Tool, Appendix L). The first two questions in the Transition Readiness Assessment tool assess transition importance and transition confidence are validated and adapted from Got Transition: Center for Health Care Transition Improvements. The additional questions on the Transition Readiness Assessment tool are validated by clinical expertise and the length of time clinical experts used this tool for transition care decision making. All adolescents greater than fifteen years of age complete the Transition Readiness Assessment tool while in an outpatient clinical setting as a pre-intervention tool. Permission to use the Transition Readiness Assessment tool is not required as the tool is a standard transition form at the study site.

The HydroAssist® Mobile Application was the intervention utilized during the project. The free, mobile application permits adolescents to keep track of their medical history by inserting screenshots of radiographic images of the shunt hardware, doctor's office contact information, emergency contacts, and previous hydrocephalus surgeries. No permission is required to use the HydroAssist® Mobile Application, but proper citation is needed. Two weeks after enrollment in the project, a post-intervention test was submitted to the participants through the REDCap.

Quality of Data

With an anticipated small sample size, power was not used in determining the sample size. Participants were informed their information would remain unidentified and utilized to assess transition education. The data were collected over six months and safely stored while using Research Electronic Data Capture (REDCap). Currently, there are no published benchmark data for comparison.

Analysis Plan

The Transition Readiness Assessment tool was completed during the initial clinic visit. Two weeks post-intervention, two questions from the Transition Readiness Assessment tool were used to evaluate transition importance and transition confidence. These two questions were sent as a post-test to the participants by REDCap. A Wilcoxon Signed Ranks Test was utilized to compare the pre-intervention and post-intervention data to reveal the transition importance and transition confidence scores (see Data Collection, Appendix M). The demographics included were age and gender (see Demographics, Appendix N). The Statistical Package for the Social Sciences (SSPS) was utilized for data processing of demographics and descriptive statistics.

Results

Setting and Participants

The project was completed at a pediatric, Midwest institution in the neurosurgery clinic and spinal differences clinic from August 2019 to February 2020. A one cohort design occurred in an outpatient setting with a total of seven participants.

The demographics of the seven participants were two females and five males, their ages ranging from fifteen to eighteen years old. The project team leader did not collect ethnicity as that information did not yield any benefit to the project.

Intervention Course, Actual

The project occurred from August 2019 to February 2020 with one cohort. During each week of the project, the clinic nurses and the project team leader assessed each clinic, Neurosurgery clinic and Spinal Difference clinic to see if any of the adolescents attending clinic that week met the inclusion requirement for the project. When the adolescent met the criteria, the clinic nurses discussed the project with the families and enrolled the adolescents if they were interested. At times, the clinics were short staffed, and the project team leader informed the adolescents about the project. Once the family and adolescent agreed to participate in the project, they were asked to provide a personal email to send the two week post-intervention test to assess transition importance and transition confidence. In this project, the focus was on the concepts of transition importance and transition confidence scores. After the Transition Readiness tool was completed, the clinic nurses helped the participant download the HydroAssist® Mobile Application and insert the medical information accordingly. The medical information inserted into the HvdroAssist® mobile application were treatments, images, and contact information. The treatment category indicated the day of surgery, type of shunt (manufacturers name), the neurosurgeon's name and contact information, and symptoms prior to surgery. Radiographic images include photos from a head CT or MRI which were captured in the HydroAssist® Mobile Application. Contact information allowed the adolescent to insert the neurosurgeon's clinic information. After the mobile application was updated with current information, the adolescent was informed to complete a post-intervention survey two weeks after the clinic visit.

Within the first three months of initiating the project, from August 2019 to November 2019, a total of nine participants enrolled with five participants who completed the pre- and post-test. From December 2019 to February 2020, an additional 4 participants were enrolled in the project with two more participants that completed the pre- and post-test.

Outcome Data

The primary outcomes were transition importance and transition confidence. Data were missing from 7 participants that did not complete the project, a total of 14 participants were enrolled. Descriptive statistics were utilized as a summary of the Transition Readiness Assessment tool (see Data Collection, Appendix M). The median pre-transition importance score was 7.0. The median post-transition score was 8.0. The median pre-confident score was 5, and the median post-confident score was 6. The pre- and post-scores improved when assessing transition importance and transition confidence with utilization of one intervention, the HydroAssist® Mobile Application. The Wilcoxon Signed Ranks Test showed a statistically significant difference between the pre and post confidence scores (Z=-.938, p= .348) and did not show a statistically significant difference between the pre and post confidence scores (Z= -1.49, p= .136; see Statistical Analysis, Appendix O). Due to the small sample, the statistical significance was not valid although clinical significance was present.

Discussion

Successes

The most important success was achieving the primary outcome. Despite a small sample size, it is considered a successful project while seeing improvement in transition importance and transition confidence scores with utilization of one intervention, the HydroAssist® Mobile Application. At the project site, a transition program from the pediatric hospital to a nearby adult hospital is in progress. A transition plan is beneficial for adolescents with complex medical health so the adolescent can provide independent care. The mobile application is one of many interventions to help adolescents gain confidence to manage their medical care. With development of future quality improvement studies, starting this project in the summer to obtain

a large sample size of school age participants would be helpful to yield statistically significant value.

Study Strengths

The project was completed at a large, midwestern, Magnet Certified Children's Hospital that supports growth and development of improvement in care. The neurosurgeons and clinic managers were the leaders in neurosurgery clinic who fully supported the project and recognized the need to enhance and develop our transition process for adolescents with spina bifida and shunted hydrocephalus. The clinic nurses were supportive of the project during the initial process. Two months after the project started, the clinic staff was no longer educating the adolescents and families about the project. The project team leader enrolled a few participants in the project due to a lack of staffing. With repeat discussion about the project and understanding the importance, the clinic nurses made sure they discussed the project with every patient that met inclusion criteria. The project team leader completed weekly reviews of the charts in the neurosurgery clinic and spinal difference clinic to determine if anyone met the inclusion criteria. Adolescents were able to download and use the HydroAssist® Mobile Application on an Apple phone or Android phone.

Results Compared to Evidence in the Literature

Minimal literature is available to compare to adolescents with spina bifida who are transitioning care. Lindsay et al. (2016) reveal literature has neglected the spina bifida population and the need for transition to adult healthcare despite spina bifida being the second most common birth defect. Spina bifida is a unique diagnosis that requires care by multiple specialists such as neurosurgery, neurology, urology, orthopedic, rehabilitation, physical and occupational therapists, and orthotics (Lindsay et al., 2016). Mobile applications for healthcare are starting to increase and reveal improvement in medical care. Yu et al. (2015) studied six participants ranging from twenty-three to thirty-six years of age. These participants utilized an innovative system called iMHere (Internet Mobile Health and Rehabilitation) which enables self-care for individuals with Spina Bifida through multiple smartphone apps and a clinician portal (Yu et al., 2015). The iMHere system is composed of five different mobile applications which are MyMeds, TeleCath, BMQs, Mood, and SkinCare, all to help support preventative self-care (Yu et al., 2015). The study revealed the participants were satisfied with the iMHere apps but noticed some challenges with inserting detailed information into the applications. Similar to this project, the adolescents had improvement in their transition importance and transition confidence scores. The adolescents appreciated a handy device to load their medical history instead of carrying multiple papers with their medication information.

Limitations

Internal Validity Effects

Investigator bias can affect internal validity. The project team leader had minimal involvement with the participants. Due to short staffing one day in the Spinal Difference clinic, the project team leader had to discuss project enrollment with two participants. The reason is unknown why neither of those two participants completed the post-test which was sent securely via REDCap. The Transition Assessment Readiness tool is a reliable and valid tool established for over nine years.

External Validity Effects

External validity was affected by a small sample size and limited to one pediatric facility. The participants were also limited as the study occurred in the fall and continued during the winter season when our clinic visits are typically lower in visits. Also, the average individuals from fifteen to twenty years of age are frequently seen in the summer months when school and college are not in session. Spinal differences clinic, a multispecialty visit, lasts for four to five hours for evaluation of the adolescent by multiple providers. The transferability of the project intervention is realist. External generalization can occur in the future with a larger sample size and participation at multiple facilities.

Sustainability of Effects and Plans to Maintain Effects

A potential exists for observed gains to weaken over time if a plan is not in place. To continue with effective transition education, the key stakeholders must continue to support adolescents with spina bifida and hydrocephalus while understanding the importance of transitioning care and addressing the fears of transitioning to adult healthcare facilities. The clinic managers and clinic nurses are aware of the benefits of the project and will maintain educating adolescents about the HydroAssist® Mobile Application while using the Transition Readiness Assessment tool.

Efforts to Minimize the Study Limitations

Limitations were minimized with use of a validated tool, Transition Readiness Assessment tool, and a HIPAA compliant intervention, HydroAssist® Mobile Application. The participants were informed their participation was voluntary and would not affect their medical care.

Interpretation

Expected and Actual Outcomes

An increase in transition importance and transition confidence scores with the use of the HydroAssist® Mobile Application was an expected and actual outcome. The pre- and post-test

scores were compared and noted to increase by fifteen percent. The participants and their families mentioned the HydroAssist® Mobile Application was convenient, helpful, and informative. The adolescents felt empowered to have their medical information on their phones, especially if they were away from their homes on a vacation and developed symptoms of a shunt malfunction. The mobile application has the function to capture previous radiographic images with or without a shunt malfunction, the neurosurgeon's contact information, previous symptoms of a shunt malfunction, and the type of shunt. This information is helpful for outside hospitals during evaluation in the Emergency Department.

Intervention Effectiveness

The HydroAssist® Mobile Application was the intervention used in this project. The mobile application is HIPAA compliant, and the information stays directly on the individual's mobile phone. During the project, there was a two to three week period when the mobile application was not available as company updates were occurring which affected enrolling some participants into the project. As technology continues to advance, more individuals are using their phones often, especially in the younger generations. Although the sample size was small and the setting for this project was limited to one pediatric hospital in the Midwest, the project can easily be replicated for future projects at other institutions.

Intervention Revision

Despite reassuring feedback from the HydroAssist® Mobile Application and improvement in the transition importance and transition confidence scores, one modification to improve the intervention is to increase the sample size by starting this project during the peak season for adolescent appointments in the summer. To replicate this project, the other institutions will need to assess the highest influx of clinic visits for adolescents and start the project at that time. Studies show it is best to start transition education between twelve to fourteen years old.

Expected and Actual Impact to Health System, Costs, and Policy

The expected and actual impact on the health system was to improve transition importance to help adolescents understand why they need to know about their medical health, how to schedule doctor's appointments, when to seek medical attention, and how to manage without parents' direct assistance. Transition confidence is a major component of health care as these adolescents must feel confident and with minimal fears while with transitioning to their adult neurosurgeon. Lemke et al. (2018) reveals the need for providers to decrease stressors, fears, and instill confidence in the adolescents while transitioning care to an adult neurosurgeon. The excepted and actual impact was met and noted with the feedback from the participants.

The project site supported the project with minimal cost. This project is sustainable for prolonged periods, especially as the clinic nurses continue to see the benefits of taking the extra time to download the mobile application and assisting the adolescents with inserting correct medical information.

Conclusion

Practical Usefulness of Intervention

Healthy People 2020 identified the need to prepare adolescents for transitioning care from pediatric to adult practices (Huang et al., 2014). The Six Core Element of Health Care Transition developed by AAP/AAFP/ACP has a useful transition framework to transition adolescents from pediatric to adult practices (American Academy of Pediatrics, 2019; Gabriel et al., 2017; Got Transition, 2019; McManus et al., 2014; McPheeters at al., 2014). Evidence reveals the importance of discussing transition care at an early age, assessing readiness to transition with the Transition Readiness Assessment tool, and utilization of technology to improved disease management and self-efficacy (American Academy of Pediatrics, 2019; Got Transition, 2019; Huang et al., 2014; Sawicki et al., 2017). Utilization of the HydroAssist® Mobile Application is practical since teenagers commonly have cell phones with ease to access the plan of care. The application is free to download with simple and stress-free insertion of the medical history. This project values adolescents with complex medical conditions and ways to improve their medical management.

Further Study of Intervention

While advancing healthcare, future studies with mobile applications for adolescents with spina bifida and shunted hydrocephalus to ease transition of care from pediatric practices to adult practices are beneficial for confidence and autonomy of the adolescent. Other additional studies include large cohorts reviewing successful transition programs for medically complex adolescents transitioning to adult care facilities. Transitioning care and mobile applications have limited data which reveals the need to support further quality improvement studies.

Dissemination

The project was presented as a poster presentation on October 4th, 2019 at an annual Pediatric Advanced Practice Nursing Conference. A manuscript will be submitted to the Journal of Neuroscience Nurses. Future studies are warranted to assess use of mobile applications further while transitioning care a pediatric practice to an adult practice. With additional quality improvement studies, results of those studies might reveal the use of mobile applications decreasing unnecessary emergency department visits, increasing follow-up visits, and preventing death of individuals with medically complex health.

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Appendix A Definition of Terms

Spina Bifida: Spina bifida is a neural tube defect that results from incomplete closure of the spinal cord during the twenty-eighth day of development in the embryonic period (Le & Mukherjee, 2015).

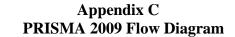
Transition Readiness Assessment: A tool utilized to measure the readiness for youth to transition care (Gonzalez et al., 2017).

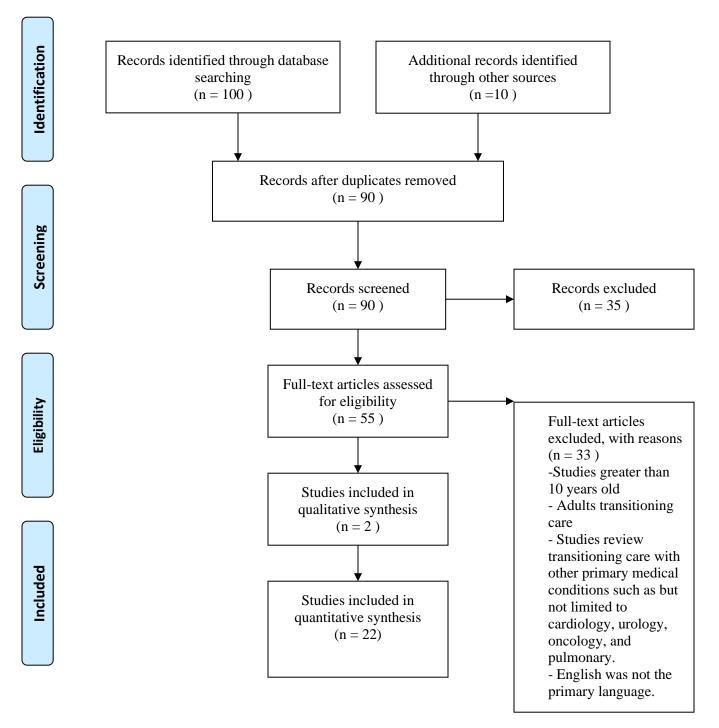
HydroAssist® Mobile Application: A mobile application that permits the adolescents to insert the previous hydrocephalus surgeries, shunt type, programmable valve setting, doctors contact information, medical emergency contacts, and screen shots of previous images such as head US, CT, or MRI (Hydrocephalus Association, 2019).

Hydrocephalus: Hydrocephalus is an accumulation of excess cerebrospinal fluid in the brain which leads to increased intracranial pressure and death when not surgically treated (Sepulveda et al., 2017).

Appendix B Project Cost

Itemized	Fee
Breakfast for teaching the clinic nurses (10)	\$40
Handouts about the project	\$5
Appreciation gift for clinic staff involved in	\$60
the study (4)	
HydroAssist® brochures from the company	No charge, company sends without a fee
Conference room at the project site	No charge, free to employees
Project Team Leader (+600 hours)	\$0
Total Cost:	\$105





From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

	Rating System for the Hierarchy of Evidence
	For an Interventional Inquiry
	(Modification by Dr. Lindholm for course N5613)
Level I	Evidence from a systematic review or meta-analysis of all relevant RCTs. Evidence-based clinical practice guidelines based on systematic reviews of RCTs).*
Level II	Evidence obtained from well-designed RCT. Quantitative systematic review of well-designed controlled trial without randomization.
Level III	Evidence obtained from well-designed controlled trial without randomization (quasi-experimental). Quantitative systematic review of case-control, cohort, or correlational studies.
Level IV	Evidence from well-designed case-control or cohort study (or cross- sectional study)
Level V	Evidence from systematic review of <i>quantitative</i> descriptive (<i>no relationships to examine</i>) or qualitative studies.
Level VI	Evidence from a single <i>quantitative</i> descriptive (no relationships to examine in the study) or qualitative study
Level VII	Evidence from the opinion of authorities and/or reports of expert committees

Appendix D Evidence Rating System

Melnyk, B.M.& Fineout-Overholt., E. (2015). *Evidence-based practice in nursing and healthcare.* Philadelphia Lippincott Williams & Wilkins.

*Italics, appropriate in this category, modification by LL 2017 based on opinions from experts to place SR at one level higher than single study design level.

Synthesis of Evidence									
First author, Year, Title, Journal	Purpose	Research Design ¹ , Evidence Level ² & Variables	Sample & Sampling, Setting	Measures & Reliability (if reported)	Results & Analysis Used	Limitations & Usefulness			
	1		Subtopic: Preparation		I				
Lestishock. (2018). Perceptions of health care transition care coordination in patients with chronic illness. <i>American Academy</i> of Pediatrics.	Examine the insight of the pediatric nurse practitioners (PNP) for healthcare transition process with adolescents and families at various institutions.	Quantitative Study, Evidence level 6 Variables: Themes-education, healthcare system, support and communication 4 broad categories- adolescent, parent/caregiver, clinician, and institution.	170 participants attending meeting at NAPNAP, answered multiple questions with one person taking notes at each table. Roughly 20 tables.	Data generated from content analysis and coded with recording units.	Transitioning care is a process and not a single event. Transition discussions should start at 12-13 years old. Need better referral coordination to adult practices. Designate a multidisciplinary team to help with transition (i.e. case managers, social worker, and group leaders).	Limitations- only one note taker at each table to collect everyone's responses with the possibility not to collect or recall all that was discussed. Primarily PNP representation with inability to assess for family nurse practitioners being present. Usefulness: study revealed nurses and NPs as imperative components toward successful transition. Mentions the use of technology to improve and promote			

Appendix E Synthesis of Evidence

						knowledge of adolescent care.
Sawicki. (2017). Preparation for transition to adult care among Medicaid-insured adolescents. <i>American Academy</i> of Pediatrics.	Review transition preparation for chronically ill adolescents with Medicaid coverage in two largely populated areas: Pennsylvania (health plan 1) and Texas (health plan 2).	Quantitative Systemic Review, Level 2 Variables: counseling on transition self- management; counseling on prescription medication; and transfer planning.	3,000 surveys randomly mailed to eligible members: 1 outpatient visit within 12 months before the study, chronic health conditions (NC-CD: non-complex chronic disease or C-CD: complex chronic disease). 1355 surveys were completed (780 plan 1, 575 plan 2).	Utilization of the Adolescent Assessment of Preparation for Transition (ADAPT) 26 item survey developed youth with chronic health conditions. Completed by adolescents age 16-17.	Low percentage of adolescents reported discussing a transition plan.	Limitations: low response rates. ADAPT survey focuses on transition discussion by the provider only, not anyone else on healthcare team. Usefulness: Chronically ill youth have more challenges with achieving milestones in life and increase risk for loss of health care coverage. Increased attention is needed to a transition plan- care coordinators, technology-based tools, and clinician training.

Waite. (2017). Human factors and data logging processes with the use of advanced technology for adults with type 1 diabetes: systematic integrative review. <i>JMIR Human</i> <i>Factors</i> .	Examine relationship between human factors and adherence to technology for data-logging.	Systematic Review, Evidence Level 2. Variables: technology, Type 1 diabetes, and self-management	18 articles were reviewed: 5 qualitative, 5 experimental, 3 observational, 4 cross- sectional, 1 mixed method	Utilized Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA).	Inclusive adherence with data logging with measurable outcomes. Increased satisfaction with advanced technologies. Data revealed higher economic statuses are more likely to have access to technology and engage in self- management.	Limitations: small sample size of quantitative studies. Usefulness: Technology in these articles revealed as beneficial. Also, mentioned additional research is needed with technology and healthcare.
Campbell. (2016). Transition of care for adolescents from pediatric services to adult health services. <i>Cochrane</i> <i>Database of</i> <i>Systematic</i> <i>Reviews</i> .	Assess interventions to increase transition from pediatrics to adult practices.	Systematic Review, Level 1 Variables- interventions to help transition care- four different interventions in each study. Two-day transition workshops for adolescents with spina bifida; web- and SMS- based education intervention; one-on- one teaching sessions;	 21,201 articles found, 68 articles eligible 4 randomized control studies, N= 238 participants met the inclusion criteria. Literature search from mid- 1940/1950's to 2015. 	Data synthesis with Grading of Recommendations Assessment, Development and Evaluation (GRADE).	Technology-based intervention allowed the adolescents to initiate communication with health care providers. Knowledge of the disease was improved with 1:1 work-shops but higher drop-out rates with workshops.	Limitations: lack of evidence to help establish transitioning care process. Large resource of articles to review, only 4 met inclusion criteria. Usefulness: Funding for transitions care is

		transition with coordinator for adolescents with Type 1 diabetes.				fragmented leaving adolescents without effective equipment for medical management. Participation in transition program leads to fewer disease related hospitalizations. Technology enhances self- efficacy and confidence in plan of care.
Rothstein. (2015). Transitional care in the pediatric neurosurgical patients. <i>Seminars</i> <i>in Pediatric</i> <i>Surgery</i> .	This study reviewed utilizing a transition model for young adults with common pediatric neurosurgical diseases.	Integrative Review, Evidence Level 7 The variables are shunted hydrocephalus, central nervous system brain tumors, myelomeningocele, transitional care, transition models	Multiple articles were reviewed to assess transitional care in adolescents.	Not reported.	Educate adult providers about the cognitive challenges the adult providers face with pediatric and adult providers. Reveals that pediatric neurosurgery is a small field with shortage of providers. Neurosurgeon face obstacles in the	Further research is needed to assess long-term outcomes of pediatric neurosurgery adolescents as adults. Usefulness- The article is help while relaying the goal to start transitioning at 14

					hospital system when caring for adult patients in a pediatric setting.	years old per AAP guidelines.
Huang. (2014). Preparing adolescents with chronic disease for transition to adult care: a technology program. <i>American</i> <i>Academy of</i> <i>Pediatrics</i> .	Evaluate approach to transition adolescents to adult care with utilization of internet or mobile phone delivered disease management.	Quantitative Systematic Review, Evidence level 2 Variables: disease management, self- efficacy, and communication Intervention group- MD2Me mobile application, cell phones provided to participants without phone. Control group- month message via email or mail (participant preference).	81 participants with Irritable Bowel Disease, Cystic Fibrosis, and Type 1 diabetes. All had no cognitive impairments. Recruited from a pediatric academic center.	MD2Me application completed over an 8 month, based on Banduras Social Cognitive Therapy. Transition Readiness Assessment Questionnaire (TRAQ) to assess transition readiness. Patient Activation measure to assess participants self- efficacy and confidence to manage their health.	Of 81 youth, 75 completed the study. 79% were compliant with MD2Me program. MD2Me technology- based intervention improved disease management, self- efficacy, and communication.	Limitation- small sample size limited to one institution. Focused on three patient populations. Usefulness- Healthy people 2020 identified the need for transition planning. TRAQ is helpful to identify transition readiness. Low parental literacy affects the

						adolescent's health outcomes.
Oswald. (2013). Youth with special health care needs: transition to adult health care services. <i>Maternal</i> & <i>Child Health</i> <i>Journal</i> .	Develop a successful transition process and identify variables associated with successful transitioning.	Cohort Study, Evidence level 4 Variables: healthcare source from personal doctor or nurse, adult healthcare provider, insurance coverage, preventative healthcare visits, satisfied with healthcare services and no recent delays in healthcare.	1065 participants were successfully contacted and interviewed from 10,933 youth aged 14- 1y.	The 2007 Survey of Adult Transition and Health dataset to assess for success. Data analysis from ovyprop and svylogit procedures statistical analysis, Stata 8.1.	21% of the youth had successful transition to adult healthcare. During the interviews, the participants felt the healthcare was better. 113 subjects were unable to interview independently due to physical, cognitive, speech of hearing difficulties so a proxy answered the questions without significant predictors of successful transition.	Limitations: not a randomized study. Usefulness: Revealed increased successful transitioning if mom has a college education, female, routine care visits as a child, aware of childhood provider, pediatric provider who listened, receives routine care.
Betz. (2010). Testing the transition preparation	Examine implementation of Transition Preparation	Systematic Review, Evidence level 2	154 youth were contacted, 80 were included in the study	Pre-intervention as a baseline study and post-	Adolescents lack attendance to workshops and completing flow	Limitation: lack of transportation to workshops, mostly Spanish

training program:	Training (TPT)		(42 treatment and 38	intervention at 4-	chart for transition.	speaking with
• • •	- · · · ·				chart for transition.	
A randomized	with spina bifida	Variables are well-	control).	months.		some issues
controlled trial.	management to	being, role mastery				completing
International	improve well-	and self0care practice.				workshops with
journal of child	being, role	and senteene practice.	Setting-Spina bifida	Well-being-		literacy concerns.
and adolescent	mastery, and self-		clinics at Children's	measured with		
health.	care practice.		Hospital Los Angeles	PARS III		
			and Los Angeles	(Personal		Usefulness-
			County Medical Center.	Adjustment and		reveals difficulty
				Role Skills) Scale		completing
				28 item		workshops for
				questionnaire.		preparation
				questionnaire.		training.
				Role-mastery-		u anning.
				measured with		
				Community Like		
				Skills Scale		
				(CLSS) a 33-item		
				tool. Cochrane		
				reported 0.69.		
				reported 0.05.		
				Self-care- Denyes		
				Self-care practice		
				instrument		
				(DSPL-90C) with		
				test-retest		
				reliability 0.84-		
				.92.		
				TPT- 3 modules,		
				8 session		
				programs with 2		
				pay work-shops.		

			Subtopic: Transition			
Corkins. (2018). Graduation Day: healthcare transition from pediatric to adult. <i>Nutrition in</i> <i>Clinical Practice</i> .	The purpose of this study consists of reviewing transition models, assessing outcomes, provider needs, and legal issues with transitioning.	Integrative Review, Evidence Level 7 The variables are healthcare transition (HCT) models, nutrition, outcomes, legal aspects to transition	4 studies were reviewed (3 quantitative and 1 qualitative) to further assess HCT models.	Not reported	Multiple transition models were reviewed with the common goal toward successful transitioning. HCT requires early intervention with the pediatric and adult provider working together for continuity of care. Patients that are developmentally able to provide self-care and responsibility, then the parents must undergo legal rights from the courts.	Limitation- inconsistent markers to determine success of the various transition models. Usefulness: This is a helpful study for displaying the variables involved with transitioning care.
Lebrun-Harris. (2018). Transition planning among US youth with and without special health care needs. <i>American Academy</i> of <i>Pediatrics</i> .	Evaluate transition planning for youth with and without special health care needs (SHCN).	Cross-sectional, Evidence Level 4 2016 National Survey Children's Health. Dependent variable- transition planning.	Randomly surveyed 20,212 individuals, 20,708 youth age 12-17 meet inclusion criteria.	Bivariate analyses were used to assess rates of transition planning within each population and variable of interest.	Effective transition planning is not occurring in youth with or without SHCN. 14% transition planning in non-SHCN and 17% in SHCN adolescents.	Limitations: information obtained from parents and not directly from the youth. Achieving transition based upon meeting 1 or 2 elements while missing the rest.

		Independent variables- doctor discussed transition to HCP that treats adults; provider worked with youth to understand transition; provider worked with youth to gain self- care; youth had alone time with provider to review preventative care.				Usefulness: Revealed the importance of educating about transitioning early by age of 12. Involving children and families in the transition process to build independence and gain self-care.
Lemke. (2018). Perceptions of health care transition care coordination in patient with chronic illness.	Assess effectiveness of utilizing health care transition care coordination for adolescents with chronic illnesses.	Cohort Study, Evidence level 4 Variables- care coordinators, transition care, quality care	209 participants with mean age of 19 from an urban adolescent practice with Medicaid coverage, non-English speaking adolescents were excluded.	Care coordination Assignment tool version 1.0 determines complexity of participants.	At 6 months post- enrollment, participants report increased patient satisfaction and receiving less conflicting advice.	Limitations- only limited to an urban setting with generalize demographic diversity.
American Academy of Pediatrics.			Interviewed at baseline, 6- month, and 12- month post enrollment, received compensation.	Patient Assessment of Chronic Illness Care (PACIC) 20 questions- used to assess patient quality care	At 12 months post- enrollment, participants are less confused about the provider role and frequent discussions about future care in comparison to the control group.	Usefulness- Study mentioned unsuccessful use of HCT leads to decreased quality of health with increased morbidity and mortality.
						Roughly 41% of adolescents are receiving healthcare

						transition guidance.
Gabriel. (2017). Outcome evidence for structured pediatric to adult health care transition interventions: a systemic review. <i>The Journal of</i> <i>Pediatrics</i> .	To assess positive outcomes with pediatric to adult transition articles using health, consumer experience and cost of care.	Quantitative Systematic Review, Evidence Level 2 The variables are population health, consumer experience, and service utilization.	43 articles met the requirement of a total 3844 articles. 20 articles were related to population health, 8 articles focused on consumer experience, and 9 studies on service utilization. Ambulatory adult settings. Searched articles from January 1995 to April 2016.	Articles were read in their entirety and assessed for methodological strength with the Effective Public Health Practice Project Quality Assessment Tool for Quantitative Studies (EPHPP).	Analyzed with the terms aligned from the AAP/AAFP/ACP Clinical Report and the framework from the Six Core Elements of Health Care Transition. Of the 43 studies, the results showed 28 had significant positive outcomes. Those 20 studies revealed improvement in population health	Limitations : lack of detailed transition process in the studies, some studies with small sample size affects statistical power, and several studies with data collection used methods of untested validity and reliability. Limited positive transition articles revealed the infancy stage of

					 while the remaining 8 articles reduced transition barriers. Only one article had positive outcomes when reviewing all three variables. Only 3 articles thoroughly examined cost of care. 	the transition process Usefulness- systemic review reveals the need for consumer feedback on transition planning, transfer of care and integrating into adult care.
Seeley. (2017). Developing a transition care coordination program for youth with spina bifida. Journal of Pediatric Health Care.	Assesses development and readiness to transition adolescents with spina bifida.	Cohort Study, Evidence Level 4 Variable- transition readiness, care coordinators	 14 youth-parent groups Completed baseline Transition Readiness Assessment Questionnaire (TRAQ)-20 items at pre- intervention and post- intervention (4-6 months later). Month contact with transition care coordinators (TCC) via 	Not reported	Increase in TRAQ scores noted in post-intervention. Early intervention leads to improved transitioning. Despite attempt to contact families monthly, average contact was 3.7 times within 6- month period.	Limitation: small sample size. Usefulness: revealed adolescents are often under supported in transitioning and providers overestimate the support available to them. Nurses are beneficial to help with the transition

			phone, email or face-to- face.			process and offering support.
McManus. (2014). Pediatric to adult transition: a quality improvement model for primary care. <i>Journal of</i> <i>Adolescent Health</i> .	Evaluate quality improvement within primary care practices and improvement in transitioning from pediatric to adult practices.	Quantitative Study, Evidence Level 5 Variables: Six Core Elements of Health Care Transition-offer policy in transition, providers transition knowledge, registry, transition preparation, transition planning, transfer of care, quality improvement	 5 large practices in Washington, D.C. 400 participants at the 3 pediatric sites and 128 participants at the adult sites. Age 14-25 with chronic medical conditions, enrolled in Medicaid. 	Not reported	Two-year study revealed completed 352 pediatric transition readiness assessments, and 2 adult sites completed 93. During the study, pediatric practices developed extensive list of adult providers.	Limitation- a designated care coordinator was not completed in this study. One site was removed from the study which affects outcomes. Usefulness: transitioned with medical summary, a transition readiness assessment, a transition plan and

						chronic condition fact sheet. The earlier the transition process, the greater the results with transferring care. Developing a checklist before first appointment with adult provider.
McPheeters. (2014). Transition care for children with special health needs. <i>AHRQ</i> <i>Publication</i> .	Review current literature on transitioning care for children with SHCN.	Systematic Review, Evidence Level 1 Variables: Six Core Elements of Health Care Transition, transition care for diabetes, solid organ and other conditions.	Reviewed 2238 articles, 30 met inclusion criteria.	Not reported.	Success of transitioning care requires further research. Decrease adherence to medications leads to increased hospitalization. Technology increased medication use and decreased rejection in liver patients.	Limitation: Usefulness: Got Transition, a federally funded organization, offers a framework to help adapt transitioning care. No consistent transition framework across practices to transition care . Affordable Care Act offer insurance extension for dependents and

			Subtopic: Education			foster children until 26 years old. Assess transition readiness with TRAQ or self- management scale.
Inouye. (2019). Hospital and ED charges for spina bifida in the Unites States between 2006 and 2014: over \$2 billion annually. <i>Disability and</i> <i>Health Journal.</i>	Evaluate economic data from nationwide hospital and emergency charges.	Quasi-experimental, Evidence Level 3 Variables: charged inpatient and emergency room, adolescents with spina bifida.	Data collected from 2006-2014 on the National Impatient Sample (NIS) and National Emergency Department Sample (NEDS). 725,646 encounters from 2006-2014.	Measured with International Classification of Disease (ICD) 9 codes and Van Walraven comorbidity index (Measured patients' comorbidity).	Increase bills noted from 2006 to 2014. 1/3 inpatient admissions are preventable.	Limitations: NEDS and NIS obtain stratified sample data. Unable to review the reason for visit on encounter. Usefulness: Beneficial in discussing and reviewing costs while discussing transition of care.
Radbron. (2019). The use of data collected from mHealth apps to inform evidence- based quality improvement: an integrative review. <i>Worldviews on</i> <i>Evidence-Based</i> <i>Nursing.</i>	Assess how mobile health (mHealth) applications are utilized to provide quality improvement in health care.	Integrative Review; Evidence Level 7 Variables: communication, illness management, clinical management, and education/information.	634 articles were reviewed from 1991- 2017; 19 studies met inclusion criteria.	The validity of the results and quality assessment was measured with the Critical Appraisal Skills Programme (CASP). Bias was examined with The Cochrane Risk of Bias Tool.	Doctor and nurses report less disruptions in work-flow with a smart device instead of phone calls. Improvement noted in clinical outcomes, quality of life, knowledge	Limitations: only one reviewer to screen and evaluate the articles which could lead to biasing. Usefulness: 17 countries were

					of patient education, medication adherence, disease management and follow-up visits.	represented within these 19 articles revealing emergence of technology in health care. As technology advances, additional research is needed to enhance healthcare.
Lindsay. (2016). Youth and parents' experiences of a new interagency transition model for spina bifida compared to youth who did not take part in the model. <i>Disability and</i> <i>Health Journal.</i>	Adolescents with spina bifida are at risk with continuity of healthcare from a pediatric center to an adult center. The purpose of this study was to assess the adolescents experience with a transition model	Quasi-experimental, Evidence Level 3 The intervention utilized in this study was a transition model.	32 adolescents and parents who are patients or parents of the outpatient spina bifida clinic in urban Canada.	The interviews were audio recorded and transcribed into NVivo a qualitative software program.	The results revealed the adolescents and parents felt supported with an ease of transitioning from the a pediatric to adult practice. The comparison group mentioned receiving transition documentation from other specialist but lacked the support to transition and fill the gaps in continuity of care.	The limitation of the study included a low response rate of participants. A larger sample size of 128 individuals received the study information with only 32 respondents. A small sample size warrants some caution when interpreting the results. This study is useful as it revealed the

						importance of a transition model.
Yu. (2015). Accessibility of mHealth self-care apps for individuals with spina bifida. Perspectives in Health Information Management.	Evaluate the iMHere (internet mobile health and rehabilitation) mobile health application to empower self-care in individuals with spina bifida.	Integrative Review; Evidence Level 7 Application variables: bowels, bladder, medications, mood, and skin breakdown.	6 participants, settings at the University of Pittsburg. Age 23-36. Each participant complete 6 tasks on the iMHere app repeating 3 times within 2 hours: n= 108.	Pearson's correlation coefficient with negative correlations between ordering test and completion of time.	Researchers monitored the participants insert the information with 28 errors entered out of 108 entries. Third time entering data resulted in less errors entered. Participants were satisfied with the app and ease of inserting information.	Limitations- small sample size. A few participants have already used the application from to enrolling in the study which affects outcomes. Usefulness: Educating participants with quick directions to use the application to decrease errors. iMHere is a beneficial tool for spinal bifida patients.
Vinchon. (2012). Adult outcome of pediatric hydrocephalus. <i>Children's Nervous</i> <i>System.</i>	To examine a database for pediatric hydrocephalus with treatment and follow-up plans as adults.	Cohort Study, Evidence Level 4 Variables- hydrocephalus. Variables: functional outcome, social outcome, mortality, surgical outcome.	Assessed from 1980- 2007, Adolescents less than 18 years old with hydrocephalus until 20- year-old adult. 1973 were reviewed, 456 met inclusion criteria.	Acturial survival assess with the Kaplan-Meier method.	Acturial mortality rate 18% by 20 years old. Poor functional outcome for hydrocephalus diagnosed at birth (malformation, post hemorrhagic, myelomeningocele)	Limitations: unknown amounts of patients without clinic visits but lost to follow-up. Usefulness: Farnofsky independent scale used for

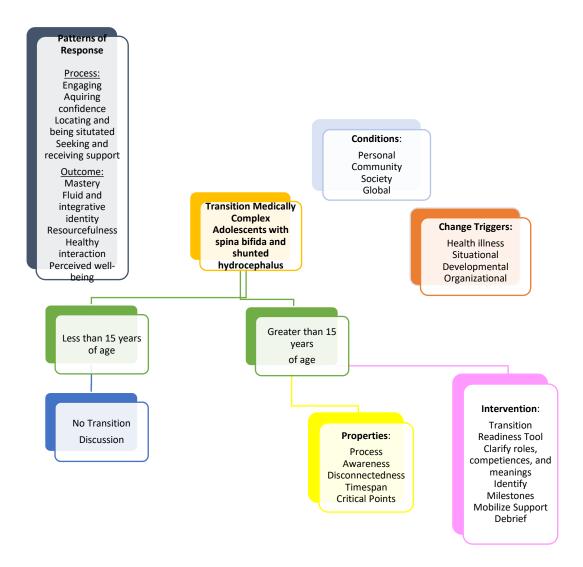
					versus arachnoid cyst and tumors. Bell curve of 15 years for life of a shunt.	measuring independence. Hydrocephalus Outcome Questionnaire helpful for to transition.
Bellin. (2011). Interrelationships of sex, level of lesion, and transition outcomes among young adults with myelomeningocele.	Assess connections of adolescents with myelomeningocele and sex, level of lesion self-care, community and quality of life.	Qualitative Study, Evidence level 4 Variables: level of lesion, community involvement and quality of life.	50 adolescents with spina bifida completed interview on self- management and questionnaire.	Self-Management and Independence scale II measure self-care. Multivariate analysis used to assess group differences.	80% of adolescents with hydrocephalus had a shunt. 64% are lumbar level lesions. 74% stay at home with parents. Sacral level lesion with higher rate of employment than lumbar lesions.	Limitations: small sample size, limited diversity. Usefulness: Self-Management and Independence scale II measure self-care.
Liptak. (2010). Youth with spina bifida and transitions: health and social participation in a nationally represented sample. <i>The</i> <i>Journal of</i> <i>Pediatrics</i> .	The purpose of this study identified various issues and outcomes in adolescents with spina bifida which affects social, health, and well- being.	Cohort Study, Evidence Level 4 The World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF) framework was used as a model to assess health and well- being of adolescents with spina bifida. Independent variables- body function and	130 adolescents with spina bifida were followed over a 4-year timeframe. Those individuals represented weighted sample of 5171 individuals with the mean age of 15 years old. The data was analyzed from the National Longitudinal Transition Study 2 (NLTS2)- assess disabilities in US schools.	The adolescents were randomly selected and deidentified with the NLTS2. The x ² test and analysis of variance was utilized to assess comparisons with the variables from WHO ICF. Data	At the beginning of the study, roughly 26% of the parents disagreed the youth was receiving the necessary support. At the end of the 4- year study, over 92% had graduated from high school. 45% report being held back grade. 47% were teased. 22% with learning disability. At end	Limitations were related to communication with Latino families with lower English proficiency that affects outcomes. Usefulness: Realistic study that assesses the overall health and well-being of adolescents with

	structure, activities,	analysis used	of 4-year study, the	spina bifida.
	environment and	SSPS 16.0	mean age was 19	Interesting to
	personal factors.		with 79% still	learn that 30% of
	dependent-		living with their	adolescents
	participation		parents, 76%	between 18-29
			employed. General	years of age
			health decreased	without insurance
			from 29% to 11%	regardless of
			with possibility	disability or not.
			related to insurance	
			coverage which	
			was not researched.	
			In this study, 48%	
			of the participants	
			with government	
			insurance.	

AAP: American Association of Pediatrics; AAFP: American Academy of Family Physicians; ACP: American College of Physicians; HCT: Health care transition; PACIC: Patient Assessment of Chronic Illness Care; Special Health Care Needs (SHCN); Mobile Health (mHealth).

Appendix F Theory of Application

Transitions Theory by Dr. Meleis and colleagues applied to medically complex adolescents transitioning from a pediatric neurosurgeon to an adult neurosurgeon (Smith & Parker, 2015).



Appendix G IRB Approval Letter

NOT ENGAGED IN HUMAN SUBJECTS RESEARCH

July 1, 2019

Lauren Mitchell

Dear Ms. Mitchell:

On 7/1/2019, the ORI staff reviewed the following protocol: Type of Review: Initial Study Title: Enhance Transition Care for Medically Complex Adolescents Investigator: Lauren Mitchell myIRB ID: STUDY0000811 Funding: Self Registration MARS OPS ID: None

Documents Reviewed: • HydroAssist Education,

Category: Recruitment Materials;

• Transition Survey_Ages 15-17_Final English.pdf,

Category: Recruitment Materials;

• HydroAssist Factsheet Hydrocephalus.pdf,

Category: Recruitment Materials; • HRP-221 Mitchell QI Project.pdf, Category: IRB Protocol

ORI staff determined that the proposed activity does not involve research as defined by DHHS regulations.

This project involves a pre and a post test. The results of the pre and post test will be used to determine if the Transition Readiness Assessment tool and the HydroAssist mobile application improves the transition scores. Your project is meant to inform practices only and is not designed to develop or contribute to generalizable knowledge according to 45 CFR 46.102(d). Therefore, it has been determined that it does not meet the definition of research involving human subjects under 45 CFR 46.102(d) (not research).

IRB review and approval by this organization is not required. This determination applies only to the activities described in the myIRB submission listed above and does not apply should any changes be made. If changes are made and there are questions about whether these activities engage in human subjects research, please submit a new request in myIRB for a determination. You can create a modification by clicking Create Modification / CR within the study.

TRANSITION CARE

Sincerely,

Dane Sommer, DMin Co-Chair, CM Institutional Review Board

Doug Swanson, MD Co-Chair, CM Institutional Review Board

Ryan McDowell Director, Office of Research Integrity



July 17, 2019

DNP Project Proposal Approval UMKC DNP Student

This letter serves to provide documentation regarding Lauren Mitchell's Doctor of Nursing Practice (DNP) project proposal. Ms. Mitchell obtained approval for her proposal, *Enhance Transition Care for Medically Complex Adolescents*, from the School of Nursing and Health Studies DNP faculty on July 17, 2019.

If we can provide further information, please feel free to contact us.

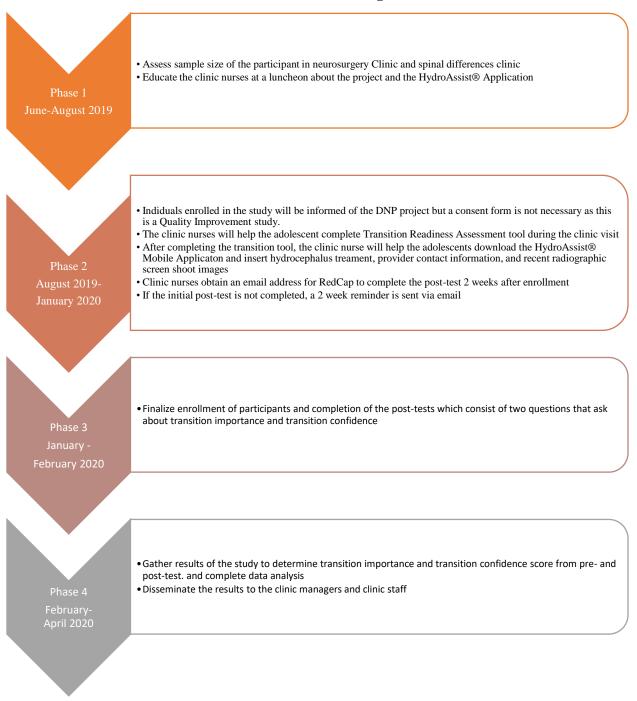
Sincerely,

Jyla Jirdholm

Cheri Barber, DNP, RN, PPCNP-BC, FAANP Clinical Assistant Professor DNP Program Director UMKC School of Nursing and Health Studies <u>barberch@umkc.edu</u>

Lyla Lindholm, DNP, ACNS-BC UMKC MSN-DNP Program Coordinator Clinical Assistant Professor DNP Faculty

Appendix I Intervention Flow Diagram



Appendix J, Logic Model	L	Intervention(s)	Outputs	Ц		Outcomes Impact	
Inputs		Activities	Participation		Short	Medium	Long
Evidence, Topics 1. Preparation with		The EBP intervention which is supported by the evidence in the	The participants (subjects)	רן	(Completed as a student).	Outcomes to be measured (past DNP student time).	Outcomes that are potentials (past DNP student)
Transitioning Care		Input column	Adolescents with spina		Outcome(s) to be	student time).	studenty
2. Components of a Transition Model		Utilization of a Transition	bifida and shunted		measured with reliable	Clinic staff confidently	A successful Transition
3. Education of Medically		Readiness Tool and	hydrocephalus		measurement tool(s) Primary- transition	executing the transition readiness tool and	Model to prepare medically complex
Complex Adolescents		HydroAssist mobile	Site		importance and transition	HydroAssist® mobile	adolescents to prevent
		application to transition	Study Institution		confidence scores	application in a timely	hospitalizations,
Major Facilitators or		care from pediatric to	-		improve from the pre-	fashion to prevent	discontinuity of care,
Contributors		adult neurosurgery	Time Frame		and post-intervention	prolonged clinic visits.	and deaths.
1. Clinic Nurse Manager		practice.	6 month period		Transition Assessment		
2. Neurosurgery Clinic		Maion of the	Consent Needed		Readiness tool	Adolescents	Implementing the
Staff 3. Neurosurgeons		Major steps of the intervention	No consent, transition		Secondary- improvement in Transition Readiness	well-prepared to transition care to adult	transition care education at an earlier
4. Transition Program		intervention	assessment tool		scores after using the	practice with ease and	age than 15 as
Manager		1. Brief training to the	currently used at facility		HydroAssist® mobile	limited conflicting	evidence recommends
		clinic staff on use of the			application in comparison	information from	12-14 years of age.
Major Barriers or		HydroAssist mobile	Persons collecting		to 6 months prior to the	providers and clinic staff.	
Challenges		application	data		intervention not using the		
1. IRB approval		2. Complete a baseline	Data collected from		mobile application.		
 Cost effective care Increasing the length 		pre-intervention assessment with the	monthly transition reports and DNP student				
of the clinic visit for		Transition Readiness	Teports and DNP student				
neurosurgery clinic staff		Tool at the start of the	Others directly				
to complete the		study.	involved				
intervention		3. At 6-months post-	Transition Care Manager		Statistical analysis to		
4. Neurosurgeons may		intervention, complete	Neurosurgery and Spinal		be used.		
not understand the		the Transition Readiness	Difference Clinic Staff		Paired-sample t-test for		
importance of the longer		Assessment Tool			the primary outcome,		
clinic visits for the families.		4. Obtain pre- and post- intervention results to			Independent sample t- test for secondary		
lammes.		assess transition			outcome		
		importance and			Descriptive statistics		
		confidence.					
				L			

Appendix K Project Timeline Flow Diagram



Appendix L Measurement Tool

Permission obtained but the tool is not to be placed into the public domain.

Appendix M Analysis, Transition Importance, Confidence

Transition Importance:

Descriptive Statistics

						Percentiles		
	Ν	Mean	Std. Deviation	Minimum	Maximum	25th	50th (Median)	75th
important_pre	7	6.57	2.070	4	10	5.00	7.00	8.00
important_post	7	8.00	1.915	5	10	6.00	8.00	10.00

Transition Confidence:

Descriptive Statistics								
							Percentiles	
	N	Mean	Std. Deviation	Minimum	Maximum	25th	50th (Median)	75th
confident_pre	7	4.57	1.272	2	6	4.00	5.00	5.00
confident_post	6	6.00	1.414	4	8	4.75	6.00	7.25

Appendix N Analysis, Demographics

Gender:

			gender		
					Cumulative
		Frequency	Percent	Valid Percent	Percent
Valid	female	2	28.6	28.6	28.6
	male	5	71.4	71.4	100.0
	Total	7	100.0	100.0	

Age:

age							
					Cumulative		
		Frequency	Percent	Valid Percent	Percent		
Valid	15	3	42.9	42.9	42.9		
	16	1	14.3	14.3	57.1		
	17	2	28.6	28.6	85.7		
	18	1	14.3	14.3	100.0		
	Total	7	100.0	100.0			

Appendix O Statistical Analysis

Wilcoxon Transition Importance

Test Statistics^a

important_post -

	important_pre
Z	938 ^b
Asymp. Sig. (2-tailed)	.348

a. Wilcoxon Signed Ranks Test

b. Based on negative ranks.

Wilcoxon Transition Confidence

Test Statistics^a

confident_post -

	confident_pre
Z	-1.490 ^b
Asymp. Sig. (2-tailed)	.136

a. Wilcoxon Signed Ranks Test

b. Based on negative ranks.

The p-value (p=.348) for pre- and post-importance scores and the p-value (p=.136) for pre- and post-confidence scores does not reveal statistical significance with a small sample size.