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Development and Evaluation of an Adolescent/Young Adult

Healthcare Transition Program

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Abstract

Problem: The 2009-2010 National Survey of Children with Special Health Care Needs revealed that almost twenty percent of adolescents in the United States have a physical, mental, emotional, or learning disability. With continued advances in treatment modalities, technologies and scientific breakthroughs, 90% (750,000) adolescents with special healthcare needs are living well into adulthood. Most adolescents/young adults (AYA) lack needed preparation for transitioning from pediatric to adult providers. A barrier for providers to transitioning AYA is lack of knowledge, confidence and experience to provide transition assessment, planning and transfer in a standardized manner.

Purpose: The purpose of this practice project was to develop the interprofessional structure, components, processes and education to support an adolescent, young adult healthcare transition (AYAHT) program, and to evaluate the initial interprofessional education on the AYAHT program.

Methods: AYAHT program development and evaluation took place in an outpatient Pediatric Physical Medicine and Rehabilitation (PMR) department in a major metropolitan hospital. Program development and implementation consisted of meetings with Information Technology department specialists and adolescent department transition experts to plan logistics of incorporating the AYAHT program into both the electronic health record and for improving current transition procedures. Using Institute of Medicine (IOM) six aim of quality healthcare (2001) and Issel's Program Theory (2014) AYAHT was developed into four phases over eight weeks. Phase I: Advance practice nurses (APN's) (3), engaged in the development of first, second and third drafts of the AYAHT program. Phase II: Pediatric Physiatrists (2) and parent volunteers (2) reviewed the AYAHT program and produced a fourth draft. Phase III: PMR

director approved the final version of the AYAHT program, featuring age specific healthcare transition interventions based on the Transition Readiness Assessment Questionnaire (2011) and the Consensus Statement on Healthcare Transitions for Young Adults with Special Healthcare Needs (American Academy of Pediatrics, American Academy of Family Physicians and American College of Physicians, 2002). Phase IV: PMR APN's developed education modules from the approved AYAHT version and PMR interprofessional staff (10) were distributed AYAHT Knowledge, Confidence, and Experience (AKCE) 25 item pretest questionnaire and educated.

Results: Post AYAHT program education the AKCE 25 item posttest was distributed among the (10) interprofessional members. Using paired T-test, the AKCE demonstrated a significant increase between pre/ post-survey scores for all areas except knowledge of community psychiatrist. Rating overall knowledge of AYA transition before education and after educational session revealed a significant difference in pre/post-test means ($M=-2.6$, $SD=.51$) and post-test ($M=3.9$, $SD=.73$); $t(9)=-4.33$, $p = .002$.

Conclusion: AYAHT program development, interprofessional engagement and education promotes safe, patient centered, timely, effective, efficient, and equitable outcomes with AYA transition. Fourteen years post publication of the AAP's Consensus Statement on Healthcare Transitions for Young Adults with Special Healthcare Needs (2002), there remains a gap in consistent, flexible, attentive, responsive, comprehensive coordinated care transition in pediatric institutions. Program replication for implementation promotes future translational research to improve practice outcomes and promote guideline development. DNP as the clinical leader has a role in practice problem evidence translation, dissemination and implementation.

Development and evaluation of an adolescent /young adult healthcare transition program

Background of Problem

The 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN) revealed that of the 25 million adolescents in the United States, almost 4 million, have a physical, mental, emotional or learning disability (Wood et al., 2014; NS-CSHCN, 2014). Due to advances in treatment modalities, technologies and scientific breakthroughs, 750,000 annually, these adolescents are living well into adulthood (Mackie et al., 2014; Betz, 2012). Clinics that care for adolescents with chronic diagnoses that require child base clinic follow-up, such as congenital heart defect (Mackie et al., 2014), cystic fibrosis (Gravelle, Paone & Davidson, 2015) and myelomeningocele (Sawin et al., 2014) are now faced with needing to transition adolescents/young adults (AYA) to adult practitioners for continued care. Most AYA lack the needed preparation for transition (Tuchman, Slap & Britto, 2008; Sawin et al, 2014) which can lead to a decline in health (Mahood, Dicianno & Bellin, 2011). Lostein, McPherson & Strickland (2005) reported from the NS-CSHCN that only “15.3% of AYA met the Maternal and Child Health Bureau (MCHB) core outcome measure of having received guidance and support in the transition to adulthood”. These outcome measures include “family professional partnerships, access to a medical home, adequate insurance, early and continuous screening, and organization of service systems for ease of use” (Lotstein et al., 2005, p. 1564).

The Consensus Statement on Health Care Transition for Young Adults with Special Health Care Needs by the American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP) and American College of Physicians (ACP) (2002) promotes adolescent transition readiness assessment, preparation and planning beginning at age 14 for eventual transfer occurring between the ages of 18-21 . This consensus statement defines

transition as an individual process that advances one from pediatrics to adult care with a goal of providing the highest quality, age appropriate services that are not interrupted during the transition (AAP, 2002). “The foundations of AYA healthcare transition are flexibility, attentiveness, responsiveness, continuity, comprehensiveness, and care coordination (AAP, 2002). Yet, fourteen years post publication of this consensus statement, there remains a gap in consistent coordinated transition of care in many pediatric institutions (Sawicki et al., 2014; Betz, 2012; McManus et al., 2015).

There are barriers to achieving successful transition (Okumura et al., 2008, Tuchman et al., 2008; Sawin et al, 2014). For AYA and their caregivers these barriers include fear of leaving the child-based environment, lack of preparation for transition, failure to establish a relationship with an adult provider and feeling abandoned by the pediatric specialist (Tuchman et al., 2008; Sawin et al, 2014). Barriers for providers include lack of time to provide appropriate assessment and transition planning (Okumura et al., 2008), skills to provide transition planning, available adult specialist to transfer the clients and information regarding community support for adults (AAP, 2009). Also, transition services are not reimbursed by insurance companies (AAP, 2009). Consequences to failing to transition have been associated with declining health (Mahood, Dicianno & Bellin, 2011), lack of care continuity (Sawicki, Keleman & Weitzman., 2014), disengagement with the medical community (Woodward, Swigonski & Ciccarelli, 2012), and delays in social advancement (Woodward et al., 2012). Promoting transition readiness and providing an organized, coordinated transition program fosters best outcomes for AYA and caregivers.

Purpose

The purpose of the proposed Doctor of Nursing Practice (DNP) student's practice project is to develop the structure, processes and staff education training modules to support an adolescent, young adult healthcare transition (AYAHT) program, and to evaluate the initial education in-service on the AYAHT program for all clinical staff. The AYAHT program will promote transition for the AYA (14-21) with special healthcare needs followed in the outpatient pediatric rehabilitation department of a national pediatric health system. The significance and anticipated outcomes of this project are that AYA and their caregivers are provided a program to be implemented that fosters transition in a safe, effective, patient-centered, efficient, timely and equitable manner (IOM, 2001) the outpatient pediatric rehabilitation department will be in compliance with the consensus statement on health care transition for young adults with special health care needs (AAP, AAFP and ACP, 2002) to provide the AYA and their caregivers with transition assessment and development of an individualized transition plan starting at age 14.

Framework

Guiding this practice project are the six aims of quality health care from the IOM (Institute of Medicine) 2001 report "Crossing the Quality Chasm: A New Health System for the 21st Century" and Issel's (2014) Program Theory. Knowles' (1970) framework "The modern practice of adult education: Andragogy to Pedagogy" was used to design the in-service.

IOM –Healthcare Quality

The IOM report (2001) "Crossing the Quality Chasm: A New Health System for the 21st Century" explains six aims for improving healthcare quality. This report addresses "safety, effectiveness, patient centeredness, timeliness, efficiency, and equity" (IOM, 2001, p.45). Safety is defined as achieving days that are free of accidental injury. It ascertains that no harm befall a

patient or a healthcare provider (Ulrich and Kear, 2014). A practice project that promotes transition for AYA with special healthcare needs addresses the IOM aim of safety. The pediatric rehabilitation specialist will communicate with the adult care specialist to assure that vital information such as diagnoses, medications, allergies, durable medical equipment, orthoses, and treatment goals are communicated (Ulrich and Kear, 2014).

Effectiveness refers to care that is consistent with best evidence based practice (Goode, 2015). It determines if the therapeutic plan of care produces better outcomes than alternatives (Goode, 2015). This practice project's foundation is based on extant literature regarding AYA transition. Patient centered care allows patients and care-givers the opportunity to be active participants in the decision making aspect of their healthcare. The six dimensions of patient centeredness are "(1) respect for patients' values, preferences, and expressed needs; (2) coordination and integration of care; (3) information, communication, and education; (4) physical comfort; (5) emotional support-relieving fear and anxiety; and (6) involvement of family and friends" (Tzelepis et al., 2014). The AYAHT program includes providing an individualized transition plan that incorporates the AYA and caregivers' preference of age at transition, selection of adult care providers, and community referral needs.

Timeliness refers to providing appointment, treatment, and diagnoses in a time frame that prevents physical harm or emotional distress (Slonim & Pollack, 2005). According to AAP, AAFP, ACA Consensus Statement on Healthcare Transitions for Young Adults with Special Healthcare Needs (2002), timely transition from pediatrics to adult centered care allows AYA to increase their ability to assume adult healthcare responsibilities and functioning. The AYAHT program adheres to that statement by providing timely assessment of transition needs and transfer to adult providers.

Efficiency is reflective of obtaining best value for resources expended, through decreasing both waste and administrative costs (Goode, 2015). The resource that is expended in the pediatric rehabilitation clinic is the time that the providers spend with the patient. This resource will be maximized by incorporating AYAHT program as part of usual clinic care, instead of having the patient return to clinic for a separate transition appointment.

Equity improves the health and functioning of populations and individuals. Equity reflects high quality care and fair treatment that is based on an individuals' needs and not gender, geographic location, social or economic status (Levitt, et al., 2014). The AYAHT program will be offered to all AYA between the ages of 14-21 in the pediatric rehabilitation clinic regardless of social or economic status.

Program Theory

Program theory is a conceptual plan that provides details in establishing the foundation for the AYAHT program. This includes the program's purpose, function and expectations for outcomes (Issel, 2014). Issel (2014) identified characteristics in program theory. These include tailoring the program to the population, researching evidence, stakeholder facilitation, and logic model development (Issel, 2014).

The interventions of the AYAHT program will be tailored to a population of AYA with physical disabilities receiving follow-up care in the pediatric rehabilitation department. This is described as tailoring a program for "cultural sensitivity, linguistic appropriateness, and group similarities" (Issel, 2014, p. 193). The population in the AYAHT program is anticipated to represent various ethnicities and socioeconomic status. Interventions for community resource for transition planning will address the needs of: 1) English and Spanish speaking, 2) AYA private insurance and Medicaid; who live in the District of Columbia, Maryland, and Virginia.

Research evidence identifies what is known to be effective in facilitating the development of transition healthcare for adolescents and young adults (Betz, Lobo & Nehring, 2013; Hallowell, 2014; Schuurs et al., 2014). This practice project incorporates what is known to be effective in the need for a transition program (Cadario et al., 2009; Dogba et al., 2014; Mackie et al, 2014; Sawicki et al., 2014; Tuchman et al, 2008; Visentin, Kock & Kralik, 2006), characteristics of a transition program(Larivière-Bastien, Bell, & Majnemer, 2013; Lotstein et al.,2005; McManus et al., 2013; Reiss, Gibson & Walker, 2005; Fair, Sullivan & Dizney, 2014; Knapp, Huang & Hinojosa., 2013), and educating adult learners on the transition program (Reed et al., 2014).

Stakeholder facilitation is another characteristic of the program theory (Issel, 2014). The stakeholders are those who have the potential to participate in the program as well as the providers of the program (Issel, 2014). For the AYAHT program this would include the advance practice nurses, psychiatrists in the pediatric rehabilitation department, and caregivers of AYA with special health care needs. This practice project is being developed in four phases. The staff in the pediatric rehabilitation department where the AYAHT program will be established will participate in developing the transition assessment, planning, transfer and educational modules components of the transition program. This will be conducted in the form of: 1) meetings to develop a draft of the program, 2) review of drafted materials with stakeholders, 3) obtaining input from stakeholders and 4) developing educational material for the staff about the AYAHT program.

Logic Model

The logic model is a visual diagram of the program planning process that demonstrates the inputs, activities of outputs, outcomes, assumptions and external factors (Issel, 2014, p.275)

(Appendix A). The inputs are those items in which will be invested in order to conduct the program and what is done for program development. For the AYAHT program inputs include the training document, staff time in program development, materials to distribute to staff, and physical and technical resource (Cerner- electronic health records). What is done for the AYAHT program is to develop the program, conduct education training and meetings for the staff regarding the program, and facilitate access to information regarding the program.

Outputs include the intended target of the program and reason for program development (short term results). The intended target for the AYAHT program in-service is to provide education for the staff in the pediatric rehabilitation department to develop a transition plan for AYA and their caregivers. The reason for the AYAHT program development is to increase awareness of the importance of transition, promote knowledge of transition planning and motivate staff regarding transition.

The outcome explains projected intermediate and long term results. The intermediate result of the AYAHT program will promote transition as the standard of care in the pediatric rehabilitation department that is a progressive planned event. The long term results for AYA and their caregivers is that they have uninterrupted care when transitioning from pediatrics to adult care.

Assumptions of the logic model are the beliefs of why the program has the desired outcome (Issel, 2014). For the AYAHT program it is assumed that the staff are active participants in the program development and that they recognize the value of transitioning the AYA in an appropriate manner, using transition assessment and transition planning to transition in an organized, timely and progressive manner.

External factors of the logic model represent those factors that have the potential of preventing a positive outcome for the program development (Issel, 2014). The literature notes potential barriers as lack of time and resources (limitation of the electronic medical records). The pediatric rehabilitation staff evaluates patients 8 hours daily. The time to develop the program needs to occur after hours which could be a deterrent in program development. Also the pediatric rehabilitation department does not have electronic medical records. The ultimate goal is to incorporate the transition plan into the electronic health records.

The use of IOM six aims for improving healthcare quality (2001), Issel (2014) program theory, Knowles (1970) to guideline development of an AYAHT program and in-service contributes not only to program development, it is assumed and anticipates that AYA and their caregivers are transitioned in an organized, timely, and progressive manner once the program is implemented.

Review of Literature

Many have concurred that there is a need for an organized, planned progressive fashion for transition that prepares the AYA and their caretaker for adult care (Lotstein et al, 2005; McManus et al, 2015). Transition program development is essential to the process of transitioning adolescents/young adults from pediatrics to adult care because it prepares the AYA and caregiver in an organized manner (Hallowell, 2014). Seven studies (Cadario et al., 2009; Dogba et al., 2014; Mackie et al, 2014; Sawicki et al., 2014; Tuchman et al, 2008; Visentin, Kock & Kralik, 2006) note the importance of developing a transition program. Programs should be individualized based on the AYA's readiness or biological age and the process should be gradual (Zhang, Ho & Kennedy, 2014; AAP, 2011). AYA in structured transition programs for juvenile idiopathic arthritis (Hilderson et al., 2016), congenital heart defects (Mackie et al., 2014),

and type I diabetes (Cadario et al., 2009) were reported to have better health behaviors, such as improved self care management and increase in clinic attendance as compared to those who were not in a structured program.

The characteristics of a transition program are noted in the consensus statement of the AAP, AAFP, ACP (2002). The consensus statement identifies six steps to transition. The first step is that the AYA with special health care needs have a professional who can assist in identifying an adult provider in order for there to be no interruptions in care and that the care is comprehensive and accessible upon completion of transition. The second step is that providers are instructed in how to educate the patient in the knowledge and skills needed for transition. The third step notes the AYA has an up to date medical summary. Step four indicates that starting at age 14 there should be an initiation of a transition plan. The plan would include services needed in transition, who will provide this service and who will finance the service. It was also noted that the plan should be reviewed annually. The fifth step involves utilizing standard guidelines for preventive care. The last step calls for ensuring continuous, affordable insurance coverage that includes compensation for transition and care coordination.

Another characteristic of a transition program is the transition assessment. Researchers concur that transition assessment should be conducted at regular intervals to assess the AYA's knowledge of their disease; self care management skills and self advocacy ability (Frederick, et al., 2010; McLaughlin et al., 2008; Van Staa, Vander Stege & Jedeloo, 2010; and Woodward et al., 2011). These assessment tools are used as the baseline for the development of the individualized transition plan based on the AYA's learning needs. Zhang et al. (2014) conducted a systematic review of the psychometric properties of transition

readiness tools in adolescents with chronic disease. Two of the non-disease specific assessment tools are the University of North Carolina (UNC) TRxansion (Ferris et al., 2012), and Transition Readiness Assessment Questionnaire (TRAQ) (Sawicki et al., 2013). The UNC TRxansion tool Cronbach's alpha was not reported (Zhang et al., 2014). The TRAQ demonstrated Cronbach's alpha of .93 (Zhang et al., 2014). For this scholarly practice project it will be suggested that future program implementations, the TRAQ tool will be utilized on yearly basis.

TRAQ

Transition Readiness Assessment Questionnaire (Appendix B) is a validated self administered tool used to assess skills needed for healthcare transition and provides a guide for transition education interventions (Sawicki et al., 2011). This tool is a 23 item questionnaire that assesses adolescent's readiness in the areas of self care management and self care advocacy. Based on 5 stages of change transtheoretical model, the TRAQ is arranged using a 5 point ordinal scale (1- I do not know how to do this; 2-I do not know how, but I want to learn; 3-I am learning how to do this; 4-I have started doing this; 5- I always do this when I need to) (Sawicki et al., 2011). Questions are related to medication management, appointment keeping, tracking health issues, talking to providers and managing daily activities. The tool is designed to be administered yearly and track the progress of transition readiness through adolescents (Sawicki et al., 2011). The TRAQ tool will be used as part of program development to educate the caregiver to determine the learning needs of the AYA regarding self care management and self advocacy and to tailor the individual transition plan according to those needs. Utilizing the TRAQ has the potential to improve health outcomes post transition (Sawicki et al., 2011).

Transition Planning

Authors in general embrace transition planning as a concept but do not give specifics regarding what the plan should contain (Larivière-Bastien, Bell, & Majnemer, 2013; Lotstein et al., 2005; McManus et al., 2013; Reiss, Gibson & Walker, 2005; Fair, Sullivan & Dizney, 2014; and Knapp, Huang & Hinojosa., 2013). Evidence supports that the discussion and planning should be ongoing throughout the teen years (van Staa, 2010; Al-Yateem, 2013). Themes noted in the literature regarding plan content are as follows: up to date medical summary (AAP, 2002), plan the timing of the transition with AYA and caregiver (Lotstein et al., 2005; Tuchman et al., 2008); prepare for the approach to care (Tuchman et al., 2008), insurance and community resources (Betz, 2014; Antle, Montgomery & Stapleford, 2009; Blomquist, 2006; Woodward et al., 2011; AAP, 2011), obtaining self care management skills (Muhmood et al., 2011; Powers et al., 2007; Sawicki et al, 2014, Al-Yateem, 2013), choice of adult care facilities (Al-Yateem, 2013), legal issues (such as guardianship) (AAP, 2011), and expresses the AYA's wishes and needs (Al-Yateem, 2013).

Transfer of care from the child based provider to an adult provider is the final characteristic of transition (Sawin et al, 2014). This occurs when the AYA is physically evaluated by an adult provider. During this phase the consent to release information is obtained and medical summary is sent to the new provider (Larivière-Bastien et al., 2013). Researchers have noted that the AYA would prefer to have a scheduled visit with the identified adult provider prior to the transfer from the pediatric institution (Sawin, et al., 2014; Tuchman et al., 2008). This gives the pediatric specialist an opportunity to coordinate with the adult provider, obtain feedback on the adult practitioner, make changes to the goals and provide physical and

emotional support as needed (Cox et al., 2011; Gee, Smith & Solomon, 2007; Psihogios & Holmberck,2013; Tuchman et al., 2008; Tsybina et al., 2012).

Education Planning

In the 1970 book by Malcolm Knowles: “the modern practice of adult education: andragogy to pedagogy” it indicates four principles of adult learners. First the learner needs to know how the presented topic will directly affect them. Secondly, adults use a multimodal style of learning: kinetic (do it), visual (see it) and auditory (hear it). Thirdly, the adult learner brings a life time experience. This experience should be acknowledged and utilized during the learning process. Lastly the new knowledge should be put into practice immediately. The most effective teaching method for an adult learner will apply these four principles. AYAHT program education and planning incorporate all of these components.

This review of the literature demonstrates that a transition program is essential for an organized planned transition that occurs in a progressive manner. The characteristics of the program included steps from the Consensus Statement on Health Care Transition for Young Adults with Special Health Care Needs by the (AAP), (AAFP) and (ACP) (2002), TRAQ, individualized plan and transfer to adult care. The dissemination of the program will be based upon Knowles (1970) principles of adult education via a training module and in-service, which includes a document review.

Methods

The purpose of the practice project was to 1) develop the interprofessional structure, components, and processes and staff education training modules to support an AYAHT program (Appendix C), 2) staff in-service and 3) evaluate the initial interprofessional education in-service on the AYAHT program. AYAHT fosters AYA transition in a safe, effective, patient- center

efficient, timely and equitable manner. The AYAHT program was conceptualized using the 6 quality healthcare aims (IOM, 2001) and Issel's (2014) program theory. The educational component supporting the AYA transitional healthcare program were based on Knowles's principles regarding adult learners. The setting for this program was an outpatient pediatric rehabilitation department located in a major metropolitan inner city pediatric teaching and research hospital, which currently does not have a formal transition program for AYA with special healthcare needs.

The patient population were newborn to forty year old with chronic conditions. The majority of the AYA were diagnosed with cerebral palsy and myelomeningocele. These patients were usually evaluated annually unless complications arose. There were approximately 8,000 clinic visits conducted yearly. The patients were seen in the main campus clinic and in area regional locations. Adults were still being cared for in this pediatric based clinic because the clinicians have not transitioned them to an adult centered outpatient care. The development of an AYAHT program was approved by the Pediatric Rehabilitation Medical Director at the host institution, May 2015.

Development of AYAHT Program

This practice project consists of preparing proposed guidelines for an AYA transitional program and evaluation of AYAHT staff development presentation. Initiation consisted of four phases. Prior to implementation, the doctorate of nursing practice (DNP) student facilitator met with a liaison from the institution's Information Technology (IT) department to discuss the logistics of incorporating the format of the transition readiness assessment, TRAQ and individualized transition plan into the electronic health records.. This was followed by a meeting with the transition specialist from the adolescent primary care department. AYA are followed by

the primary care department for preventive care needs. Recommendations from specialists, such as the pediatric rehabilitation department, are routinely sent to the primary provider in the form of a dictated clinic note. The note includes the history, physical assessment, functional status and planned therapeutic recommendations. The purpose of the meeting with the adolescent primary care department was to inform that department of the pending transition program and the transition plans that are generated from the AYAHT program.

Electronic invitation was extended to the pediatric rehabilitation staff participating in the four phases of the AYAHT program development following the meeting with the adolescent primary care department. The invitation included the date that their assistance was needed. Once the AYAHT is implemented the adolescents' primary care providers were sent information regarding transition from the pediatric rehabilitation such as: timing of transition from the pediatric rehabilitation department, TRAQ, transition plan, and community resource information that will be provided to the AYA and their caregiver.

Phase One

Phase One occurred during weeks one, two, and three of program development. Participants of this phase were pediatric rehabilitation transition champions (PRTC) and the DNP student facilitator. The PRTC included the pediatric rehabilitation clinical nurse specialist and nurse practitioner electronic medical records liaison. The components of Phase One were two meetings and email communication with the PRTC. The deliverables were the first, second, and third drafts of the AYAHT program.

Phase One Procedures

One week prior to the initiation of program development the agenda for PRTC's first meeting were emailed by the DNP student facilitator. The expectation was that the PRTC review

the agenda prior to the meeting. The agenda with bullet action items included: a) the purpose and goals for the PRTC; b) overview of the AYAHT program as accepted by electronic medical records (Cerner) representative and transition specialist from the adolescent medicine department; c) timeline of the program development; d) AAP, AAFP, ACP (2002) “A consensus statement on health care transitions for young adults with special health care needs”; e) review of the literature; and f) reference list.

The first meeting with the PRTC included a brief review of the literature and timeline of the program development that was sent electronically. There was a request for questions regarding the material. The PRTC and the DNP student facilitator reviewed the assessment, planning and transfer elements of the AYAHT program as accepted by the electronic medical records representative and adolescent medicine department. During the first meeting the PRTC provided input about the AYAHT program. Based on decisions made during the first meeting, the initial draft of the AYAHT program was formulated.

One week prior to the second PRTC meeting, the AYAHT program first draft was sent electronically to the PRTC. During week two of the program the PRTC replied to the DNP student facilitator with feedback. The second draft was developed incorporating the PRTC input. Week three of the AYAHT program development, the PRTC reconvened for the second one hour meeting. The agenda of the second meeting included a) discuss the changes to the program that were suggested by the PRTC via electronic communication b) reviewed the AYAHT program in its entirety and c) discussed any additions, deletions, comments, questions, or concerns regarding the AYAHT program. Based on the results of the second meeting with the PRTC, the third draft was developed.

Phase Two

Phase Two of program development took place during week four. The participants were two volunteer pediatric physiatrists and two caregiver of AYA with special healthcare needs that are cared for in the pediatric rehabilitation clinic and the DNP student facilitator. The component of phase two was feedback on the email of the third draft of the AYAHT program. The third draft incorporated the input from PRTC. The deliverable of phase two was the formation of the fourth draft.

Phase Two Procedures

The physiatrists were sent electronically the third draft of the AYAHT program, TRAQ, review of the literature and reference list. They were asked: a) was the program clear in what information is to be given to the AYA and when it is to be distributed? b) was there any additional information that should be given to the AYA? c) was there any information that should be deleted from the program and why? d) do they have any additional comments, questions or concerns regarding the AYAHT program? The physiatrists had one week to provide this feedback to the DNP student facilitator. Based on the physiatrists' responses to the questions the fourth draft would be developed.

Two volunteer caregivers of AYA with special health care needs who provide care for in the pediatric rehabilitation clinic were emailed a draft of the AYAHT program. They were asked: a) was the program clear in what information they will receive and when? b) was there any additional information that they would like to receive? c) was there any information that should be deleted from the program and why? d) did they have any additional comments, questions or concerns regarding the AYAHT program?

Phase Three

Phase Three of AYAHT program development took place during week 5. The participant was the pediatric rehabilitation medical director. The component of phase three was an oral presentation of the AYAHT program by the DNP student facilitator. The deliverable for phase three was the fifth and final version of the AYAHT program which included the feedback from PRTC, draft one, two, and three, and from the psychiatrists, draft four.

Phase Three Procedures

Three days prior to the meeting with the pediatric rehabilitation medical director, the director was sent electronically the fourth draft of the AYAHT program, TRAQ, review of literature, and reference list. The fourth draft was presented in person by the DNP student facilitator to the pediatric rehabilitation medical director. The director was asked a) was the program clear in what information is to be given to the AYA and when it is to be distributed? b) was there any additional information that should be given to the AYA? c) was there any information that should be deleted from the program and why? and d) did she have any additional comments, questions or concerns regarding the AYAHT program?

Recommendations from the medical director were incorporated into the final version of the AYAHT program to be presented to the entire staff in the pediatric rehabilitation department.

Phase Four

Phase Four took place during weeks six, seven, and eight of the AYAHT program development. The participants of Phase Four were the entire staff in the pediatric rehabilitation department. The components of phase four included meeting for the third time with the PRTC, email of the fifth version of the program, and in-service delivery regarding AYAHT program. The deliverables for Phase Four are the AYAHT program education module and distribution of

the pre and post test of the AYAHT Knowledge, Confidence, and Experience (AKCE) questionnaire.

Phase Four Procedures

During week six the DNP student facilitator sent electronically to the PRTC the fifth and approved version of the AYAHT, education modules, and agenda for the third PRTC meeting. The agenda for the third meetings included: a) review of the educational healthcare module include general transition information, transition assessment, planning, and transfer. The educational module instructed the psychiatrists on the use of the AYAHT program, based on Knowles' (1970) principles regarding adult learners.

Week seven of AYAHT program development, the final approved version of the AYAHT was distributed in written module format. It was emailed to all end users in the outpatient pediatric rehabilitation department, along with the pre test AYAHT AKCE questionnaire. The expectation was that all end users review the educational module and complete pre test AYAHT AKCE. The pretest was printed, completed and submitted to a secure location in the department by all clinic staff. During week eight of program development, there was an in-service for the department. The agenda for the in-service included: a) review of the education module, including documentation of the transition plan and b) address questions regarding the AYAHT program. After the in-service, a post test of the AYAHT AKCE was distributed by the PRTC regarding the AYAHT program as presented in written format.

Staff Training

The providers were instructed during a 60 minute in-service. The educational content of the in-service explained: the purpose and goals of the AYAHT program, current position statement by the AAP, AFNP and AACP (2002), departmental transition statement, barriers to

transition, TRAQ, community transition resources, legal issues, obtaining up to date medical summary, adult approach to care, transferring to adult providers, and documentation (Appendix D).

Survey Methods

A pre-test/post-test survey design was used to assess the provider's knowledge, confidence and experience before and after the educational intervention regarding AYA healthcare transition (Appendix E and F). We invited all 10 providers to participate in the educational session. The questionnaire was a 25-item survey comprised of close-ended questions. Sixteen questions were Likert-type response scale along with general demographic information (years on practice and discipline). There were four questions regarding previous exposure to transition (e.g. heard or read about transition, attended lecture or training or assisted with transition) and one question regarding preference for obtaining new knowledge (e.g. literature, website, webinar, didactic/lectures, standardized patient encounter, and experiences). With permission, the AYAHT AKCE questionnaire was adapted from an instrument from the University of Florida's Resident's Knowledge, Confidence, and Experience in Healthcare Transition questionnaire (Hess, Straub, & Mateus, et. al., 2015). It was administered through a pen and paper method.

The provider's knowledge of standardized transition resources and tools, self-management skills, adult physiatrists in the community, healthcare coverage and health, social services and resources for AYA in the community were rated from not familiar to very familiar. Confidence was reported as level of confidence in pediatric rehabilitation provisions of care for AYA as well as ability to develop a coordinated, comprehensive transition plan for AYA. It was rated from very comfortable to very uncomfortable. Provider's overall experience reported the

frequency in transition discussions with regard to self care management skills, insurance options, individualized transition plan, standardized tools, communication with adult psychiatrist to facilitate transition and spending sometime without the caregiver (when appropriate). Items were rated from never experienced to always participate in the experience.

Data source and analysis

The AYAHT AKCE questionnaire was distributed and collected by members of the PRTC. Data collection was anonymous and de-identified. The questionnaires were accessed and data abstracted by the DNP student only. The AYAHT AKCE questionnaires were secured in a locked cabinet in the pediatric nurse practitioner's (DNP student) office which only she had access and that door was also kept locked. Analytic tests were conducted to compare pre- and post-test mean scores before and after the educational session, using SPSS Statistics 23. A paired T-test was used to determine whether differences between the pre- to post-test were statistically significant.

Human Protection

The practice project proposal was submitted for review at the University of Maryland Institutional Review Board (IRB). It was also submitted and approved by the Nursing Research Advisory Committee (NRAC) in the department of Nursing Research and Quality Outcomes per the host institution's recommendations. Submission to the institution's and University of Maryland's IRB indicated that the project is undertaken as a quality improvement initiative and did not constitute human subject research. The project was deemed not to require oversight by the IRB at either institution. No protected health information was utilized during the four phases of the program development. Participants were staff from the outpatient pediatric rehabilitation department and volunteer caregivers of AYA with special healthcare needs. Collaboration during

AYAHT program development and completion of the survey was voluntary. The participants were made aware that the results of the survey may be published, using only aggregate, anonymous data.

The results of this project are not proposed to generate knowledge that is generalizable, universally or widely applicable to other institutions. This practice project is not an inquiry for ascertaining facts or a careful examination for research development, testing or the evaluation of a program. It is also not a systematic investigation involving a system, method, or plan. Results of the survey will be presented only as aggregate data, with complete protection of individual's anonymity.

Results

The program was developed in four phases. During phase one, after meeting with the PRTC, no changes were recommended to the first draft. In phase two, a meeting was held with the pediatric physiatrist and the parent volunteers. There were no recommendations for changes. In the third phase, a meeting was conducted with the pediatric rehabilitation director. No additions or subtractions to the original program were recommended. In phase four, the education modules were developed and presented.

Final AYAHT Program

The AYAHT program consists of anticipatory guidance for transition, including assessment, planning and transfer of AYA and their caregivers. The program outlines the activities, resources and associated documentation to be implemented each year. Each task is documented in the electronic health records so that the plan can be reviewed by other providers. Below is a summary of each clinic visit, starting at age 14 (Appendix G).

14 year-old visit

AYA, who are being evaluated in the Pediatric Rehabilitation clinic starting at age 14-year-old visit, will receive usual care which includes but is not limited to review of interim history since last clinic appointment, review of systems, current functional status (Fluid, electrolyte and nutrition, bowel and bladder function, communication ability, mobility, positioning devices, durable, and medication equipment), physical examination and recommendations based on the examination. As part of the review of the clinic visit and the first steps towards transition, the AYA and caregiver will be told by the provider about the departmental statement on transition (Appendix H). The department's transition statement will be attached to the AYA's visit summary and printed out along with other recommendations from the clinic visit. The rehabilitation provider will document as part of the clinic note that is sent to the primary care provider. It will read "As part of a comprehensive transition plan _ (patient's name) was provided a copy of the department's transition statement that informs them that transition from Children's National Medical Center (CNMC) Pediatric Rehabilitation Department is expected to occur between the ages of 18 and 21.

15 year-old visit

During the 15-year-old annual clinic visit, the AYA will receive usual care by the rehabilitation practitioner. The provider will explain to the AYA and caregiver that annually AYA's should review their transition readiness in the areas of medication management, appointment keeping, tracking health issues, how to communicate with providers and management of daily activities. AYA and caregivers are encouraged to share results of TRAQ with their primary care providers and case manager to obtain additional guidance in self care management. The TRAQ (Appendix B) will be attached to the AYA's visit summary and

printed out along with other recommendations from the clinic visit. The rehabilitation provider will document as part of the clinic note that is sent to the primary care provider: “As part of a comprehensive transition plan _ (patient’s name) was provided a copy to the transition assessment readiness questionnaire (TRAQ). AYA were encouraged to share the TRAQ results with the primary care provider. This step is a part of the transition process. Transfer from CNMC Pediatric Rehabilitation Department is expected to occur between the ages of 18 and 21.

16- year-old visit

During the 16-year-old annual clinic visit the AYA will receive usual care by the pediatric rehabilitation provider. At the conclusion of the visit the practitioner will provide information regarding transition related community resource, especially the Developmental Disability Agency (DDA) and Department of Rehabilitation Services (DORS). DDA is a community based service delivery system that provides persons with special healthcare needs with services and support such as housing, adult day programs and respite for caregivers. DORS provides vocational training and supported employment. If the family has other community resource needs they will be referred to the hospital-wide social worker or their insurance based care manager. The information regarding these two programs and a transition planning tool will be attached to AYA’s visit summary and printed out for the AYA and caregiver upon clinic discharge. The rehabilitation provider will document as part of the clinic note that is sent to the primary care provider “As part of a comprehensive transition plan (patient’s name) was provided with community resources information and encouraged to investigate the resources available through the Developmental Disability Agency (DDA) and the department of rehabilitation services (DORS). They were also provided with a transition planning tool.

Transfer from CNMC Pediatric Rehabilitation Department is expected to occur between the ages of 18 and 21.

17-year-old visit

During the 17-year-old annual clinic visit the AYA will receive usual care. At the conclusion of the visit the pediatric rehabilitation healthcare provider will discuss consent for care vs. guardianship. It will be explained that at age 18, under the Federal Health Information Portability and Accountability Act (HIPPA), access to their health records and any discussion about their health is only provided to people that the AYA consent to, including caregivers. If they wish to have their caregivers continue to discuss their health on their behalf written consent is required. Copy of the form to consent to share health information with their parents will be attached to the patient summary and will need to be returned during their first health encounter after the age of 18. If the AYA is unable to independently make decisions secondary to cognitive delays, the caregiver must obtain legal guardianship. Information regarding how to obtain guardian will be attached to the patient summary.

During the 17-year-old clinic visit the provider will explain that at 18-some patient are given the option of changing from Medicaid to Medicare. Medicare is limited in providing care such as home health, adult day program and respite. AYA and caregivers will be provided with information regarding Medicaid and Medicare to assist them in making an informed decision. The provider will document as part of the clinic note that is sent to the primary care provider “As part of a comprehensive transition plan_ (patient’s name) was provided with information regarding consent (or guardianship) and state insurance for adults with special healthcare needs.”

18 year-old visit

During the 18-year-old annual clinic visit the young adult who is cognitively able must consent to their caregiver being present for all or part of the clinic visit. The AYA will be given information regarding obtaining past medical records from CNMC and other institutions. The AYA and caregiver will also be encouraged to develop a health inventory and to become knowledgeable about their past medical history, as they will need to be their own historian and not the parent. Health inventory information, planning tool and information to obtain past medical records will be printed out along with other recommendations at the conclusion of the clinic visit. The provider will document as part of the clinic note that is sent to the primary care provider: “As part of a comprehensive transition plan _ (patient’s name) was provided information regarding developing a past medical history inventory, planning tool and obtaining past medical records. Utilizing the adult care model of care the caregiver was in (out) the room per (patient’s name) request and all questions during the clinic visit were directed to the AYA. Transfer from CNMC Pediatric Rehabilitation Department is expected to occur between the ages of 18 and 21.

19 year-old visit

During the 19-year-old annual clinic visits, after usual care the provider will discuss adult psychiatrist options in the community. Adult providers contact information will be attached to the AYA visit summary and printed out along with other recommendations at the conclusion of the clinic visit. The rehabilitation provider will document as part of the clinic note that is sent to the primary care provider: “As part of a comprehensive transition plan _ (patient’s name) was provided with information regarding a psychiatrist who cares for adults. Utilizing the adult care model of care the caregiver was in (out) the room per _(patient’s name) request. The next PMR

clinic will visit occur with the adult practitioner. AYA was instructed to call this office with the name and contact information for the selected adult provider. We will follow-up with (patient's name) in two years for the final clinic visit. Transfer from CNMC Pediatric Rehabilitation Department is expected to occur between the ages of 18 and 21.

20 year-old visit

The 20 year-old annual clinic appointments will be conducted with the adult provider. Prior to the AYA appointment the pediatric rehabilitation provider will call the adult provider to give a verbal and written report regarding AYA past medical interventions and current plan of care.

21 year-old visit

At the 21-year-old annual clinic visit the AYA will return to pediatric rehabilitation provider for the potentially final clinic visit. After the usual care the provider will discuss any questions or concerns that the AYA has regarding transferring to the adult provider. Transfer will occur as a collaborative decision among all stakeholders (AYA, caregiver (if applicable), pediatric and adult provider). The clinic visit note will be sent to the primary care provider, adult practitioner and the AYA for their records. Providers were given information regarding documentation of the AYAHT program (Appendix G)

AYAHT Program Education Evaluation

The pediatric rehabilitation department consisted of three advance practice nurses, six physiatrists, one pediatric rehabilitation fellow, and two rehabilitation residents from area hospitals that rotate through the department monthly. The advance practice nurses consisted of one pediatric nurse practitioner, one family nurse practitioner, and one clinical nurse specialist.

Three of the six physiatrists were double boarded in pediatrics. Years of experience in the department ranged from two years to thirteen years.

Sample demographic indicates 2 of the participants were advanced practice nurses (n=2, 20%) and 8 of the participants were physicians (n=8, 80%). Six have been practicing in pediatric rehabilitation for less than 5 years (n=6, 60%) with the remaining practicing greater than 5 years (n=4, 40%).

Twenty percent (2), of the providers had received training about AYA healthcare transition. One hundred percent (10) of the provider heard about transition and read information about transition. None (0), providers had attended a lecture or training session that focused on transition. Thirty percent (3), providers reported assisting a patient with transition in the pediatric rehabilitation clinic.

Using a paired sample T-test pre-test/post-test means were compared (Appendix I). Rating the overall knowledge of AYA healthcare transition before in-service education and after the in-service educational session reveal a difference in the pre and post test mean scores (M=2.6, SD=.51) and post test M=3.9, SD=.73); $t(9)=-4.33$, $p = .002$. Rating the provider's familiarity with standardized transition resource and tools, (M=2.3, SD=1.5) and (M=4.3, SD=.67); $t(9) = -5.0$, $p = .001$ Regarding the provider's knowledge of the self-management skills that the youth need to develop in transition (M=2.3, SD=1.05) and (M= 4.0, SD=.68), $t(9) = -5.4$, $p = .00$. The question pertaining to the provider's knowledge of adult physiatrist in the community (M=3.4, SD= .96) and M= 3.3, SD= .63), $t(9) = .23$, $p = .82$. Regarding the healthcare coverage option for young adults (M=2.3, SD= 1.15) and (M= 4.0, SD=.47), $t(9) = -5.66$, $p = .00$. Health, social services and legal resources for AYA in the community rating of provider's knowledge in this area reveals (M= 2.6, SD=.56 and (M= 4.2, SD= .42, $t(9) = -11.69$, $p = .00$.

The question regarding how comfortable the providers are with giving care for AYA in the pediatric rehabilitation clinic ($M= 2.7$, $SD= 1.05$) and ($M= 4.1$, $SD= .99$), $t(9) = -4.58$, $p= .001$. Regarding the provider's comfort in their ability to develop a coordinated, comprehensive transition plan for AYA ($M=2.1$, $SD=.31$) and ($M= 4.2$, $SD=.00$), $t(9)= -11.69$, $p= .00$.

Experience questions inquired about the provider's past experience with transition and compared it how often do they anticipate participating in the activity after the education session. The experiences were rated as never experienced to always participate in the experience. Question 9 inquires about the provider's overall level of experience in transitioning AYA from pediatrics to adult care ($M= 2.2$, $SD= .63$) and ($M=4.2$, $SD=.66$), $t(9) =-4.46$, $p=.001$. Question 10 inquires about providers discussing the process of transition with AYA and caregivers ($M= 2.7$, $SD= .67$) and ($M= 4.2$, $SD=.78$), $t(9) =-4.88$, $p= .001$. Encouragement of the AYA to participate in self care management skills ($M= 3$, $SD= .94$) and ($M= 4.3$, $SD=.48$), $t(9)=-3.28$, $p= .009$. Discussion of insurance options in adulthood ($M= 2.3$, $SD= 1.5$) and ($M= 4.3$, $SD=.48$), $t(9) = -6.12$, $p= .000$. Develop and individualized transition plan ($M=$, $SD= .$) and ($M=4.1$, $SD=.73$), $t(9) = -7.85$, $p=.000$. Use of standardized tools and resources when facilitation transition ($M= 1.7$, $SD= .48$) and ($M= 4.4$, $SD= .51$), $t(9) = -16.00$, $p= .000$. Communicating directly with adult physiatrist to assist transition revealed ($M= 1.1$, $SD= .31$) and ($M= 4.1$, $SD= .73$), $t(9) = -14.23$, $p= .000$. Spend time during office visits talking privately to the AYA without the parent ($M= 1.4$, $SD= .15$) and ($M= 4.1$, $SD=.56$), $t(9) = -12.65$, $p= .000$.

Discussion

In 2002 the AAP, AAFP and ACP consensus statement on health care transitions for young adults with special health care needs recommended ongoing training for practicing physicians regarding transition services (AAP, 2002). However like many healthcare providers

the interprofessional team in the physical medicine department lacks the needed training, skills, knowledge, confidence and experience to appropriately provide transition (Hess, 2015). Reports showed that less than half of pediatricians routinely refer AYA to adult physicians, and only 12% create individualized transitional care plans” (Hess, 2015). Previous studies indicate the most commonly reported barrier to transitioning AYA was a lack of training and knowledge, and fear (Tuchman et al., 2008; Sawin et al., 2014). The purpose of this project was to act as a first step toward the implementation of formalized a transition program, increase the provider’s knowledge on the components of transition, and booster confidence in the process. Consist with other studies, findings of this project suggested the majority of the providers lacked the needed knowledge in standardized transition resources and tools, adolescent self-management skills and healthcare coverage options for adults (Okumura et al., 2008 and Lostein, McPherson & Strickland, 2005),. Similarly to other providers, most indicated that they knew adult physiatrists in the community that did not translate into developing a relationship that would transition the AYA to the adult facility (Lostein et al., 2005). Comments indicated that the known adult providers were not interested in caring for AYA with pediatric onset healthcare needs. Survey results reported improved knowledge and confidence. In addition, after attending the educational session all the participants indicated they would incorporate AYA transition into their clinical practice.

Implications for Future Practice

The development of the AYA healthcare transition program has the potential to influence the frequency and quality of transition in the pediatric rehabilitation department. Pediatric Rehabilitation staff services approximately 8,000 patients annually. Twenty-five percent (2000) are between the ages of 14-21 and ten percent (800) are over the age of 21. Incorporating

transition services as a part of the usual care and comprehensive evaluation would be a valued intervention for the population that they service. Adopting a transition program enables the healthcare providers have an opportunity to promote comprehensive, individualized, responsive, coordinated program for the AYA and caregivers.

Since the staff has been educated about the AYAHT program, the next step will be to implement the program. All staff members will be provided an electronic copy of the AYAHT manual and documentation guideline.

There are two outcome measures that will be investigated after implementation:

1) one year additional knowledge, confidence and experience beyond the in-service as indicated by improvement in the ACKE questionnaire score and 2) number of transition plans that the healthcare providers have developed for the AYA. The first outcome measure is a sustained increase in the provider's knowledge, confidence and experience beyond the in-service. This outcome measure can be operationalized by analyzing the pre- intervention /post- intervention scores by re-administration of the AKCE questionnaire. The scores will be analyzed using a paired T-test to determine if there is a statistically significant difference in the immediate post in-service and one year post in-service scores. The second outcome measure is number of transition plans that have been developed by the healthcare providers for the AYA. This can be operationalized by the numerical results of a chart audit. One year after the implementation of the program, using data mining from the electronic medical records, charts from patients 14 years and older will be audited. The percentage of patients who have a transition plan will be determined.

In a complex healthcare arena the clinician participates in the role of clinical expert, educator and leader and has an opportunity to transform evidence into practice. Guided by the

DNP essential practice established by the Association Colleges of Nursing (Chism, 2013), the nurse practitioner has clinical expertise to identify clinical problems that need further investigation. Nurse Practitioners can easily “integrate the theoretical, research-based and practical knowledge” (ANA, 1995, pg.14). This reduces the research to practice gap and increases evidence based practice regarding transition into their clinic practice.

The clinical expert as educator and leader can improve the scientific underpinning for practice by being the quality improvement leader for systemic thinking and participate in Interprofessional collaboration for improved patient and population health outcomes (Chism, 2013). It is essential that the clinical expert, acting as the clinical leader disseminate the results of a process improvement project through local, national and international conferences, publications and poster presentations. Sharing and disseminating results has the potential to encourage other providers to develop an AYA healthcare transition program in their clinic site.

Limitations

There were several limitations to this scholarly project. First, the sample was a small, convenient cohort of pediatric rehabilitation staff members in a large institution. Since this is a process improvement project and is not research, the results are not generalizable, universally or widely applicable to other institutions or department. Second, since the education session was conducted by a member of the pediatric rehabilitation department the results may be falsely positive as a result of social desirability and bias. Lastly, the survey questionnaire was not tested for reliability and validity.

Recommendations

Recommendations remain based on the IOM (2001) 6 aims of quality healthcare, safety, timeliness, efficiency, effectiveness, patient centeredness, and equity. For AYA safety it is

imperative that pediatric sub-specialties initiate transition education at every level from students, residents, and fellows to continuing education for independent providers to promote moving the adolescents starting at age 14 through the trajectory transitional care. While transition might be addressed by the primary care provider, for the youth with special healthcare needs it is the pediatric sub-specialist who provider a majority of care. Conducting appropriate transition management has the opportunity to improve health outcomes into adulthood. However a single education session alone is not enough to change behaviors or sustain a program. Additionally providers need to seek continuing education with such websites as www.gottransition.org, didactic lectures, conferences, peer reviewed articles, and webinars. Quality Improvement activities will be required to assure sustained transition care for AYA and their caregivers in the pediatric rehabilitation clinic.

As compared to a single provider Interprofessional collaborative can be most effective in AYA transition with ongoing review of the literature. AYA transition is a relevant topic. Protocols, guidelines and translational research are being conducted frequently. Continual review of available studies and noted available funding for research from organizations such as the National Institute on Disability, Independent Living and Rehabilitation Research can contribute to the extent literature.

Timeliness refers to providing AYA healthcare transition in a time frame that prevents physical harm or emotional distress (Slonim & Pollack, 2005). However transition care can be expensive and for many providers funds are not available for additional staff or an excess in time to facilitate the process. However devoting time to transition care during the usual clinic visits from ages 14-21 mitigate this problem and also prepares AYA and caregiver for future move to

adult care. While evidence does not support a specific model of transition there should be an incorporation of transition assessment, planning, coordination, self care management, and meeting with AYA independent from caregiver at the annual clinic visits.

Efficiency is reflective of obtaining best value for resources expended, through decreasing both waste and administrative costs (Goode, 2015). Providers who are knowledgeable concerning available resources can contribute to the efficiency of AYA transition. This includes but is not limited to parent volunteers (support groups), community resources, schools, disability services, state/federal programs, insurance, or hospital based family advocates (Okumura, Saunders, and Rehm, 2015).

Six dimensions of patient centeredness are “(1) respect for patients’ values, preferences, and expressed needs; (2) coordination and integration of care; (3) information, communication, and education; (4) physical comfort; (5) emotional support-relieving fear and anxiety; and (6) involvement of family and friends” (Tzelepis et al., 2014). It is recommended to provide respect for the patients’ values, preferences and expressed needs that the AYA, caregiver and healthcare provider work together to initiate and execute the transition process. In addition to our planned program for coordinated and integrate care each AYA needs a care coordinator through such state programs as Maryland’s Rare and Expensive Management (REM), who can assist in facilitating the transition progress. This can also be achieved by working closely with the social worker in the pediatric and adult facilities.

It is well documented that there is significant fear and anxiety associated with transition (Sawin et al., 2015 and Tuchman et al., 2008). In addition to providing the AYA with the information on the components of transition, the healthcare providers need training in assisting AYA and caregiver to provide emotional support to alleviate fear and anxiety. Some providers

might also need to acknowledge their own concerns regarding transitioning patients they have cared for for several years (Okumura et al., 2008). Intervention from a mental health provider may be required for the healthcare provider, AYA or caregiver.

Mackie (2014) indicated that a single nurse provided information, education and communication for AYA with heart defects with positive results. It is recommended that when possible that a nurse or health educator be designated to provide ongoing transition education.

Equity provides high quality care, including adolescent healthcare transition, regardless of the individuals' geographic location (Levitt, et al., 2014). However currently AYA healthcare transition varies depending on where care is provided. Therefore it is recommended that a state and national healthcare transition policy that facilitates transition in an organized coordinated manner be developed. While there is the Consensus Statement on Healthcare Transitions for Young Adults with Special Healthcare Needs (AAP, 2002) without federal and state level support it will be difficult to establish equitable care. Best practices and guidelines should also be developed, depending on the AYA diagnosis.

Conclusion

Fourteen years after the publication of the Consensus Statement on Health Care Transition for Young Adults with Special Health Care Needs (AAP, 2002), there remains a gap in consistent coordinated care transition in pediatric institutions (McManus et al., 2015). This practice program contributes to the body of knowledge regarding AYA healthcare transition, Interprofessional knowledge, confidence and experience on transition and an opportunity for establishing an AYAHT program. Results show a development of transition interprofessional structure, process and staff education training has a positive effect on selected dimensions of transition. AYA transition program development and dissemination builds extant literature and

promotes research regarding transitions of care. Program replication for implementation promotes future translational research to improve practice outcomes. Educating providers to the AYA transition program facilitates safe, patient centered, timely, effective and, equitable outcomes (IOM, 2001). Education is a first step in promoting policy development ensuring successful transition for AYA and caregivers.

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Appendix A
Logic Model

Program: Adolescent/Young Adult Transition Program					
Goal: Transition Youth with special health care needs from Outpatient Pediatric Rehabilitation to Adult Care.					
<u>INPUTS</u>		<u>ACTIVITIES</u>		<u>OUTCOMES</u>	
What we invest	What we do	Who we reach	Why this project: short-term results	Why this project: intermediate results	Why this project: long-term results
Training Module Staff time in developing the program Materials to distribute to staff Physical and Technical resource-electronic medical records	Develop program Conduct training and meetings Facilitate access to information	Adolescents Young adults Caregivers Pediatric Rehab Dept. Staff	Awareness of transition needs Promote Knowledge of transition planning Motivate pediatric rehabilitation staff	Transition will be: Standard Care Organized, Timely, Progressive, Planned Event	Youth will have uninterrupted Care when transitioning from pediatrics to adult care

Assumptions:	Limitations:
Transition will occur in safe, patient-centered, effective and equitable manner. Staff will actively participate in the four phase of program development. Staff recognizes the value of transition in an organized, timely and progressive fashion.	Lack of time to do the transition program Limitations in electronic medical records (Cerner)

Appendix B

Transition Readiness Assessment Questionnaire (TRAQ)

Patient Name: _____ Date of Birth: ___/___/___

Today's Date ___/___/___

Transition Readiness Assessment Questionnaire (TRAQ)

Directions to AYA and Young Adults: Please check the box that best describes *your* skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.

Directions to Caregivers/Parents: If your AYA or young adult is unable to complete the tasks below on their own, please check the box that best describes *your* skill level.

	No, I do not know how	No, but I want to learn	No, but I am learning to do this	Yes, I have started doing this	Yes, I always do this when I need to
<i>Managing Medications</i>					
1. Do you fill a prescription if you need to?					
2. Do you know what to do if you are having a bad reaction to your medications?					
3. Do you take medications correctly and on your own?					
4. Do you reorder medications before they run out?					
<i>Appointment Keeping</i>					
5. Do you call the doctor's office to make an appointment?					
6. Do you follow-up on any referral for tests, check-ups or labs?					
7. Do you arrange for your ride to medical appointments?					
8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?					
9. Do you apply for health insurance if you lose your current coverage?					

10. Do you know what your health insurance covers?					
11. Do you manage your money & budget household expenses (For example: use checking/debit card)?					
<i>Tracking Health Issues</i>					
12. Do you fill out the medical history form, including a list of your allergies?					
13. Do you keep a calendar or list of medical and other appointments?					
14. Do you make a list of questions before the doctor's visit?					
15. Do you get financial help with school or work?					
<i>Talking with Providers</i>					
16. Do you tell the doctor or nurse what you are feeling?					
17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?					
<i>Managing Daily Activities</i>					
18. Do you help plan or prepare meals/food?					
19. Do you keep home/room clean or clean-up after meals?					
20. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?					

Appendix C

AYAHT Procedure

PROGRAM DEVELOPMENT				
Adolescent/Young Adult Healthcare Transition				
<u>Phase</u>	<u>Participants</u>	<u>Components</u>	<u>Week</u>	<u>Deliverable</u>
Phase I	Pediatric Rehabilitation Transition Champions (PRTC); Nurse Practitioner Facilitator	First Meeting: a) Purpose and goals b) Consensus statement c) Timeline d) AYAHT Program	One	First Draft
		First draft emailed to PRTC with request for input	Two	Second Draft
		Second Meeting a) discuss the changes to the program that were suggested by the PRTC via electronic communication b) review the AYAHT program c) discuss any additions, deletions, comments, questions or concerns	Three	Third Draft
Phase II	Two Volunteer Pediatric Physiatrist and two caregivers of AYA with special healthcare needs	Emailed third draft: Questions a) Is the program clear in what information is to be given to the AYA and when it is to be distributed? b) Is there any additional information that should be given and why? c) Is there any information that should be deleted from the program and why? d) Additional comments	Four	Fourth Draft

<p>Phase III</p>	<p>Pediatric Rehabilitation Medical Director; Nurse Practitioner Facilitator</p>	<p>Emailed Fourth draft- 3 days later face to face meeting. Medical Director will be asked:</p> <ul style="list-style-type: none"> a) Is the program clear in what information is to be given to the AYA and when it is to be distributed? b) Is there any additional information that should be given and why? c) Is there any information that should be deleted from the program and why? d) Additional comments 	<p>Five</p>	<p>Final Approved Version</p>
<p>Phase IV</p>	<p>Pediatric Rehabilitation Transition Champions; Pediatric Nurse Practitioner Facilitator</p> <p>Pediatric Rehabilitation Staff</p>	<p>Third Meeting with PRTC</p> <ul style="list-style-type: none"> a) review of the educational healthcare module <p>Staff emailed education Module</p> <p>Staff In-service</p>	<p>Six</p> <p>Seven</p> <p>Eight</p>	<p>Education Module</p> <p>Survey</p>

Appendix D

In-service Outline

1. Introduction

A. American Academy of Pediatrics (AAP), American Academy of Family Practice (AAFP), & American College of Physicians (ACP). (2002). A consensus statement on health care transitions for young adults with special health care needs

B. Purpose of in-service

1. Consistent Information throughout the department

2. Progressive Information for all our patients and their caregivers.

2. Barriers/Facilitator to Transition

3. Pediatric Rehabilitation Department Transition Statement

4. Transition Readiness Assessment Questionnaire (TRAQ)

A. Medication management

B. Appointment keeping

C. Tracking health issues

D. Communicate with providers

E. Management of daily activities

5. Community Resources

A. Developmental Disability Agency (DDA)

B. Department of Rehabilitation Services (DORS)

6. Legal Issues

A. Self Consent

B. Guardianship

7. Developing a Personal Health Record and Obtaining Medical Records

8. Adult Approach to Care

9. Adult Providers

A. Identifying

B. Transfer of Care

C. Post Transfer follow-up

10. Documenting Transition Plan and Transfer

Appendix E

AYAHT Knowledge, Confidence and Experience (AKCE) Pre-Test with Introduction

The 2009-2010 National Survey of Children with Special Health Care Needs revealed that almost twenty percent of adolescents in the United States have a physical, mental, emotional or learning disability (NS-CSHCN, 2014). Advances in treatment modalities, technologies and scientific breakthroughs, 90%, 750,000 children annually are living well into adulthood (Betz, 2012). Most adolescents/young adults (AYA) lack the needed preparation for transition from the pediatric providers. A barrier for healthcare providers to transitioning AYA is the lack of skills to provide transition assessment and planning (AAP, 2009). Consequences to failing to transition have been associated with declining health, lack of care continuity, and disengagement with the medical community. Promoting transition readiness and providing an organized, coordinated transition program fosters best outcomes for AYA, and caregivers.

As outlined in the AAP’s 2011 Clinical Report on transition from adolescence to adulthood, “optimal health care is achieved when each person, at every age, receives medically and developmentally appropriate care. The goal of a planned health care transition is to maximize lifelong functioning and well-being for *all youth*, including those who have special health care needs and those who do not. This process includes ensuring that high-quality, developmentally appropriate health care services are available in an uninterrupted manner as the person moves from adolescents to adulthood”.

Transition to adult health care is more the transfer of care. Transition involves ongoing discussion with the AYA and caregiver throughout the teen years regarding potential for self-care management and decision-making (Hess, Straub, & Mateus, et. al., 2015)

Please answer the following questions based on these definitions, as well as your own understanding of healthcare transition.

Section 1: Knowledge

1. How would you rate your overall knowledge of AYA health care transition?

1	2	3	4	5
Very minimal	Minimal	Moderate	Extensive	Very Extensive

2. Have you received training about AYA health care transition? ___Yes ___No

3. I have heard about transition ___Yes ___No

4. I have read information about transition ___Yes ___No

5. I have attended a lecture/training session focused on transition. ___Yes ___No

6. I have assisted a patient with transition in the pediatric rehabilitation clinic.

___Yes ___No

What is your degree of familiarity with health care transition? Rate from 1 (not at all familiar) to 5 (very familiar)

7. Standardized transitioning resources and tools.

1	2	3	4	5
Not at all Familiar	Slightly Familiar	Somewhat Familiar	Moderately Familiar	Very Familiar

8. Self-management skills that youth need to develop

1	2	3	4	5
Not at all Familiar	Slightly Familiar	Somewhat Familiar	Moderately Familiar	Very Familiar

9. Adult Physiatrist in the community

1	2	3	4	5
Not at all Familiar	Slightly Familiar	Somewhat Familiar	Moderately Familiar	Very Familiar

10. Health care coverage options for young adults

1	2	3	4	5
Not at all Familiar	Slightly Familiar	Somewhat Familiar	Moderately Familiar	Very Familiar

11. Health, social service, and legal resources for AYA in the community

1	2	3	4	5
Not at all Familiar	Slightly Familiar	Somewhat Familiar	Moderately Familiar	Very Familiar

12. How would you prefer to learn new knowledge about health care transition? All that applies

- Peer reviewed literature_____
- Transition website (online self search)_____
- Webinar/ web based module_____
- Didactic lectures or training sessions_____
- Standardized patient encounters_____

Experiences transitioning youth in your own clinic _____
 Other (please specify) _____

Section 2: Confidence

13. How comfortable are you in providing care for AYA?

1	2	3	4	5
Very uncomfortable	Slightly Uncomfortable	Comfortable	Moderately Comfortable	Very Comfortable

14. How comfortable are you in your ability to develop a coordinated, comprehensive transition plan for AYA?

1	2	3	4	5
Very uncomfortable	Slightly Uncomfortable	Comfortable	Moderately Comfortable	Very Comfortable

Section 3: Experience

15. How would you rate your overall level of experience in transitioning AYA from pediatrics to adult care?

1	2	3	4	5
Very minimal	Minimal	Moderate	Extensive	Very Extensive

16. In your experience caring for adolescents, how often do you: Discuss the process of transition with AYA and caregivers?

1	2	3	4	5
Never	Rarely	Sometime	Often	Always

17. Encourage health care self-management skills?

1	2	3	4	5
Never	Rarely	Sometime	Often	Always

18. Discuss insurance options in adulthood?

1	2	3	4	5
Never	Rarely	Sometime	Often	Always

19. Develop an individualized transition plan?

1	2	3	4	5
Never	Rarely	Sometime	Often	Always

20. Use standardized tools and resources when facilitating transition?

1	2	3	4	5
Never	Rarely	Sometime	Often	Always

21. Communicate directly with adult physiatrist to assist transition?

1	2	3	4	5
Never	Rarely	Sometime	Often	Always

22. Spend some time during office visits talking privately to the AYA? (without caregiver present)?

1	2	3	4	5
Never	Rarely	Sometime	Often	Always

Section 4: Demographics

Please answer the following demographic questions:

23. Years in Practice in Pediatric Rehabilitation: _____ <5 years _____ >5 years

24. ____APRN _____MD

25. Please share any additional comments that you have regarding health care transition.

Appendix F

AYAHT Knowledge, Confidence, and Experience Post-Test

Section 1: Knowledge

1. How would you rate your overall knowledge of AYA health care transition?

1	2	3	4	5
Very minimal	Minimal	Moderate	Extensive	Very Extensive

2. Have you received training about AYA health care transition? ___Yes ___No

3. I have heard about transition ___Yes ___No

4. I have read information about transition ___Yes ___No

5. I have attended a lecture/training session focused on transition. ___Yes ___No

6. I have assisted a patient with transition in the pediatric rehabilitation clinic. ___Yes ___No

What is your degree of familiarity with health care transition? Rate from 1 (not at all familiar) to 5 (very familiar)

7. Standardized transitioning resources and tools.

1	2	3	4	5
Not at all Familiar	Slightly Familiar	Somewhat Familiar	Moderately Familiar	Very Familiar

8. Self-management skills that youth need to develop

1	2	3	4	5
Not at all Familiar	Slightly Familiar	Somewhat Familiar	Moderately Familiar	Very Familiar

9. Adult Psychiatrist in the community

1	2	3	4	5
Not at all Familiar	Slightly Familiar	Somewhat Familiar	Moderately Familiar	Very Familiar

10. Health care coverage options for young adults

1	2	3	4	5
Not at all Familiar	Slightly Familiar	Somewhat Familiar	Moderately Familiar	Very Familiar

11. Health, social service, and legal resources for AYA in the community

1	2	3	4	5
Not at all Familiar	Slightly Familiar	Somewhat Familiar	Moderately Familiar	Very Familiar

12. How would you prefer to learn new knowledge about health care transition? All that applies

- Peer reviewed literature_____
- Transition website (online self search)_____
- Webinar/ web based module_____
- Didactic lectures or training sessions_____
- Standardized patient encounters_____
- Experiences transitioning youth in your own clinic_____
- Other (please specify)_____

Section 2: Confidence

13. After the in-service, how comfortable are you in providing care for AYA?

1	2	3	4	5
Very uncomfortable	Slightly Uncomfortable	Comfortable	Moderately Comfortable	Very Comfortable

14. How comfortable are you in your ability to develop a coordinated, comprehensive transition plan for AYA?

1	2	3	4	5
Very uncomfortable	Slightly Uncomfortable	Comfortable	Moderately Comfortable	Very Comfortable

Section 3: Experience

15. How would you rate your overall level of experience in transitioning AYA from pediatrics to adult care?

1	2	3	4	5
Very minimal	Minimal	Moderate	Extensive	Very Extensive

16. How often will you?: Discuss the process of transition with AYA and caregivers?

1	2	3	4	5
Never	Rarely	Sometime	Often	Always

17. Encourage health care self-management skills?

1	2	3	4	5
Never	Rarely	Sometime	Often	Always

18. Discuss insurance options in adulthood?

1	2	3	4	5
Never	Rarely	Sometime	Often	Always

19. Develop an individualized transition plan?

1	2	3	4	5
Never	Rarely	Sometime	Often	Always

20. Use standardized tools and resources when facilitating transition?

1	2	3	4	5
Never	Rarely	Sometime	Often	Always

21. Communicate directly with adult physiatrist to assist transition?

1	2	3	4	5
Never	Rarely	Sometime	Often	Always

22. Spend some time during office visits talking privately to the AYA? (without caregiver present)?

1	2	3	4	5
Never	Rarely	Sometime	Often	Always

Section 4: Demographics

Please answer the following demographic questions:

23. Years in Practice in Pediatric Rehabilitation: _____ <5 years _____ >5 years

24. _____APRN _____MD

25. Please share any additional comments that you have regarding health care transition.

Appendix G

Anticipatory Guidance for Transition

<u>Age</u>	<u>Information Provided</u>	<u>Documentation for electronic health record</u>
14	Pediatric Rehabilitation Transition Statement	As part of a comprehensive transition plan _ (patient's name) was provided a copy of the department's transition statement that informs them that transition from the Pediatric Rehabilitation Department is expected to occur between the ages of 18 and 21
15	Transition Readiness Assessment Questionnaire	As part of a comprehensive transition plan _ (patient's name) was provided a copy to the transition assessment readiness questionnaire (TRAQ). They were encouraged to share the TRAQ results with the primary care provider. This step is a part of the transition process. Transfer from the Pediatric Rehabilitation Department is expected to occur between the ages of 18 and 21
16	Developmental Disability Agency and Department of Rehabilitation Services	As part of a comprehensive transition plan _ (patient's name) was provided with community resources information and encouraged to investigate the resources available through the Developmental Disability Agency (DDA) and the Department of Rehabilitation Services (DORS). They were also provided with a transition planning tool. Transfer from the Pediatric Rehabilitation Department is expected to occur between the ages of 18 and 21
17	Consent for Care vs. Guardianship	As part of a comprehensive transition plan _ (patient's name) was provided with information regarding consent (or guardianship) and state insurance for adults with special healthcare need
18	Past Medical Records and Health Inventory	As part of a comprehensive transition plan _ (patient's name) was provided information regarding developing a past medical history inventory and obtaining past medical records. Utilizing the adult care model of care the caregiver was in (out) the room per _ (patient's name) request and all questions during the clinic visit were directed to the AYA. Transfer from the Pediatric Rehabilitation Department is expected to occur between the ages of 18 and 21".
19	Referral to Adult Psychiatrist	As part of a comprehensive transition plan _ (patient's name) was provided with information regarding a psychiatrist who cares for adults. Utilizing the adult care model of care the caregiver was in (out) the room per _ (patient's name) request. The next PMR clinic will visit occur with the adult practitioner. AYA was instructed to call this office with the name and contact information for the selected adult provider. We will follow-up with _ (patient's name) in two years for the final clinic visit. Transfer from CNMC Pediatric Rehabilitation Department is expected to occur between the ages of 18 and 21
20	Appointment with Adult Psychiatrist	Prior to the AYA appointment the pediatric rehabilitation provider will call the adult provider to give a verbal and written report regarding AYA past medical interventions and current plan of care
21	Transfer	Transfer (Discharge) will occur as a collaborative decision among all stakeholders (AYA, caregivers (if applicable), pediatric and adult providers)

Appendix H

Pediatric Rehabilitation Transition Statement

The Pediatric Rehabilitation Department is committed to assisting our patients and their caregivers to make a smooth transition from pediatrics to adult health care. This process includes working with you to plan and prepare your transition starting at 14 years of age. According to hospital policy all patients are expected to transition from pediatrics to an adult provider by 22 years old. We will provide you with ongoing resources to support you in making this transition. However the individualized decision regarding when transition will occur will be determined collaboratively between you and your pediatric rehabilitation health care provider.

For Young Adults

At age 18, under the federal Health Information Portability and Accountability Act (HIPPA), access to your health records and any discussion about your health is only provided to people that you consent to, including your parents. If you wish your parents to discuss your health on your behalf, you must provide written consent to your Pediatric Rehabilitation by completing a form that is to be returned to staff.

Caregivers

If you need access to your young adults' records or you would like to discuss their care, your young adult must consent in writing to provide you access. Under HIPPA, medical providers are no longer permitted to discuss health issues without express consent from the young adult. Exceptions are extended for those with intellectual disabilities. However starting at age 18 the caregiver must possess legally valid custodial care, power of attorney or an adjudicated guardianship arrangement.

Appendix I

Pre-Test/Post-test Paired Differences

		Paired Differences					t	df	Sig. (2 tailed)
		Mean Difference	Std. Deviation	Std. Error Mean	95% Confidence Interval Of the Difference				
					Lower	Upper			
Pair 1	Overall knowledge	-1.30000	.94868	.30000	-1.97865	-.62135	-4.333	9	.002
Pair 2	Knowledge of standardized transition resources and tools	-2.00000	1.24722	.39441	-2.89221	-1.10779	-5.071	9	.001
Pair 3	Knowledge of the self-management skills	-1.90000	1.10050	.34801	-2.68725	-1.11275	-5.460	9	.000
Pair 4	Knowledge of adult physiatrist in the community	.10000	1.37032	.43333	-.88027	1.08027	.231	9	.823
Pair 5	Knowledge of healthcare coverage	-1.70000	.94868	.30000	-2.37865	-1.02135	-5.667	9	.000
Pair 6	Knowledge of health, social services and legal resources	-2.10000	.56765	.17951	-2.50607	-1.69393	-11.699	9	.000
Pair 7	Comfort in caring for AYA	-1.40000	.96609	.30551	-2.09110	-.70890	-4.583	9	.001
Pair 8	Comfort in their ability to develop transition plan	-2.10000	.56765	.17951	-2.50607	-1.69393	-11.699	9	.000
Pair 9	Experience in overall transition	-2.2000	.63246	.20000	2.20897	.63009	--4.460	9	.001
Pair 10	Experience discussing the transition process	-1.50000	.97183	.30732	-2.19520	-.80480	-4.881	9	.001
Pair 11	Experience encouraging participation in self care management skills	-1.30000	1.25167	.39581	-2.19539	-.40461	-3.284	9	.009
Pair 12	Experience in discussing insurance options	-2.20000	1.13529	.35901	-3.01214	-1.38786	-6.128	9	.000
Pair 13	Experience in developing an AYA	-2.40000	.96609	.30551	-3.09110	-1.70890	-7.856	9	.000

	individualized transition plan								
Pair 14	Experience in the use of standardized transition tools and resources	-3.20000	.63246	.20000	-3.65243	-2.74757	-16.000	9	.000
Pair 15	Experience in communicating directly with adult psychiatrist	-3.00000	.66667	.21082	-3.47690	-2.52310	-14.230	9	.000
Pair 16	Experience in spending time with AYA without the parent	-2.70000	.67495	.21344	-3.18283	-2.21717	-12.650	9	.000