

University of San Diego

Digital USD

Doctor of Nursing Practice Final Manuscripts

Theses and Dissertations

Spring 5-21-2016

Health Care Transition Program for Adolescents with Spina Bifida

Teresa M. Scavone

University of San Diego, tmscavone@sandiego.edu

Follow this and additional works at: <https://digital.sandiego.edu/dnp>



Part of the [Musculoskeletal Diseases Commons](#), [Pediatric Nursing Commons](#), and the [Urology Commons](#)

Digital USD Citation

Scavone, Teresa M., "Health Care Transition Program for Adolescents with Spina Bifida" (2016). *Doctor of Nursing Practice Final Manuscripts*. 8.

<https://digital.sandiego.edu/dnp/8>

This Doctor of Nursing Practice Final Manuscript is brought to you for free and open access by the Theses and Dissertations at Digital USD. It has been accepted for inclusion in Doctor of Nursing Practice Final Manuscripts by an authorized administrator of Digital USD. For more information, please contact digital@sandiego.edu.

UNIVERSITY OF SAN DIEGO
Hahn School of Nursing and Health Science

DOCTOR OF NURSING PRACTICE PORTFOLIO

by

Teresa M. Scavone RN, MSN, PNP-BC

A portfolio presented to the

FACULTY OF THE HAHN SCHOOL OF NURSING AND HEALTH SCIENCE
UNIVERSITY OF SAN DIEGO

In partial fulfillment of the
requirements for the degree

DOCTOR OF NURSING PRACTICE
May/2016

Kathleen Sweeney, PNP, Faculty Chairperson
Scot Nolan, DNP, CNS, CCRN, CNRN, Seminar Faculty
Craig McDonald, M.D., Clinical Mentor

Table of Contents

I. Acknowledgements.....	iii
II. Opening Statement: Purpose in Pursuing the Doctor of Nursing Practice (DNP).....	1
III. Documentation of Mastery of DNP Program Outcomes Copy of Approved Final Manuscript.....	3
IV. Concluding Essay: Reflections on Growth in Advanced Practice Nursing Role	28

Acknowledgements

I would like to express my sincere gratitude and appreciation to the administration and medical staff at Shriners Hospitals for Children, Northern California, for their support throughout the completion of my evidence-based practice project, Healthcare Transition for Adolescents with Spina Bifida. My clinical mentor, Dr. Craig McDonald was instrumental in the design and development of this Spina Bifida (SB) transition project. Dr. McDonald has mentored me for over 18 years, endowing me with vast amounts of knowledge, which guide my practice and care of these SB children. I am grateful to the wonderful SB teens and their families; clearly I could not have completed this project without their full and willing participation.

I wish to thank my professors at the University of San Diego Hahn School of Nursing and Health Science for their guidance, support, mentorship, and scholarly wisdom. I want to mention specifically my faculty chair, Dr. Kathleen Sweeney, for her encouragement, guidance, knowledge, mentoring, enthusiasm and unwavering support over these past two years. Dr. Sweeney has surpassed the traditional role of a professor by providing extra time, sound advice and thoughtful consideration to me.

Most importantly, I wish to thank my beloved husband, Dr. John Scavone, who has been tremendous in his understanding, commitment, encouragement, and unending support, throughout my academic and professional career. John has provided guidance, countless editing and financial support as I pursued my DNP, for which I am extremely grateful. I would like to also acknowledge my mother for encouraging my pursuit of higher levels of education early in life and her loving support throughout.

A major thank you to Eric and Leslie Scavone for providing a home away from home, transportation, meals and many enjoyable evenings spent with our grandchildren. My fellow student, Jenilyn emerged as a special person for her generosity in providing rides to the airport every week and the wonderful friendship that we have developed. Thanks to all my family and friends that contributed their support and love throughout this wonderful journey.

Opening Statement

The nursing profession advances by continual learning and nurse practitioners must acquire special expertise that is far reaching. The advanced training and knowledge helps to further delineate their roles to better position NPs to have a more significant impact on the current healthcare environment. I have interest and expertise in caring for children with special health care needs and endeavor to improve their health condition as well as their future quality of life.

The DNP program clearly represents the next level of discipline necessary to improve the care of patients in a pediatric specialty practice. As I have moved beyond my Masters program, I have observed the evolution of both scientific research and technology in healthcare and have found the DNP program attractive because it afforded the acquisition of new leadership skills and mentoring. A developing issue is the burgeoning use of information technology (IT) in health care, which at this point leaves Advanced Nursing Practice unrecognized and unaccounted. Training in the DNP program offers to close this gap, because NPs with a doctoral degree can utilize their new skills to build evidence-based studies, which can lead to improved practice guidelines. At the same time, this process strengthens the bond with these patients, which is compassionate and trusting care. I value and embrace this philosophy of advanced learning and application as I strive to meet the demands of my patients, against constraints in practice, and the overall work environment. I am highly interested in healthcare transition services and programs for children with special health care needs.

As a professional working with SB children and their families, I understand the enormous commitment to their care. Due to the large investment of time and resources expended during their early development, I aspire to provide the necessary tools that will allow the adolescents to become successful young adults. I hope to learn methods that impart self-care skills and self-advocacy in the adolescent and young adult SB patients. I envision two special goals: improvement their overall health condition, and prevention of morbidity and mortality.

As advanced practice professionals, we have ideas and strategies that need further refinement and shaping. Through the wisdom and teaching by the academic faculty, I will be able to develop clinical projects that produce outcomes that guide my ability to make improvements in pediatric health care delivery. The DNP serves as the best opportunity to advance my education and skill set and to better position myself in the future healthcare environment. The demand for care due to patient complexity and sheer volume will ultimately require an advanced level of training to match that of the professionals with whom I will be working. I look forward to the new learning opportunities and interaction with scholarly professionals at the University of San Diego.

Health Care Transition Program for Adolescents with Spina Bifida

Teresa Scavone, PNP-BC, MSN, DNP Student

Kathleen Sweeney, DNP, CPNP-PC

University of San Diego

Correspondence to Teresa Scavone, MSN, PNP-BC
University of San Diego, Hahn School of Nursing and Health Science
5998 Alcala Park San Diego, CA. 92110
tmscavone@sandiego.edu

Conflict of Interest Statement

The authors report no actual or potential conflicts of interest.

KEYWORDS:

Spina Bifida, Transition Readiness,
Self-care management, Transition
to adult care

Abstract

The purpose of this evidence-based project was to evaluate the feasibility of implementing an NP facilitated formal transition program for adolescents with Spina Bifida. There is an increased awareness of the need for health care transition for youth with special health care needs (YSHCN) due to the 2009-2010 Maternal Child Health Branch National Survey findings that only 40% of YSHCN receive adequate support for transition that meets the core outcome measures. Recent studies have investigated transition in youth with chronic disease specific conditions such as diabetes, cystic fibrosis, and congenital heart defects, and provide valuable insight into possible strategies for transition management. However, there is limited translation of the evidence to transition programs specific to adolescents with Spina bifida (SB) that are focused on transition readiness or knowledge related to self-care management. Adolescents with SB face many challenges due to their medical complexities and potential development of secondary health conditions as young adults. Adolescents with Spina bifida often have difficulty with knowledge acquisition, attention, organization, and problem solving, all factors that are necessary to facilitate successful healthcare transition. An NP transition program was successfully implemented into a multidisciplinary SB clinic. The results of this transition program support a structured needs assessment and specific educational interventions with this unique population. The SB healthcare transition project can serve as a model for future programs with youth that have complex medical conditions.

Background and Significance

Transitions in healthcare for adolescents with complex care needs present a significant challenge along their journey to adulthood. Healthcare transition has variable meanings, therefore the definition set forth by the Society for Adolescent Medicine (SAHM) from 1993, is best suited for the context of this article as it describes transition as “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems” (Reiss & Gibson, 2002, p. 1309). Healthcare transition for Youth with Special Health Care Needs (YSHCN) is a developmental and individual process that represents more than the reassignment of care to adult providers. Inadequate planning and lack of transitional support leads to ineffective preparation for YSHCN, and decreases their ability to navigate the new systems of adult health care. The lack of proper transition strategies can lead to negative outcomes for YSHCN due to lack of knowledge, and the inability to manage self-care. These issues surrounding chronic illness management may culminate into a significant decrease, or outright lack of follow up (Applebaum, Lawson, & Von Scheven, 2013; Stinson et al., 2014). In turn, this lack of continuity of on-going healthcare for YSHCN results in increased use of emergency rooms and frequent hospitalizations, further driving up medical costs and resulting in poor outcomes (Lemly, Weitzman, & O’Hare, 2013).

It is estimated that there are approximately 750,000 youth with special health care needs (YSHCN) who will require increased support to transition their healthcare from pediatric to adult services each year (Davis, Brown, Lounds-Taylor, Epstein, & McPheeters, (2014). To examine current US performance on transition from pediatric to

adult health care, the 2009-2010 National Survey of Children with Special Health Care Needs (CSHCN) was administered to a nationally representative sample with 17,114 parent respondents who have youth with special health care needs (YSHCN) ages 12 and 18. Parents were asked about whether a provider has discussed the following issues: transition of care to an adult provider, changing health care needs, increasing responsibility for self-care management, and maintaining insurance coverage. Only 40% of YSHCN were found to meet the national transition core outcome. Several factors associated with increased likelihood of transition preparation included female gender; younger age at initiation of transition; white race; non-Hispanic ethnicity; income $\geq 400\%$ of poverty; little or no impact of condition on activities (mobility, ADLs); having a condition other than an emotional, behavioral, or developmental condition; having a medical home; and being privately insured (McManus et al., 2013). There were no discernible improvements since this transition outcome was initially measured in the 2005-2006 National Survey of Children with Special Health Care Needs. Although most providers are encouraging YSHCN to assume responsibility for their healthcare, far fewer are discussing transfer to an adult provider and insurance continuity, therefore the conclusion is that most YSHCN are not receiving adequate transition preparation.

The American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP) developed an initial Consensus Statement in 2002, recommending that all CSHCN have a written transition plan by 14 years of age (AAP, AAFP, ACP & ASIM, 2002; Zuckerman et al., 2010). These professional organizations highlight the importance of these children having access to and receiving high quality care that is developmentally appropriate and continues

uninterrupted throughout their life. The stated primary goal of transition is to maximize their lifelong potential with care that is coordinated, comprehensive, and responsive to the needs of patients and their families to

improve self-care, and self-advocacy. Despite this collaboration and strong support, significant progress in developing transition programs did not occur.

As a follow up, in 2011 this same coalition, along with the Transitions Clinical Authoring Group (TCRAG), further defined the need for adolescent healthcare transitional services via the development of a detailed algorithm to assist providers with transition implementation. These specialty groups also strongly support the provision of healthcare transition services as a benchmark, which is necessary to be fully recognized as a medical home (AAP, AAFP, ACP & TCRAG, 2011). Healthy People 2020 have also set a goal to increase the proportion of YSHCN, whose health care provider has discussed transition planning from pediatric to adult health care.

Despite the CSHCN data and major support from the various medical associations (AAP, AAFP, ACP, ASIM & SAHM) to provide a Medical Home Model and to assist with transitional care for YSHCN, minimal improvement has been demonstrated over the past two decades (Bloom et al., 2012; Lemly, Weitzman, & O'Hare, 2013). There continues to be major health care disparities for at risk populations with limited access to specialty care, further creating the inability to meet the transitional outcome goals for YSHCN (McManus et al., 2013). This persistent lack of transition implementation has led to the recent collaboration between the Maternal and Child Health Bureau (MCHB) and the National Alliance to Advance Adolescent Health to promote transition initiatives and further their partnerships with medical associations and other health professionals.

Together these stakeholders have developed quality improvement studies that have produced important evidence-based resources under the name “Got Transition” known as the Center for Health Care Transition Improvement (www.GotTransition.org).

Spina Bifida Condition

Spina Bifida is a chronic illness that requires lifelong, comprehensive care due to associated multiple and complex conditions. SB is a type of neural tube defect occurring very early in the pregnancy, and is due to the failure of the neural elements, both spinal cord and vertebral processes to close properly (National Institutes of Health, 2013). Liptak & El Samra, (2010) refer to Spina Bifida as “the most complex birth defect that is compatible with survival”. While the incidence of spina bifida has steadily declined the survival rate has increased, and it is estimated that 85% of these children will live well in to adulthood with further implications for health care systems (CDC, 2006; Le & Mukherjee, 2015). The spectrum of spina bifida patients extends from the most common and severe form (80-90%), known as myelomeningocele and presents as an open defect at birth. In this situation, there are certain brain malformations, hydrocephalus and Chiari II, as well as orthopedic defects resulting in limited mobility, and complications from neurogenic bladder and bowel (Fletcher & Brei, 2010). There is a less severe presentation of spina bifida termed lipomeningocele, which is a closed defect without brain involvement and minimal to no mobility issues. Nevertheless, this type of closed defect causes SB patients to have significant issues secondary to a neurogenic bladder and bowel (Sarris, Tomei, Carmel, & Gandhi, 2012).

SB youth are experiencing a greater life expectancy due to surgical and technological advancements, with an estimated 166,000 children diagnosed with SB

currently living in the U.S., increasing the demand for services to assist with their transition to adult health care (NIH, 2013). Furthermore, with increasing age come new comorbidities for adults with SB. This is related to the spinal cord abnormalities causing a decrease in mobility, which often leads to obesity and the subsequent development of Type II diabetes. SB patients have decreased sensation and are at substantial risk for pressure ulcers due to prolonged sitting and incontinence. Latex allergies are also prevalent and can cause severe anaphylactic reactions. Since 85-90% of SB children now survive well into adulthood, several problems begin to emerge with their health care transition (Burke & Liptak, 2011; Mukherjee, 2007). Most importantly, they must become informed about their own condition, while learning self-care skills to better manage symptoms and to prevent further development of secondary medical problems. Knowledge acquisition can be particularly challenging for SB adolescents, because they often have cognitive deficits which may be related to poor brain development, hydrocephalus and subsequent shunt malfunctions, and/or infections. The cognitive impairments are given the term nonverbal learning disorder (NLD), and include poor memory, decreased problem solving ability, and lower executive functioning, even though their documented IQ may be within the normal range (Lollar, n.d).

Spina Bifida Adolescents

By the time the SB child enters adolescence, they have increased limitations in mobility, and continue to struggle with organization, all contributing factors that lead to decreased self-care management, especially keeping up with their daily routine for bladder and bowel care (O'Hara & Holmbeck, 2013). Throughout the literature review it was challenging to find transitional research that dealt with adolescents that have

cognitive issues. This is an interesting phenomenon as many of the YSHCN may also have cognitive issues and/or learning disabilities, requiring an increased need for interventions and supportive services to reach their goals (Zhang, Ho & Kennedy, 2014).

The SB adolescents are also concurrently grappling with school and other life decisions, making it a very difficult time to accomplish these new tasks and sever the bonds that the pediatric providers and families have developed over the years. Ultimately, the SB adolescent typically fails to engage proactively in self-initiated care, and this becomes even more problematic as the SB young adult moves over to the adult medical model. There are major differences between pediatric and adult practice, which can contribute to the confusion, dissatisfaction, and poor advocacy of a SB patient. For one, pediatric care management is family centered; focusing on growth and development, with a proactive approach utilizing shared decision-making to prepare for the future. In contrast, adult health care attempts to manage illness and disease, and generally concentrates on the individual. Providers caring for adults are often unfamiliar with and lack knowledge of pediatric congenital problems. These adult providers also have a preference for interacting with an autonomous patient, responsible for their own self-care (White, McManus, McAllister, & Cooley, 2012).

Parental Influence

SB children are born with a very serious anatomic defect, and the parents are immediately forced to make major medical and healthcare decisions starting in infancy. Early on, parents assume significant responsibility for the care needs of their child with SB, and thus may find it difficult to relinquish decision making to the adolescent, who may desire independence, but who may also have limited understanding. The parents

often view the SB teen as incapable of understanding their condition or managing their healthcare, as reported on readiness assessment questionnaires (Sawicki, Kelemen, & Weitzman, 2014). This in turn leads to parental overprotectiveness and a subsequent “learned helplessness” by the SB teen (Holmbeck et al., 2002). Furthermore, the parents tend to have lower expectations of their child’s abilities if they have not received adequate education on how to increase the child’s self care abilities (AAP, AAFP, ACP & TCRA, 2011). Parents must acquire sufficient knowledge of the transition plan and should be encouraged to increase their child’s involvement during this process (Reiss, 2012).

Healthcare Transition Process

Transitioning to adult care for adolescents with special health needs is a comprehensive process that should be planned and initiated early with a gradual increase in youth participation and responsibility. The SB adolescents and their families often feel inadequately prepared to move forward in the transition process because the multidisciplinary clinics have insufficient time or resources to deal with all the important transitional issues. The literature strongly supports that a designated coordinator, who serves as the bridge between the pediatric and adult providers, is key to assisting with this process (Kaufmann-Rauen et al., 2013). Adult and pediatric providers should also initiate on-going medical discussions and share other pertinent information for several months prior to the transfer of care. Transitioning the adolescent and young adult SB patient moves them away from the comprehensive care team into unfamiliar territory, where the multidisciplinary adult SB clinics are in short supply and where fewer physicians are available to provide this specialty level of care. Since these adult

providers do not have adequate training or the available clinic time required to evaluate SB patients, they are less likely to enroll a SB patient into their practice. In addition, there is a negative impact attributable to the fact that SB patient have higher costs associated with their care and require more resources (Davis, et al, 2014).

Purpose and Goals

Healthcare transitional planning for the SB adolescent is quite complex as it requires the consideration of multiple factors: patient readiness, knowledge, self-care deficits, resources, adequate healthcare coverage, access to appropriate specialty care, advocacy and support. The primary objective of this project is to evaluate the feasibility of implementing an NP facilitated formal transition program for adolescents with Spina Bifida, ages 15 to 19 years. The project aims were to identify gaps in transition readiness and knowledge in SB adolescents and their caregivers, and to develop appropriate interventions.

Setting

This transition project was implemented in a pediatric outpatient specialty clinic in Northern, CA, part of a larger pediatric hospital system which serves a sizeable geographic area. This site is a designated California Children's Services (CCS) Regional Center with a multidisciplinary team providing specialty and routine follow-up care. The SB adolescents are evaluated every 4 to 6 months by a team consisting of pediatric specialists in physical medicine and rehabilitation, orthopedics, and urology, to provide developmentally appropriate care. This team is also supported by a PNP, who provides clinical coordination, education and care management, as well as a licensed clinical social

worker, who provides support to the parents and child through counseling and assisting with connecting them to appropriate resources in their community.

The PNP in this clinic has direct care experience with this large SB patient population and has known many of these children for their entire lives, which contributes to a trusting relationship. The SB patient appointments routinely consist of urologic tests, laboratory studies, and radiologic imaging occurring throughout the day, which allowed adequate time for the Transition Readiness and SB Knowledge Assessments to occur during breaks between these appointments. The program involved direct interaction of the PNP and adolescent SB patients and caregivers during their clinic visits. The assessment tools identified gaps in both readiness skills and knowledge, therefore setting the stage for individualized and developmentally appropriate interventions. NP's are well positioned to bridge the pediatric and adult care service lines, promoting quality improvement in the transition process and making a significant impact.

Conceptual Model

This evidence-based project was implemented based on several principles of the Chronic Care Model (CCM). The CCM emphasizes improvement in the quality of care provided to patients with chronic illness and systems that allow collaboration between providers (Wagner et al., 2001). This Chronic Care Model is multi-layered, and transition represents one area that is facilitated by this model with the primary focus on self-care management. Transitions of care are periods of great vulnerability and risk in our health care system. The lack of preparation, planning, coordination and support during the transition from pediatric primary and specialty care to adult focused care can lead to lack of follow up, poor clinical outcomes, and increased health care costs (Swanson, 2010)

Ethical Considerations

This project was initially sent to the Shriners Headquarters Division in Tampa, FL. and their research board determined that this program qualified as a quality improvement project. The local Shriners Hospital for Northern CA is affiliated with University California Davis Medical Center (UCDMC) and utilizes their Institutional Review Board (IRB) for authorization. After a process review and further questioning regarding the involvement of minor children, UCDMC approved this initiative and granted permission to disseminate de-identified clinical findings. The University of San Diego's (USD) IRB also granted permission for this project.

Intervention and Implementation

SB adolescents, ages 15-19 years, were identified as potential participants through the electronic health record (EHR) prior to their routine clinic appointments. There were no exclusions for gender, race or ethnicity as the instruments were provided in both English and Spanish. Teens with documented cognitive impairment met inclusion criteria if they were able to independently complete the assessment forms. The project involved administering the Got Transition Readiness Assessment to both the teen and their parent / caregiver and the PNP further provided a SB knowledge assessment to each of the SB youths. The SB Knowledge Quiz was given before and after the educational session. Then the PNP critically evaluated the test results and individualized the necessary educational interventions based on gaps appearing in readiness and knowledge revealed by the assessment tools. SB experts and professionals on the Advisory Council, as well as input from adult SB patients, developed a *Health Guide for Adults Living with Spina Bifida* (2005) that assisted with the structural components for the educational

interventions used in this project. There are many health issues for SB young adults and this project centered on seven specific domains of this complex condition which included: general SB condition, VP shunts, bladder and bowel management, skin, reproductive, latex allergy, and future health care needs. The PNP augmented the teaching of the adolescents by providing a verbal review, visual handouts and instruction on the use of technology to locate appropriate websites to provide further information. The majority of patients were able to complete the assessments in one day, however, the teens with cognitive impairment often required a second session on another day for the educational intervention and SB Knowledge post-test.

Assessments

Readiness assessments are good indicators that assist with identification of the teen's knowledge, decision-making and self-care management and when consistently evaluated they can be used for personalized transition planning to develop the appropriate skill set (Zhang, Ho, & Kennedy, 2014; Schwartz et al., 2014). The readiness assessment questionnaire was further comprised of two main categories: Health Condition ("My Health"), which included 10 items, and Healthcare Utilization ("Using Healthcare"), which included 14 items. The check boxes were labeled: *Yes, I know this, I need to learn, or Someone needs to do this..who?* Since transition assessments are known to potentiate successful transition management, the individual results were discussed with the SB adolescent and their parents/caregivers. The SB adolescents and parents used these discussions to identify lack of understanding, or barriers that would prevent the accomplishment of these various tasks. The youth were further engaged in this process by setting future goals for independence to facilitate

improving their readiness skills through actual practical experience. The parents were also encouraged and supported in their role to gradually relinquish control and increase their teen's autonomy in self-care management of tasks such as initiating medication refills and bladder care supplies. A very important educational aspect was the facilitation of creating a resource binder, computer document, or phone contacts that list the various care agencies and supply vendors for easy reference. The parents and/or PNP, mentored the teens on how to prepare for these particular calls, simulated the process, and then facilitated the adolescent in performing the task.

The SB Knowledge Test consisted of 22 questions encompassing both multiple choice and true/false items. The construct of this quiz was developed by content experts from our SB team and from information obtained from the Spina Bifida Association (SBA) website. The SB test utilized questions to assess general SB condition knowledge, as well as to identify their problem solving ability by presenting scenarios related to the key issues requiring medical attention. On average, it took the SB teen approximately 15 to 20 minutes to complete the assessment, but the adolescents with cognitive impairments required 30 minutes.

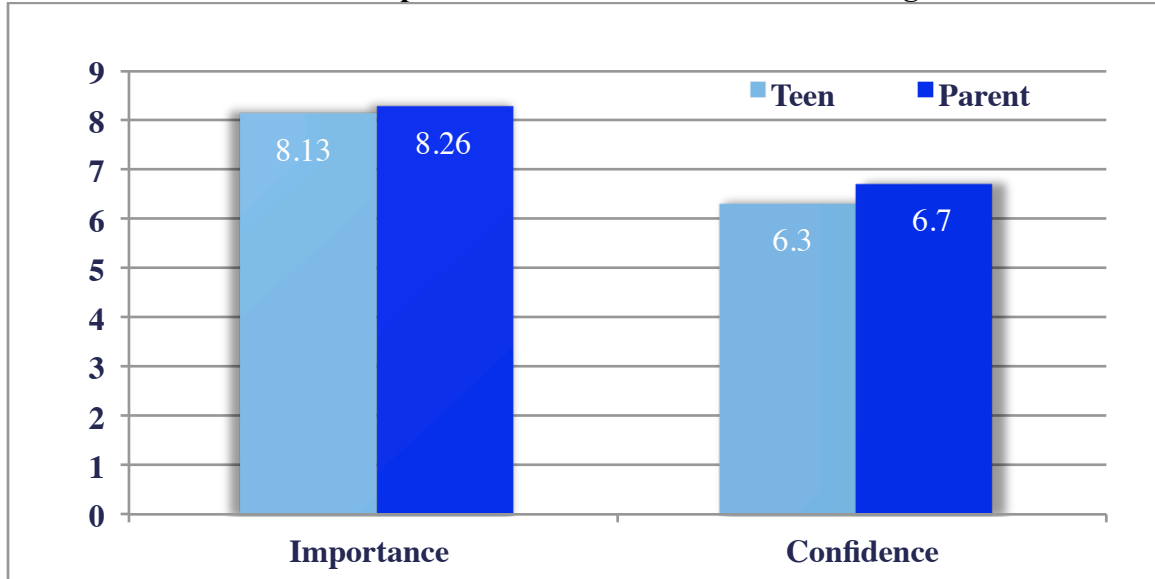
Results

This transition program included a total of 23 participants with completion of all the program elements; 2 teens were unable to complete the SB Knowledge post-test within the designated timeframe and therefore are not included in the final analysis. (See Appendix: Table 1 Demographics and Table 2 Cognitive and Caregiver Status). Of the adolescent transition participants, 83% were born with a myelomeningocele, and 17% had a diagnosis of a lipomeningocele. The adolescent

group consisted of 74% with a VP shunt, and 26% not requiring a VP shunt. The SB participants were further classified into 3 cognitive subgroups: 1.) regular classroom and receiving passing grades (57%), 2.) mild delay and receiving resource support for math and/or reading (26%, and 3.) moderate delay as enrolled in special education classes (17%). The majority of the caregivers who attended the appointment were mothers (53%), yet another interesting outcome was that several fathers (26%) were identified as primary caretakers of the adolescent. If possible, both parents were encouraged to attend the appointment and complete the readiness assessment, for which 17% did, however only the mothers were used for comparison in reporting this data to maintain consistency.

All participants and their parents completed the Got Transition Assessment forms. I deliberately chose this transition instrument for its simplicity, recognizing that some SB adolescents struggle when there are too many options for selection. This tool utilizes validated questions on “Transition Importance and Confidence” scored on a 10-point Likert scale. The parents rated how important it was for their child to prepare for transition and how confident they felt about their child’s ability to prepare for the change to adult medicine. The teens also rated the same questions related to their perception of the importance of transition preparation and their own ability to transfer into adult care. The parents and teens were consistent and closely rated the importance of transition, parents rated this 8.26 versus the teens at 8.13. However, their confidence in the teen’s ability to successfully achieve transition goals fell to 6.7 for the parents, and to 6.3 for the adolescents.

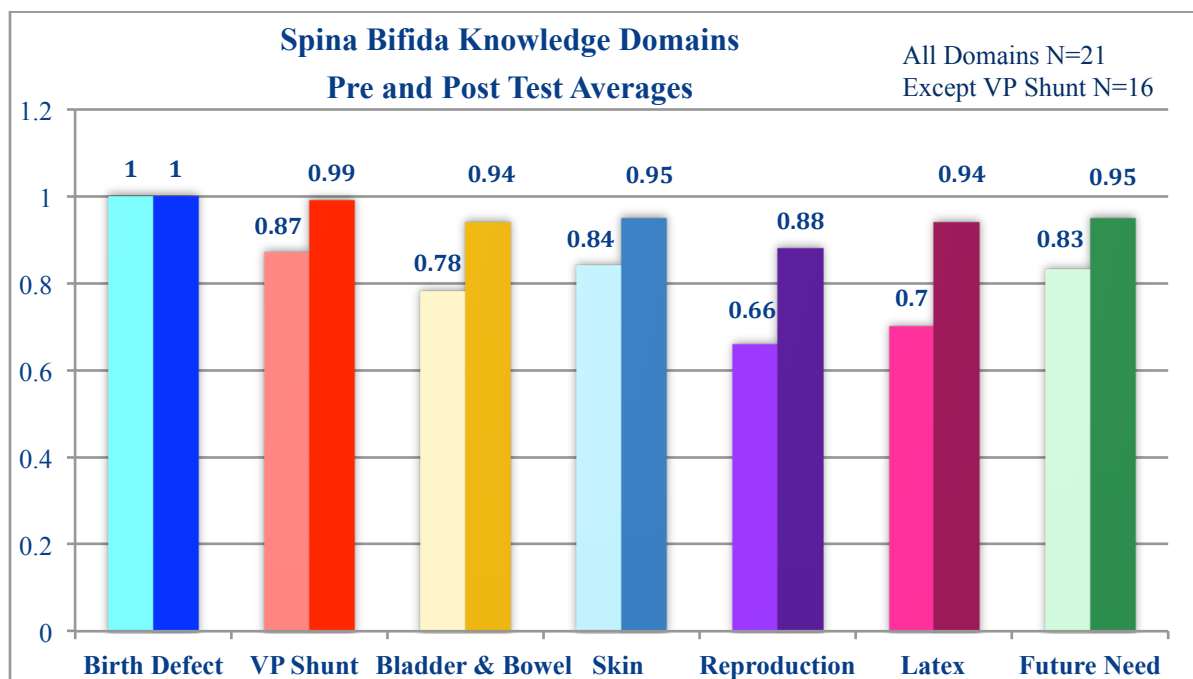
Teen and Parental Views of Importance of Transition Preparation and Confidence in Achieving Outcomes



The results for readiness assessment skills related to *Health Condition* revealed that the 3 lowest rated were: 1.) Can explain his/her medical needs to others 2.) Carries important health information with him/her (insurance card, allergies, medications) and 3.) Understands how healthcare privacy changes at 18 years of age. Of note, item 3 drew the poorest scores. The second category, *Healthcare Utilization*, revealed the following deficiencies: 1.) Teen knowing how to complete medical forms 2.) Teen having a plan to keep health insurance after age 18 and 3.) Teen is able to make his/her own doctor appointments. This later category produced the lowest scores. The PNP verified these findings through verbal dialogue, and identified that the SB adolescents demonstrated a true lack of understanding regarding changes in healthcare privacy at age 18, and the majority of the participants did not know how to complete medical forms or make a health care appointment. During this project, the teens projected a willingness to participate, but the lack of experience and increased anxiety about performing certain self-care tasks prevented them from advancing these skills. The checklist of readiness

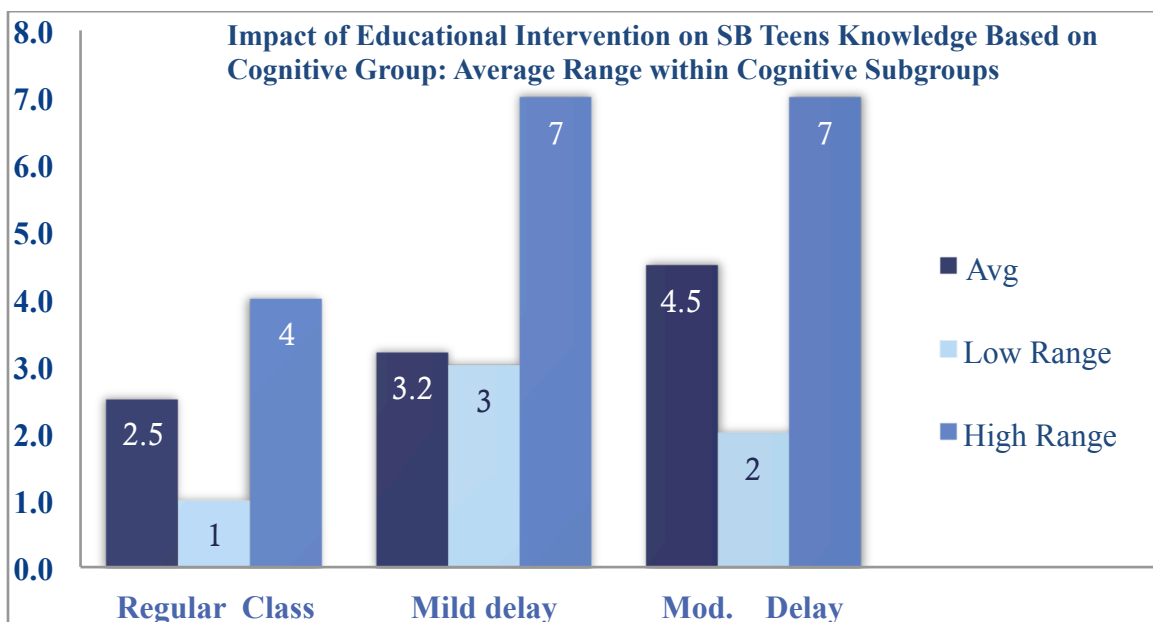
skills clearly facilitated the parents understanding of the progress that their child would need to make in order to succeed as they enter the adult care model. Confirming this was the fact that many of the parents requested a blank copy of this assessment form to use as a reference guide, which demonstrated their willingness to participate in the transition process when provided with this guidance.

Overall, the SB teens did well on the SB Knowledge test, and many of them stated that they were able to solve the particular scenarios if they had prior experience with the identified problem. Of the seven SB specific domains, Reproduction and Latex allergy were the lowest scoring items on the pre and post-test. The reproductive issue was not surprising since many of the SB parents are particularly uncomfortable discussing matters of sex and reproduction with their teens. The lack of knowledge regarding latex allergy was a surprising and concerning finding since the team consistently provides extensive education on this topic as this is a critical and potentially life-threatening issue for these young adults.



The SB teens seemed to be particularly savvy with the use of their cell phones, and this assisted with their education by creating SB condition specific lists and bookmarks for appropriate healthcare websites. They were also given permission to call the NP with questions and any follow-up concerns, which many of the adolescents did. This area of engaging the youth in managing their own care proved to be very rewarding as setting and attaining goals for their care increased their confidence, and also demonstrated their capabilities to their parents.

This EBP supported the unique inclusion of all SB teens that were capable of independently completing the assessments providing increased insight into their important needs of this population. It was discovered that the teens in the mild and moderate categories required additional time to complete the written assessments, and their understanding improved greatly with verbal instruction. The results showed dramatic improvements on the pre and post-tests of the SB teens with cognitive delays. This improvement in SB knowledge scores was both surprising and encouraging as it showed that the interventions were effective.



Despite the overall program success, there were situations where it became clear that a few of the adolescents were not going to be capable of managing their care. This, however, opened the door for further conversations with their parents about setting up a future advocacy plan either through guardianship and/or conservatorship. One of the fathers spoke about being extremely grateful for this opportunity, which gave him the ability to arrange a modified independence plan for his son's future.

In conclusion, this pilot project demonstrates the successful integration of an evidence-based health care transition program into a SB multidisciplinary outpatient clinic. Formal transition programs are lacking for youth with multiple and complex diagnoses in specialty clinics due to lack of time and resources; the role of the NP required experience, coordination, flexibility and organizational support to incorporate healthcare transition. SB young adults must learn to manage their self-care and anticipate future health concerns in addition to dealing with cognitive impairments and other simultaneous life events. The challenges presented with these complex health conditions require ongoing follow up. NPs can play a pivotal role in the development, education, implementation, and translation of this very important healthcare transition process.

References

- American Academy of *Pediatrics*, American Academy of Family Physicians, American College of Physicians & Transitions Clinic Report Authoring Group. (2011). Supporting the health care transition from adolescent to adulthood in the medical home. *Pediatrics*, *128*, 182-200. <http://dx.doi.org/10.1542/peds.2011-0969>
- American Academy of *Pediatrics*, American Academy of Family Physicians and American College of Physicians-American Society of Internal Medicine. (2002). A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*, *110*, 1304-1306.
- Applebaum, M. A., Lawson, E. F., & von Scheven, E. (2013). Perception of transition readiness and preferences for use of technology in transition programs: Teen's ideas for future. *Int J Adolesc Med Health*, *25*, 119-125. <http://dx.doi.org/10.1515/ijamh-2013-0019>
- Bloom, S. R., Kuhlthau, K., Van Cleave, J., Knapp, A. A., Newacheck, P., & Perrin, J. M. (2012). Health care transition for youth with special health care needs. *Journal of Adolescent Health and Medicine*, *51*, 213-219. <http://dx.doi.org/10.1016/j.jadohealth.2012.01.007>
- Burke, R., & Liptak, G. (2011). Providing a primary care medical home for children and youth with spina bifida. *Pediatrics*, *128*, 2011-2219. <http://dx.doi.org/10.1542/peds.2011-2219>
- Centers for Disease Control and Prevention. (2006). *Spina bifida: Data and statistics*. Washington, DC: Government Printing Office.

Child and Adolescent Health Initiative. (2009-2010). *National Survey of Children with Special Health Care Needs*. Retrieved from:

<http://www.childhealthdata.org/docs/cshcn/ outcome-6>.

Davis, A., Brown, R., Lounds-Taylor, J., Epstein, R., & McPheeters, M. (2014).

Transition care for children with special health care needs. *Pediatrics*, *134*, 900-908. <http://dx.doi.org/10.1542/peds.2014-1909>

Holmbeck, G., Johnson, S., Wills, K., McKernnon, W., Rose, B., Erklin, S., & Kemper,

T. (2002). Observed and perceived parental overprotection in relation to psychosocial adjustment in preadolescents with a physical disability: The mediational role of behavioral autonomy. *Journal of Consulting and Clinical Psychology*, *70*, 96-110.

Kaufmann-Rauen, K., Sawin, K. J., Bartelt, T., Waring, W. P., Orr, M., & O'Connor, C.

(2013). Transitioning adolescents and young adults with a chronic condition to adult healthcare-An exemplar program. *Rehabilitation Nursing*, *38*, 63-72.

<http://dx.doi.org/10.1002/rnj.74>

Le, J. T., & Mukherjee, S. (2015). Transition to adult care for patients with spina bifida.

Phys Med Rehabil Clin N Am, *26*, 29-38.

<http://dx.doi.org/10.1016/j.pmr.2014.09.007>

Lemly, D. C., Weitzman, E. R., & O'Hare, K. (2013). Advancing healthcare transitions in

the medical home: tools for providers, families and adolescents with special healthcare needs. *Current Opinion Pediatrics*, *25*, 439-446.

<http://dx.doi.org/10.1097/MOP.0b013e3283623d2f>

- Liptak, G., & El Samra, A. (2010). Optimizing health care for children with spina bifida. *Developmental Disabilities Research Reviews, 16*, 66-75.
- Liptak, G. S., Garver, K., & Dosa, N. P. (2013). Spina bifida grown up. *Journal of Developmental & Behavioral Pediatrics, 34*, 206-215.
<http://dx.doi.org/10.1097/DBP.0b013e31828c5f88>
- Lollar, D. J. (2001). Spina Bifida Association of America “Learning and Spina Bifida” Fact Sheet. Retrieved from www.spinabifidaassociation.org
- McManus, M. A., Pollack, L. R., Cooley, W. C., McAllister, J. W., Lotstein, D., Strickland, B., & Mann, M. Y. (2013). Current status of transition preparation among youth with special needs in the United States. *Pediatrics, 131*, 1090-1097.
<http://dx.doi.org/10.1542/peds.2012-3050>
- Mukherjee, S. (2007). Transition to adulthood in spina bifida: Changing roles and expectations. *The Scientific World Journal, 7*, 1890-1895.
- National Healthcare Transition Center: Got Transition. (2014). *Current assessment of health care transition activities for transitioning youth to adult health care providers* [Six Core Elements of Health Care Transition 2.0]. Retrieved from www.GotTransition.org
- National Institute of Health. (2013). *National Institute of Neurological Disorders and Stroke: Spina bifida fact sheet* (13-309). Washington, DC: Government Printing Office.
- O’Hara, L.K., & Holmbeck, G.N. (2013). Executive functions and parenting behaviors in association with medical adherence and autonomy among youth with spina bifida.

Journal of Pediatric Psychology 38, 675-687.

<http://dx.doi.org/10.1093/jpepsy/jst007>

Reiss, J. (2012). Health care transition for emerging adults with chronic health conditions and disabilities. *Pediatric Annals*, 41, 429-435.

<http://dx.doi.org/10.3928/00904481-20120924-16>

Reiss, J., & Gibson, R. (2002). Health care transition: Destinations unknown. *Pediatrics*, 110, 1307-1314.

Sarris, C. E., Tomei, K. L., Carmel, P. N., & Gandhi, D. D. (2012).

Lipomyelomeningocele: Pathology, treatment, and outcomes. *Neurosurgery Focus*, 33, E-3. <http://dx.doi.org/10.3171/2012.7.FOCUS12224>

Sawicki, G. S., Kelemen, S., & Weitzman, E. R. (2014). Ready, set, stop: Mismatch between self-care beliefs, transition readiness skills, and transition planning among adolescents, young adults, and parents. *Clinical Pediatrics*, 53, 1062-1068.

<http://dx.doi.org/10.1177/0009922814541169>

Sawyer, S. M., & Macnee, S. (2010). Transition to adult health care for adolescents with spina bifida: Research issues. *Developmental Disabilities Research Reviews*, 16, 60-65. <http://dx.doi.org/10.1002/ddrr.98>

Schwartz, L. A., Daniel, L. C., Brumley, L. D., Barakat, L. P., Wesley, K. M., & Tuchman, L. K. (2014). Measures of readiness to transition to adult care for youth with chronic physical health conditions: A systematic review and recommendations for measurement testing and development. *Journal of Pediatric Psychology*, 39, 588-601. <http://dx.doi.org/10.1093/jpepsy/jsuo28>

- Spina Bifida Association of America (2005) Health guide for adults living with spina bifida. [http:// www.spinabifidaassociation.org](http://www.spinabifidaassociation.org)
- Wagner, E. H., Austin, B. T., Davis, C., Hindmarsh, M., Schaefer, J., & Bonomi, A. (2001). Improving chronic illness care: Translating evidence into action. *Health Affairs*, 20, 64-78.
- White, P. H., McManus, M. A., McAllister, J. W., & Cooley, W. C. (2012). A primary care quality improvement approach to health care transition. *Pediatric Annals* 41, e91-e97. <http://dx.doi.org/10.3928/00904481-201204-06>.
- Zhang, L. F., Ho, J. S., & Kennedy, S. E. (2014). A systematic review of the psychometric properties of transition readiness assessment tools in adolescents with chronic disease. *BMC Pediatrics*, 14(4), 1-11. <http://dx.doi.org/10.1186/1471-2431-14-4>
- Zuckerman, J. M., Devine, K. A., & Holmbeck, G. N. (2010). Adolescent predictors of emerging adulthood milestones in youth with spina bifida. *Journal of Pediatric Psychology*, 36, 265-276. <http://dx.doi.org/10.1093/jpepsy/jsq075>

Appendix A

Table 1 Demographic Data for SB Transition Program

Participants	23
Male	52%
Female	48%
Age Range	15-19 years
Race / Ethnicity	
Filipino	4%
Hispanic	35%
Indian	4%
Caucasian	57%
Lesion Level	
Myelomeningocele (open)	83%
Lipomeneningocele (closed)	17%
VP Shunt	74%
No VP Shunt	26%

Table 2 Cognitive Status and Caregivers

Cognitive Factors	
Regular Class	57%
Mild Delay (Resource Assistance)	26%
Mod. Delay (Special Ed. Services)	17%
Primary Caregivers	
Mothers	53%
Fathers	26%
Both parents	17%
Grandparents	4%

Concluding Essay

“Reflections on Growth in Advanced Practice Nursing Role ”

As I reflect on my growth over the past two years at the University of San Diego, I see the period as rich with new knowledge and professional development. While traveling from Sacramento to San Diego every week, I was energized by the anticipation of new academic pursuits and the interaction with the scholarly faculty at this inspiring institution.

The days were long and significant effort went in to my doctoral preparation, starting with the completion of the DNP curriculum. A variety of courses were offered and I will discuss the highlights for areas of significant growth. I have developed further insight into health policy and the potential impact on Advanced Nursing Practice. I appreciate the efforts by our APRN nurse leaders and fully understand the importance of supporting professional organizations to continue lobbying for full scope of practice. Importantly, the early curriculum also focused on the essentials of literature review and translation of the scientific inquiry to the development of an evidence-based project (EBP). The elements of project planning were critical to designing and developing the numerous phases of this important project.

The DNP capstone project was both exciting and challenging, and by far became the most rewarding aspect of my development as a future DNP. There were many aspects of this process that provided new knowledge and increased leadership skills. The Institutional Review Board (IRB) is an informative and valuable experience that required persistence and patience. During the implementation phase, I learned to be flexible and manage clinic time more efficiently. After six months of project implementation and data collection, the next step was to analyze. The data analysis is where I was taught several new skills and began to see the positive outcomes of this EBP. The process of preparing for my stakeholders presentation required a

review of the background and evidence of the problem, practice innovation, results, conclusions and implications for clinical practice. I learned how to organize the project components and present a concise overview that would assist with translating this new knowledge and findings. The presentation of the EBP transition project to the students, faculty and stakeholders was very rewarding. I am passionate about improving the care and quality of life for children with special needs and I think this resonated to the audience.

The poster presentation also required assembling the important pieces to create a pictorial overview of the DNP capstone project. Attending the Western Institute of Nursing (WIN) allowed further sharing of this information with other academic professionals. During the poster presentation there was positive feedback, which helped me to visualize how my hard work paid off and how it benefitted both the patients as well as my educational development. I fully appreciate the clinical and faculty mentoring that I received during the project development, implementation and dissemination phase. My faculty mentor provided superb guidance and her expertise was invaluable.

One of the major accomplishments of my DNP education experience is that I definitely improved my writing skills. The coursework involved composing many papers with the added benefit of faculty critiques. The courses, together with the capstone project, also enhanced my leadership skills. Ultimately, I gained a new perspective of academic achievement and a desire to expand this knowledge to attain professional goals.