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Quality of Life Among Young Adults With Spina Bifida

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ABSTRACT

Approximately 1,500 infants born in the United States each year are diagnosed with Spina Bifida. Spina Bifida is a congenital disorder that affects the spinal cord and neurological function. Improved medical treatment has allowed a longer life expectancy for patients with Spina Bifida, and an increasing rate of these patients are surviving through pediatric clinics and preparing for the transition into adult care. Although the number of patients preparing for the transition into adult care continues to increase, there continues to be a scarcity of literature relevant to this population. Furthermore, there is currently no systematic, evidence-based method that reliably assists young adults with a successful transition and long-term health maintenance. This study seeks to fill that gap in literature and provide suggestions for better informed social work evidence-based practice. Existing data from 46 patients in a transitional urology clinic at a pediatric hospital in the southwestern United States was used in this current study. Participants were asked to complete three questionnaires addressing their transition readiness level, quality of life (QoL), and sexual function. Demographic information was collected by the clinic social worker during the patient's clinic visit. Appropriate parametric and nonparametric analyses on transition readiness and quality of life were completed with the latest version of SPSS. Female participants tend to report themselves as mastering more skills to independently maintain their health than males. Participants identified physical barriers as the most significant limitation associated with their condition.

Quality of Life Among Young Adults With Spina Bifida

A Thesis

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Master of Science

In Social Work

By

Leah Bonita Colsch

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This thesis is dedicated to the medical staff and patients that have contributed to this study. Their efforts in beginning this research will help bridge the gap in current literature on this important topic. They will pave the way for social work and medical practice to improve patient satisfaction and health as we hope the findings will promote patient medical compliance.

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CHAPTER I

INTRODUCTION

Approximately 1,500 infants born in the United States each year are diagnosed with Spina Bifida, a congenital disorder that affects the spinal cord and neurological function (Centers for Disease Control and Prevention, 2015; Greenley, 2010; Peny-Dahlstrand, Åhlander, Krumlinde-Sundholm, & Gosman-Hedström, 2009; Spina Bifida Association, 2015; West, Brodie, Dicker & Steinbeck, 2011). Spina Bifida is most commonly diagnosed prenatally, but in some cases after birth (National Institute of Health, 2015). There are four types of Spina Bifida, and all leave patients with some level of permanent physical limitations (Schoenmakers, Uiterwaal, Gulmans, Gooskens, & Helders, 2005; Spina Bifida Association, 2015; Stringer et al., 2015; Verhoef et al., 2005). There is not enough scientific evidence to pinpoint a cause of this condition. Due to the brain and spinal cord damage brought on by Spina Bifida, a majority of patients with Spina Bifida will have neurogenic bladder or lack control of their bladder (De Jong et al., 2008; National Institute of Health, 2016; West et al., 2011). Patients with this chronic condition may require more medical oversight than other children their age.

Parents and providers of patients with Spina Bifida are often very involved throughout the patient's life due to the high level of care required to maintain the patient's health. This level of involvement can cause increased stress and a variety of emotions during the patient's transition into adult care as parents and pediatric providers learn to relinquish responsibilities to the patient (Colver et al., 2013; DiFazio, Harris,

Vessey, Glader, & Shanske, 2014; Geerts, Van De Wiel, & Tamminga, 2008; Jensen et al., 2015; Rutishauser, Akre & Suris, 2011; Rutishauser, Sawyer, & Ambresin, 2014; Scal & Ireland, 2005; Stringer et al., 2015). Dr. Hadley Wood outlined this process in six core elements: transition policy, transition tracking, transition readiness, transition planning, transfer of care, and transfer completion (Wood, 2014, p. 14). The patient's and family's experience is affected by the success in completing each step. If the transition is unsuccessful, the number of patients completing regular visits with their adult provider decreases and ultimately put these patients at a higher risk of complications and visits to urgent care facilities (Stephany et al., 2015).

Studies have examined the effectiveness of different transition models by looking at various clinics and their medical providers' ability to address the needs of patients with a chronic condition. The programs varied on the medical information discussed with the patient, the multidisciplinary team makeup, the age the transition process is first introduced, and the duration of the transition process. The focus of all models is to prepare these patients to manage their own healthcare (Betz, 1998; Casanova & Park, 2013; Dogba et al., 2014; Fair, Sullivan, & Gatto, 2010; Kreindler & Miller, 2013; Olds et al., 2012; Pai & Ostendorf, 2011; Sawyer et al., 1998; Sawyer & Macnee, 2010; Wood, 2014). These studies have consistently found that the program's policies, composition, and length are all factors in the patient's future in adult care. While there is not a standardized transition process among urology clinics, medical providers in these studies have identified the need to rigorously follow patient outcomes after intervention and the factors outside of their medical care that affects patients' overall perception of life (Betz, 1998; Casanova & Park, 2013; Dogba et al., 2014; Fair et al., 2010; Kreindler & Miller,

2013; Olds et al., 2012; Pai & Ostendorf; 2011; Sawyer et al., 1998; Sawyer & Macnee, 2010; Wood, 2014).

These studies surveyed medical staff, patients' parents and patients of all ages, conditions, and various countries to identify the elements in the transition most significant to them. The patients have varied experiences in a wide range of transition programs. Self-management, vocational skills, insurance, and education on the patient's specific condition are all topics identified by the parents and patients as the most significant items to be discussed during the transition (Casanova & Park, 2013; Greenley, 2010; Jensen et al., 2015; Kreindler & Miller, 2013; Liptak & Samra, 2010; Pai & Ostendorf, 2011; Scal & Ireland, 2005; Stringer et al., 2015). These findings align with the purpose of Healthy People 2020, a 10-year agenda for improving the Nation's health, which mandates, "youth with special health care needs receive the services necessary to make transitions to all aspects of adult life including adult health care, work and independence" (Healthy People 2020, 2016, MICH 31.2). These topics create the three themes found in the literature regarding transition.

The adjustment to adulthood, learning to live independently and maintain one's own health can be a difficult process for some patients. This is likely impacted by the fact that many pediatric patients with a chronic condition receive assistance with their daily care regimen from their family and do not learn how to manage their daily care prior to transition (Dellon et al., 2013; DiFazio et al., 2014; Fair et al., 2010; Olds et al., 2012; Pai & Ostendorf, 2011; Scal & Ireland, 2005; Stringer et al., 2015). One study reported that providers should consider a patient's cognitive level when determining the most appropriate time to begin the transition with the patient (Fair et al., 2010). The

patients, providers, and families must also use their experience to determining the most appropriate interventions to address these needs for each individual patient. It is important that young adults with congenital conditions, their providers, and their families all have a strong understanding of the young adult's medical needs by the completion of the transition. Studies have found that patients with a chronic condition are most successful in maintaining their physical health as an adult if they fully comprehend all physical and mental aspects of their diagnoses (Dellon et al., 2013; Ferris et al., 2012; Sawin & Bellin, 2010; Wood, 2014). In 2012, the Academy of Science suggested that “an assessment of the patient's comprehension can be done by three empirically based principles: (1) evaluation of an individual's preconceptions, (2) provision of new information at an appropriate level and in an appropriate format, and (3) opportunities for the learner to apply the new information” (as cited in Ferris et al., 2012, p. 745).

Multiple studies have also found that multidisciplinary and interdisciplinary clinics are most effective in facilitating successful transitions (Dellon et al., 2013; Jensen et al., 2015; Scal & Ireland, 2005). The patients surveyed in the current literature discussed the significance of being able to meet with professionals representing multiple disciplines. Patients were able to discuss a wide range of their concerns including transportation assistance, community resources, adult providers available, adult insurance options, and the progression of their condition with the appropriate personnel (Betz, 1998; Casanova & Park, 2013; Dellon et al., 2013).

Finally, since 1973, survival rates for patients with Spina Bifida have increased by 20-30% resulting in more patients with Spina Bifida surviving to adulthood (Casanova &

Park, 2013). As with other adults, people with Spina Bifida's quality of life depends on many factors including sexual ability, social interactions, and the ability to live independently. These become key topics discussed during transition (Cullerès, Sugranyes, & Bolívar, 2005; Sawin & Bellin, 2010; Shiomi, Hirayama, Fujimoto, & Hirao, 2006).

Despite these findings, there is still a scarcity of literature regarding the factors affecting the quality of life of patients with Spina Bifida and how they affect the patient's ability to sustain their health as an adult. This study attempts to close this gap as this interdisciplinary team looks at another model of the transition process specifically for patients with Spina Bifida. The goal of this preliminary study is to identify the factors affecting quality of life among patients with congenital urologic conditions preparing to transition from pediatric to adult healthcare. A series of questionnaires were distributed to patients of a transitional urology clinic in the southwestern United States. Participants identified the surgeries, treatments and medications they have already received prior to their transition; factors positively contributing to their quality of life; and suggestions for an easier transition. This research team hypothesized that the quality of life for patients with neurogenic bladder, primarily Spina Bifida, will be affected by a number of psychosocial issues and not simply the number of surgeries they have had. This will be an attempt to identify those specific psychosocial factors impacting this patient population and the factors' level of influence on this process. The information gathered will inform other medical providers and multidisciplinary teams in the development of improved approaches to current transition processes.

CHAPTER II

LITERATURE REVIEW

In 2002, the American Academy of Pediatrics made a consensus statement declaring the goal of transition “as maximizing lifelong functioning and potential through the provision of high quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood” (p. 1304). Transitioning into adult care is a complex, multi-step process in healthcare initiated by the patient’s primary providers during adolescence (Dellon et al., 2013; Kreindler & Miller, 2013). The transition process may require a longer amount of time to fully prepare the patient and their family for transition into adult care. This process will consist of addressing: the patient’s current condition, the patient’s daily needs, the process of acquiring insurance, and the potential need for future surgeries when appropriate (Fair et al., 2010; Kreindler & Miller, 2013; Olds et al., 2012; Rutishauser et al., 2011). Many transition models have been evaluated in current literature and found to have benefits and deficits as identified by the patients and their parents. Although there is a scarcity of literature addressing the transition for young adults with Spina Bifida, it is apparent that the transition process is important in assisting patients to successfully maintain their health independently.

The lack of literature suggests Spina Bifida is one of the less frequently studied chronic conditions. While there is currently no cure, improvements in medical management and technology has increased life expectancy for individuals with Spina

Bifida. Self-management has been increasingly discussed with patients and families as patients prepare to transition into the adult world (Ridosh, Braun, Roux, Bellin, & Sawin, 2011; Verhoef et al., 2005). Spina Bifida affects physical and neurological development, which makes the quality of life evaluation important during the patient's transition. Patients with Spina Bifida may face social stigma with their disability, so it is important to know what social factors are impacting the patient's quality of life during this phase of their life (Barf et al., 2009; Chan, Adams, Irwin, Thiessen, & Sawatzky, 2010; Hayter & Dorstyn, 2014; Padua & Rendeli, 2004; Sawin & Bellin, 2010; Sawyer & Macnee, 2010; Woodard, Belman, Walker, Kaplan, & Firlit, 1977). Some of these patients may need accommodations in order to live independently. Accommodations include adaptable vehicles, regular catheterizing, and physical therapy (Centers for Disease Control and Prevention, 2015; Chan et al., 2010; Cullerès et al., 2005; Greenley, 2010; Ridosh et al., 2011). These accommodations may be minimal for some patients. With that, there are still social factors that stigmatize those coping with this condition that are not being addressed.

There are few validated quality of life questionnaires specific to Spina Bifida (Chan et al., 2010; Lemelle et al., 2006; Sawin & Bellin, 2010; Schoenmakers et al., 2005). Those that do exist focus on physical health factors and not psychosocial factors. Thus, it is important a questionnaire is created that allows patients to identify social factors affecting their quality of life. This is significant in the transition process, as patients preparing for independent living may have less tangible, physical support than they had during their youth (Chan et al., 2010; Feldman et al., 2007; Sawyer & Macnee,

2010). Once social factors are identified, specialists can also address any social concerns during the transition in an effort to improve the overall quality of life of the patient.

Transitioning Into Adult Care With Patients of Chronic Conditions

In 2011, over 30% of youth aged 10 to 17 years old had been diagnosed with a chronic condition (Pai & Ostendorf, 2011). That year, 90% of those children were expected to live past 20 years of age, and medical technological advances have helped this percentage continue to increase (Pai & Ostendorf, 2011). Therefore, there is an increasing amount of adolescents preparing to transition into adult healthcare (Betz, 1998).

Betz (1998) explained the goal of transition planning “is to provide comprehensive, continuous health care that meets the adolescent’s developmental and psychosocial needs” (p. 98). Though there is no uniform transition program that is effective for all patients with Spina Bifida, this paper will utilize the framework presented by Hadley Wood, MD, in her article “Transitional Urology and Urological Congenitalism.” Research shows that medical providers and their patients have differing opinions on how to approach each of those elements.

Transition Policy

Wood (2014) believes there are two ways to improve the transition process: development of a more coherent policy guiding the process, and better education of staff. Development of policies would help to determine practitioners’ approach in guiding patients during transition. Multiple models have been evaluated in current literature, and those studies have found common themes.

In 2014, physicians at a pediatric orthopedic hospital conducted a study to analyze their transition program in an osteogenesis imperfecta (OI) clinic. Specifically, they found inconsistent transition exercises with patients and a decline in patients consistently completing follow-up appointments with adult providers. Providers suggested the implementation of a multi-site transition model with cross-site personnel would best resolve the issue of limited referral sources as well (Dogba et al., 2014). In that study, Dogba and colleagues (2014) established the following findings:

...a “one-size-fits-all” transition model for patients with OI would be inappropriate across, or even within institutions. Opportunities should be seized to create tailored, theoretically-sound transition programs that reflect patient preferences, especially those of young adults with complex and chronic health conditions. Alignment with other organizational activities should be considered, and ongoing evaluation of transition programming may be required. (p. 102)

Another study analyzed transition models for patients with Cystic Fibrosis, and discussed the Social-Ecological Model of Adolescent/Young Adult (AYA) Readiness for Transition (SMART) (Kreindler & Miller, 2013). This model consisted of two phases of care: pediatric-based care and adult-oriented care (p. 1225). During each phase, the transition readiness of the patient was evaluated using an 11-point questionnaire to assess: socioeconomic status, cultural influence, disease history, self-efficacy, expectations, and social relationships. This study found that transition readiness cannot be evaluated by one tool alone, and there are multiple additional factors effecting the success of each patient’s transition.

Studies addressing patients with a chronic condition agree that patients need a multidisciplinary team to address the patient's medical, psychosocial, and vocational needs (Casanova & Park, 2013; Greenley, 2010; Kreindler & Miller, 2013; Liptak & El Samra, 2010; Pai & Ostendorf, 2011; Sawyer et al., 1998). More than 750,000 adolescents with special health care needs enter adult care each year (Dellon et al., 2013; Jensen et al., 2015; Scal & Ireland, 2005). Patients' primary providers have been expected to help each of all of patients develop the decision-making skills necessary to manage their own medical care as an adult. Thus, providers and patients have recommended designating a specific transition coordinator as one of the positions on this multidisciplinary team. This transition coordinator would address work very closely with the patients in identifying the patient's goals of the transition and assisting them in developing the skills to maintain appointments and regularly taking medications on their own (Dellon et al., 2015; Jensen et al., 2015; Pai & Ostendorf, 2011).

Patients state that providers should consider the patient's age is also when deciding the starting date of the patient's transition. Some providers suggest beginning earlier in adolescence in order to allow the patient more time to fully comprehend the future transition. Patients suggested waiting until they were old enough to grasp the complexity of their condition (Fair et al., 2010; Kennedy et al., 1998; Pai & Ostendorf, 2011; Rutishauser et al., 2011; Rutishauser et al., 2014). Parents and patients identified the most significant topics addressed during the patient's transition: education on their chronic condition, identification of available adult providers, access to health insurance, and self-management skills. The transition model needs flexibility in the timespan specifically, which depends on the volume of information that must be communicated to

patients to assist them in living independently. The transition coordinator would complete multiple evaluations throughout the transition to see the patient's transition readiness and assess patient's concerns.

Transition Tracking and Monitoring

These evaluations performed by the transition coordinator would make up the Transition tracking and monitoring. Transition tracking and monitoring is a phase that also consists of establishing criteria, registry, and electronic medical record (EMR) incorporation (Wood, 2014). The transition coordinator would play an important role in managing the enrollment of patients, maintaining an individualized plan for each patient, monitoring the patient's progress throughout the transition, and overseeing the appointment scheduling and attendance (Dellon et al., 2013; Jensen et al., 2015; Pai & Ostendorf, 2011). The coordinator would also serve as the main point of contact and liaison when transferring medical data between families and both pediatric and adult providers. This position was suggested by patients of various chronic conditions in light of the organizational issues they had experienced during their transition, because they believed the coordinator would assist their pediatric medical providers in preparing for a smoother transition.

Patient populations will have varying levels of intellectual capacity within, and thus transition models need flexibility in order to address the needs of all their patients. Patients surveyed in current literature states the importance of providers considering their patients' developmentally cognitive age versus their chronological age when initiating the transition (Fair et al., 2010). The patients state the cognitive age would help providers plan the timespan of the transition. Developmentally, patients with a history of trauma

face additional difficulty with the transition into adult medical care (Pai & Ostendorf, 2011). For people with chronic conditions, trauma can include a history of major surgery or living with a condition that results in permanent disability. The chronological age range of the respondents in the literature is 14 and 25 years old, and the participants recommend beginning the transition into adult care between ages 16 and 20 (Barf et al., 2009; Brumfield & Lansbury, 2004; Ridosh et al., 2011; Rutishauser et al., 2011; Rutishauser et al., 2014; Stringer et al., 2015; Verhoef et al., 2005). Thus, there is a difference in opinion between providers and patients on the most appropriate age to begin the transition process.

As providers start enrolling patients into their transition program, it is important they are aware of the level of parental involvement at that time. Research has found that patients with over-involved parents tend to be less independent and less prepared for the transition (Dellon et al., 2013; Feldman et al., 2007; Geerts et al., 2008; Kreindler & Miller, 2013; Pai & Ostendorf, 2011; Ridosh et al., 2011; West et al., 2011). Parents have stated that being involved in their child's medical care serves as their own coping mechanism and buffer as they prepare for their child's transition to live independently (Feldman et al., 2007; Geerts et al., 2008).

Respondents have also said the complexity of the patient's condition is important to take into consideration when monitoring the transition. Studies have found the amount of psychosocial and physical needs affect the patient's transition readiness. One study found that patients with more psychosocial needs are more likely to discuss the transition process with their parents and have a stronger relationship with their medical providers than those with minimal medical issues (Scal & Ireland, 2005). The medical team's

knowledge of their condition assists the providers in addressing all medical needs and communicating these to the patient's adult providers (Dogba et al., 2014; Kreindler & Miller, 2013; Ridosh et al., 2011; Sawyer et al., 1998). This communication is important as adult care is different from pediatric care. Adult medical care is more disease-centered, patient-focused and puts a greater emphasis on medical health than psychosocial needs versus pediatric care, which focuses on the family's comprehension (Sawyer et al., 1998). Without proper communication, the ability of adult providers to provide adequate care to these patients is limited.

Due to the multiple factors that influence a patient's transition readiness, it is difficult to establish a set timeline and program for transition that are applicable to all patients. This leaves the hospital with the challenging task to create appropriate measures throughout the transition that are adjusted each patient's physical and social situation.

Transition Readiness

Transition readiness, as described by Wood (2014), addresses the assessment of a patient's biopsychosocial situation, the development of a transition plan based off of the assessment, and the documentation of any progress the patient makes throughout the transition. There are multiple goals these medical staff would base their evaluations off of. When evaluating patient readiness, providers should assess the patient's knowledge of medical needs, ability to plan and make appointments, and self-advocacy skills (Dellon et al., 2013; Olds et al., 2012). Two studies have broken down these three categories.

One of the primary goals to achieve before patients complete their transition is their total comprehension of their diagnosis and medical needs. Typical assessments of patient comprehension listed in current literature focused on patient's understanding of

their condition's effect on their sexuality and reproduction, and the patient's demonstration of responsibility for their own healthcare. Providers also look for the patient's knowledge of medical supplies and prescriptions, the supply company, the purpose of supplies, and how to maintain or order these supplies (Dellon et al., 2013; Olds et al., 2012). Parents and patients agreed that the best assistance in achieving this goal of full comprehension is through multiple educational materials. The education materials could consist of pamphlets, online resources and presentations discussing the patient's specific condition. Patients and parents hope these materials would help facilitate discussion between each other during the transition (Dellon et al., 2013; Olds et al., 2012). Patients found the more time they had to discuss provided the patient with more opportunities to ask questions regarding their medical condition. The parents stated the more time let them become more comfortable with decreasing their amount of involvement in their child's daily medical care.

A second important skill identified by providers is the patient's ability to maintain their health and make routine appointments (Dellon et al., 2013; Olds et al., 2012). Once patients fully understand their physical condition and its potential consequences if they non-adhere, it is expected that patients demonstrate with their treatment plan. Patients may include taking their medications as prescribed, finding transportation to appointments, and scheduling appointments around work or school. Current literature has suggested strong communication between the medical and social service providers when assisting the patient in finding appropriate adult providers. The communication would help the patients achieve this goal as the established relationship between the

patient and adult provider would encourage the patient to maintain their medical appointments as an adult (Betz, 1998; Dellon et al., 2013).

Lastly, providers should assess the patient's self-advocacy. There are multiple factors the providers are looking at when assessing the patient's self-advocacy skill. Providers are evaluating the patient's ability to communicate medical needs, including different prescriptions or non-ordinary medical visits, or if they need a trip to the ER. An example of self-advocacy in this situation is patient's ability to identify an abnormal symptom and knowing when to schedule an irregular visit or if they need adjusted medication. For patients with Spina Bifida, abnormal symptoms may include pain, constipation, or stiffness in their limbs. Providers in current literature state they also look to see how patient's confidence to live independently and meet with a new provider (Dellon et al., 2013; Olds et al., 2012). The providers will often wait to hear a statement of readiness by the patient before proceeding with the planning of the physical transition. Another component of the self-advocacy criteria includes the patient's knowledge on maintaining insurance coverage (Dellon et al., 2013; Jensen et al., 2015; Pai & Ostendorf, 2011). Within the United States specifically, the recent provision of the Affordable Care Act affects young adults who are now able to be covered by their parent's insurance until the age of 26. This assists with the transition by providing insurance coverage for six additional years for many patients. However, some patients' parents are also uninsured, which leaves the patient to figure out their insurance coverage prior to the physical transition.

Transition Planning

When planning any event, it is important to identify any barriers one may face. Barriers identified by patients during their transition include: lack of educational materials, multidisciplinary team makeup, preparation for insurance changes, or individualized transition plans. Patients states these barriers had a negative effect on their transition (Brumfield & Lansbury, 2004; Dellon et al., 2013; Jensen et al., 2015; Pai & Ostendorf, 2011; Rutishauser et al., 2014). Transition planning is the phase that seeks to resolve these barriers. This element consists of creating the actual plan of care, preparing patients for this plan, and identifying their future adult providers (Wood, 2014).

Preparing the patient to live independently has been found to be more achievable with the coordination of other resources. This is why communication continues to be a key systematic component in successful relationships with adult providers (Dellon et al., 2013; Fair et al., 2010; Sawyer & Macnee, 2010; Rutishauser et al., 2014). Some transition programs facilitate multiple visits with multiple adult providers to help the patient choose their future primary physician (Sawyer & Macnee, 2010). Once an adult provider is chosen, communication between pediatric and adult providers helps develop the transition plan as they discuss the patient's condition, the patient's ability to maintain self-care, the level of parental involvement, and each person's expectations and concerns (Betz, 1998; Brumfield & Lansbury, 2004). Communication assists with all providers having the same understanding of patient's current transition readiness. This will ease patient and parent resistance to transition as well (Betz, 1998; Dellon et al., 2013; Geerts et al., 2008; Pai & Ostendorf, 2011; Rustishauser et al., 2011; Sawyer & Macnee, 2010). Once communication is established, patients would ideally establish a relationship with

their adult provider, set up their next appointment without their pediatric provider, and have the contact information for all companies needed to supply their own medical equipment and prescriptions (Fair et al., 2010; Olds et al., 2012; Sawyer & Macnee, 2010).

Patients identify financial issues regarding their insurance coverage as the main cause of their medical non-compliance (Pai & Ostendorf, 2011). Today, the Affordable Care Act has assisted multiple patients gain insurance coverage, but these insurance plans can severely limit the pool of adult providers from which patients can choose. Another area of concern exists of patients who have a gap in their coverage and may be forced to delay their medical treatment (Pai & Ostendorf, 2011). The role of the providers to prepare the patient for the transition would involve assisting the patient in finding an adult provider that accepts the insurance plan they have as an adult before the transfer can be completed.

Transfer of Care

The transfer of care from a pediatric to adult clinic is a pivotal moment, and is the physical transfer of the patient's medical history to the adult provider. This transfer will need to be completed prior to the first appointment with the adult provider (Wood, 2014). It is important the difference in pediatric versus adult care is communicated to the patient prior to the transfer. Pediatric clinics identify the support system provided in the family, and they typically have less emphasis on developing patient decision-making abilities, as they depend on parental decisions. In adult care, providers can only depend on the patients themselves to give accurate reports of their health and support system (Sawyer et al., 1998). One study found that 96% of patients with Spina Bifida were satisfied with

the care from the pediatric clinic (within a span of 10 years after transition) while only 52% were satisfied with their adult care. Communication is shown to have an influence on the patient's satisfaction of the transition as well. Ninety-six percent of patients in the same study had a family physician, but only 61% felt that their physician understood Spina Bifida (Chan et al., 2010). Thus, it is important that transfer of patient information is completed with thorough communication between providers and patient to ensure the patient follows up with adult care.

Transfer Completion

Transfer completion has been designated as 36 months after patient is connected with an adult provider and consistently attending medical appointments (Colver et al., 2013, Pai & Ostendorf, 2011). Evaluations of the patient's medical compliance will be evaluated at this 36-month mark. If the transition was not completed successfully, then the patient has failed to follow up with adult medical providers, and considered medically non-compliant (Wood, 2014). It has been suggested that adolescents with chronic conditions are less likely to follow up with adult providers, especially if they have not had the proper transition preparation (Colver et al., 2013; Pai & Ostendorf, 2011; Sawyer & Macnee, 2010). This has been shown to lead to more emergency visits, progression of condition, as well as multiple other complications of their condition (Colver et al., 2013). Three factors have been identified that are the most likely to influence an incomplete transition: ongoing confusion, not knowing whom to contact, and the inability to choose their adult providers and/or compare their services (DiFazio et al., 2014).

A disjointed transition may predispose patients to future issues with medical compliance. One study found that daily self-management deteriorated in 54% of

adolescent patients with chronic conditions once transferred as an adult (Pai & Ostendorf; 2011). The decrease in daily care and appointment attendance ultimately resulted in a fragile physical condition. Patients with Spina Bifida in this situation would likely lose their bladder control and develop pressure ulcers (Dellon et al., 2013; Kreindler & Miller, 2013; Pai & Ostendorf, 2011). These studies reported that the patient's age, psychological functioning, and insurance status are all associated with medical non-compliance as well.

Adolescents with Spina Bifida are among the growing population preparing for the transition into adult care. They have a complex chronic condition and typically are established with a consistent urologist for the first 18 years of their life (Schoenmakers et al., 2005; Verhoef et al., 2005; West et al., 2011). Thus, this transition can be a nerve-racking phase in the patient's life. It is critical these adolescents have the proper amount of time to prepare for their medical needs, find an adult urologist they prefer, address insurance options, and schedule their future appointments. As the number of patients with Spina Bifida preparing to transition rises, it is important to note the specific medical needs of these patients that must be addressed during the transition.

Urologic Congenital Conditions Including Spina Bifida

Spina Bifida is a complex permanently disabling condition that affects eight babies born each day in the United States (National Institute of Health, 2015; Spina Bifida Association, 2015). It is a neural defect and discoverable during pregnancy (West et al., 2011). The name literally means "split spine" and occurs when the spinal column does not form completely (Greenley, 2010; Spina Bifida Association, 2015).

There are four types of Spina Bifida: Occult Spinal Dysraphism (OSD), Spina Bifida Occulta, Meningocele, and Myelomeningocele, also known as “Spina Bifida Cystica” (National Institute of Health, 2015; Spina Bifida Association, 2015). OSD is often spotted by a dimple, lumps, or red spots on the baby’s lower back. Those diagnosed with OSD may not show physical and neurological symptoms until later in life. Spina Bifida Occulta has earned its nickname, “hidden Spina Bifida”, by having very minimal symptoms, making it less likely the parents or caregivers will identify any concerns in the patient’s childhood. The 15% of patients that have this condition have seemingly normal spinal cords and nerves. Meningocele occurs when a spinal cord pushes through the spine and creates a fluid sac. Patients with Meningocele have disabilities that are typically non-life-threatening, but harmful enough to produce significant physical delays including difficulty with feeding, swallowing, breathing, and upper extremity mobility. Spina Bifida Cystica is the most severe form, in which both the spinal cord and nerves push their way through the spine. A fluid sac develops at their protrusion site, and excess fluid may remain in the skull and put increased pressure on the brain. This form requires much monitoring as increased intracranial pressure has the potential to cause brain damage if left untreated.

The extent of the physical issues brought on with Spina Bifida makes this condition very complex (Liptak & El Samra, 2010; Sawyer & Macnee, 2010; Spina Bifida Association, 2015). Neurogenic bladder is a common characteristic of people with Spina Bifida that can lead to renal damage and failure as one of the major issues (De Jong et al., 2008). Patients with a neurogenic bladder can have a paralytic or overactive pelvic floor (De Jong et al., 2008). Patients with Spina Bifida may also face urinary tract

infections, paralysis, and fractures as a complication from losing feeling in their legs, hydrocephalus, and complex spinal complications (Barf et al., 2009; Chan et al., 2010; Kalfoss & Merkens, 2006; Liptak & El Samra, 2010; Schoenmakers et al., 2005; U.S. National Library of Medicine, 2015; Verhoef et al., 2005). Patients with Spina Bifida are at an increased risk of death from chronic renal or respiratory failure, pressure area associated sepsis, or shunt dysfunction (West et al., 2011). The complexity of this condition may require much medical oversight throughout the patient's life.

Low bladder pressure and clean intermittent catheterization are necessary to maintain the patient's renal health (De Jong et al., 2008). Urologic, neurologic, and orthopedic surgeries begin in the second and third days of patients' lives and may continue if their condition is not managed by catheterization and proper medication (De Jong et al., 2008; Greenley, 2010; U.S. National Library of Medicine, 2015; West et al., 2011; Wood, 2014). These surgeries often aim to relieve bladder pressure and protect renal functioning. Patients with an overactive pelvic floor may require an augmentation through either ileocystoplasty or colcystoplasty (De Jong et al., 2008). Patients with a paralyzed pelvic floor may require bladder neck surgery. Specific sling suspensions may also be necessary to improve bladder continence. Patients with hydrocephalus require a surgery to implant a shunt. Vesicostomy and clam cystoplasty are other surgical procedures to improve bladder drainage which prevents reflux and further kidney damage. Multiple providers from different specialties are often needed to address all of the Spina Bifida patient's needs.

The Spina Bifida Association (2015) has supported the findings of these current literature addressing the transition of patients with chronic conditions by publishing the

following statement on its website: “The best way to manage Spina Bifida is with a team approach. Members of the team may include neurosurgeons, urologists, orthopedists, physical and occupational therapists, orthotists, psychologists, and medical social workers” (para. 21). Patients with this complex condition may face multiple barriers during their transition, and a multidisciplinary team will be able to most effectively psychosocial concerns with the goal of improving the patient’s quality of life.

Of the limited literature addressing adolescents with Spina Bifida, there are more studies addressing their patient’s the sexual history of patients with Spina Bifida more than their quality of life. As the life expectancy for patients with Spina Bifida continues to improve, sexual history has become a central focus for medical providers (Cullerès et al., 2005; Dellon et al., 2013; Kennedy et al., 1998; Shiomi et al., 2006; Verhoef et al., 2005).

Sexual History

The sexual function of patients with Spina Bifida has become a newly researched topic in the last 18 years. Research has shown that urinary incontinence interferes with sexual relationships (Cullerès et al., 2005; De Jong et al., 2008; Dellon et al., 2013; Kennedy et al., 1998; Shiomi et al., 2006; Verhoef et al., 2005; Wood, 2014). Patients with Spina Bifida may use intermittent catheters to drain their bladders and assist with their urinary incontinence. Diapers or pads may also be used as a precaution for patients with urinary incontinence. The urinary incontinence has been found to have a negative effect on the patient’s sexual experience (Chan et al., 2010; Chowanadisai et al., 2013; Cullerès et al., 2005; Lemelle et al., 2006; Ridosh et al., 2011; Verhoef et al., 2005; West et al., 2011). Patients’ lumbar neurological level or sacrum have found to also affect their

sexual function (Cullerès et al., 2005). For male patients, urologists have performed surgeries connecting the ilioinguinal nerve to the dorsal nerve of the penis to improve the penile sensation in males, and it has shown positive results (De Jong et al., 2008). Of young adults with Spina Bifida that have sexual relationships, it has been found that females tend to be more sexually active than males (Cullerès et al., 2005). Both the quality of the transition and sexual function are factors that impact a Spina Bifida patient's quality of life, but other studies have found additional psychosocial factors that have an influence on one's quality of life.

Quality of Life Factors

“Quality of life” is defined by the World Health Organization (WHO; 1997) as “an individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, and concerns” (p. 1). This definition encompasses the person's physical health, psychological health, ability to live independently, personal relationships, self-image, and ability to interact with others. The current study for this paper focuses on health-related quality of life, which looks at the impact of one's health status on their quality of life (Office of Disease Prevention and Health Promotion, 2010). Past research highlights the health-related quality of life of patients with a chronic condition. Health-related quality of life is important during transition as patients' self-perception is highly influenced by others' behaviors towards them, which can be negative if there is a stigma attached to their condition (Fair et al., 2010; Kalfoss & Merckens, 2006; Sawin & Bellin, 2010). This can be especially true for adolescents. In addition to the increased time spent on daily urinary care, Spina Bifida can have a detrimental effect on patients' physical and mental

capabilities. Some patients with Spina Bifida may have a difficult time achieving their desired employment opportunities and social involvement due to their medical needs. Despite these struggles, there are few validated health-related quality of life instruments developed for patients with Spina Bifida (Parkin et al., 1997).

Most quality of life evaluations focus on the patient's physical health, but fail to explore the emotional, social, and school domains that need to be taken into consideration (Barf et al., 2009; Lemelle et al., 2006; Sawin & Bellin, 2010). Typically, providers focus on the impact the condition and medical care have made on patients' life. By using this approach, one misses the external factors that affect patients and the problems that may require medical provider's assistance. Medical researchers have found the quality of life of patients decreases as the complexity of physical disability increases (Greenley, 2010; Padua & Rendeli, 2004; Verhoef et al., 2005; Woodard et al., 1977; Wright, 2007). Social stigmas often accompany physical and mental delays, and there is a higher rate of mental health disorders amongst patients with Spina Bifida compared to those without a chronic health condition (Feldman et al., 2007; Padua & Rendeli, 2004; Sawin & Bellin, 2010; Sawyer & Macnee, 2010; Schoenmakers et al., 2005; West et al., 2011). Multiple studies found depressive symptoms present in over half of adolescent and adult patients with Spina Bifida (Dicianno et al., 2015; Essner & Holmbeck, 2010; Feldman et al., 2007). These studies suggest interventions should be provided earlier to reduce symptom severity. Interventions that encourage development of self-esteem and self-management have been found to build resilience among patients with Spina Bifida and prevent depressive factors (Hayter & Dorstyn, 2014; Ulus et al., 2012). Race and ethnicity do not

have a significant effect in patients with Spina Bifida's ability to take care of themselves (Chowanadisai et al., 2013; Kalfoss & Merkens, 2006).

The patient's mental health or mental delay can affect patients' mobility, education, employment, day-to-day function, and ultimately their potential to live independently (West et al., 2011). One study found that only 16% of their participants were living independently by the age of 21 years old. Over 33% had a higher level of education beyond high school, and 53% of those did not have a consistent job. 71% of the total participants did not have a significant other (Barf et al., 2009). Factors that negatively affect one's quality of life include difficulty finding adaptable vehicles, inconvenience of Medicaid payments across state lines, limited social opportunities, sexual limitations, the challenges obtaining higher education or finding a job (Kennedy et al., 1998).

Minimal research in the past had addressed the physical and social limitations on patients' ability to live independently. In a series of papers presented in the urology session at the American Academy of Pediatrics in 1976, the extent of incontinence in patients with Spina Bifida is outlined. Urinary tract infections (UTIs), hypertension, and renal scarring are more common in patients with Spina Bifida (Woodard et al., 1977). These conditions are associated with delayed renal growth and urinary incontinence. Patients have reported these complications as stressors that inhibit their independence (Verhoef et al., 2005; Wright, 2007). Patients may need to complete intermittent catheterization several times a day, complete daily bowel programs, and perform daily skin checks to identify signs of injury (Greenley, 2010). Some provider's may focus on

improving the bladder function in order to improve the patient's quality of life (Sawyer et al., 1998).

By focusing on incontinence, providers have taught patients skills to keep up with their catheterization and skin care starting in elementary school (Greenley, 2010). The problem is that patients are found to still have physical and financial limitations that keep them from completing school and/or living independently (Peny-Dahlstrand, et al., 2009; Wright, 2007). One study surveyed patients with Spina Bifida over the course of 10 years after transition (Chan et al., 2010). They found that 96% graduated from high school, but only 63% enrolled into post-secondary, and 30% were never employed. Eighty-five percent continued to live with their parents, and 48% had never been in a relationship. Fifty-eight percent used a wheelchair for ambulation, and 74% of participants used public transit. Ninety-three percent were satisfied with life in general, but there are barriers that keep them from being completely independent.

During a literature analysis completed by Sawin and Bellin in 2010, 41 articles addressing the quality of life of patients with Spina Bifida were examined to get a picture of the validated questionnaires used during these evaluations. Of the 41, they found 17 tools, and 11 of those focused on Health Related Quality of Life (HRQOL). Two of these measures are consistently confirmed by researchers to paint an accurate, holistic picture of the patient's quality of life. The SF-36 measure addressed physical functioning, role limitations, pain, social functioning, mental health, vitality, and general health. The WHQOL-BREF measure addressed the physical, psychological, social, and environmental domains (Sawin & Bellin, 2010). The other single item/generic measures,

although most commonly used, do not collect all the information necessary to assess one's quality of life.

Ultimately, there is research addressing quality of life of patients with a chronic condition transitioning into adult care, but a gap remains in research on the social factors affecting the quality of life of patients with Spina Bifida. Wood (2014) agreed and identified the following topics as a focus for further research for the urology population: medical risks, long-term effects of pediatric treatments, screening recommendations for bladder cancer, development of advanced training opportunities for urologists, and the quality of life in adulthood. This study will attempt to close this gap and explore quality of life as a more holistic picture of patients with Spina Bifida in the beginning stages of transitioning into adulthood.

CHAPTER III

METHODOLOGY

The current study is an exploratory descriptive design that used existing data from the transitional urology clinic at the Children's Health Specialty Clinics. Children's Health is a pediatric health care system based in Dallas, Texas. This clinic is located on the Dallas campus in the Outpatient Specialty Center. Children's Health opened in 1913, and has since grown to be one of the largest pediatric hospitals in the United States. It now holds 595 inpatient beds and the healthcare system includes 50 specialty clinics.

Setting

The young adult urology clinic, opened in 2013 as a partnership between Children's Health and the University of Texas Southwestern (UTSW) Medical Center. This interdisciplinary clinic was specifically designed to serve patients over 16 years old and diagnosed with Spina Bifida or neurogenic bladder, who have been discharged from their pediatric clinic. Patients in this clinic are able to meet with a pediatric urologist, registered nurses, and a social worker during their clinic visits.

Sample

Patients with a diagnosis of congenital urologic conditions were referred to the transitional urology clinic by Scottish Rite, a local pediatric clinic. They were referred after January 2013. After agency Institutional Review Board (IRB) approval (see Appendix A), patients over the age of 16 years old with a neurogenic bladder that attended a visit at the Children's Medical Center urology clinic and deemed mentally

competent were recruited to participate in this study. This study examined the answers provided by 46 consenting patients that had a clinic visit after September 15, 2013.

The sample consisted of 20 males and 26 females from the state of Texas. They ranged in age from 17 to 25 years old. Professional and educational levels varied among participants were broken down into four categories: preparing to graduate high school, studying in college, unemployed, and part-time or full-time employment. Although a majority of the patients in seen in this clinic are diagnoses with Spina Bifida, there is a small percentage of patients with other conditions that caused their neurogenic bladder. All patients included in this specific study have some form of Spina Bifida.

Procedure

This clinic staff acquired consent (see Appendix B) of patients during their first visit at the clinic. These patients were asked to meet with the clinic social worker and complete three questionnaires (see Appendix C), which were completed by the participants during a single private visit and collected by the clinic staff. English and Spanish versions of the consent and three questionnaires were available. Staff offered assistance to write out participant's answers if participant had limited writing skills. Information collected from the social worker's visit was used to provide participant demographic information. Completed questionnaires were collected from February 2014 to present. No follow-up questionnaire on quality of life has been performed. The preliminary findings of this study have been presented at international urology conferences.

Additionally, clinic staff tracked the reasons for missed clinic appointments following referral from the facility where patients had received pediatric care prior to age 18.

As a Master of Science in Social Work candidate, this author shadowed Sarah Culver, social worker in this urology clinic, for a graduate practicum placement and expressed interest to join this study in September 2015. This author received approval from UTSW, Abilene Christian University, and clinic staff to assist in the analyses of these three questionnaires during her graduate placement.

The appropriate Children's Health IRB approval was forwarded to Dr. Megan Roth at Abilene Christian University on December 16, 2015. The IRB was officially approved by the university on March 28, 2016.

Materials

First of the three questionnaires was the Transition Readiness Assessment Questionnaire (TRAQ), a validated tool which allowed participants to self-evaluate their level skills needed to successfully sustain their health once transitioned to adult care. This questionnaire was developed in 2010 (Wood et al., 2014). The TRAQ contained 29 questions in two domains: skills for chronic condition self-management and skills for self-advocacy and health care utilization. Responses were scaled from 1 to 5 with higher numbers representing the participant's greater comfortability level in utilizing the specific skill: (1 = I don't need to do this, 2 = I don't know how but I want to learn, 3 = I am learning to do this, 4 = I have started doing this, 5 = I always do this when I need to). This overall scale has high reliability (Cronbach's alpha = .94). This medical team argues that the 29-item version is superior for patients with neurogenic bladder as it assesses the

use of, and payment for, medical equipment and supplies (i.e. catheters) while the newer version of TRAQ does not.

The second questionnaire was a non-validated four-item survey on the quality of life of the participants. This consisted of four open-ended questions asking participants to identify barriers associated with their condition, procedures that have positively and negatively affected their quality of life, and factors to improve their transition experience. This questionnaire was designed by Dr. Gwen M. Grimsby under the supervision of Dr. Micah Jacobs through UTSW

The last questionnaire was a 10-item, non-validated survey asking participants to describe their sexual history. This questionnaire was developed by Dr. Gwen N. Grimsby. Versions directed specifically to female or male participants were available. Answers ranged from identifying whether the situation does or does not apply to their current sexual activity. This will not be analyzed in the current study. It is currently being analyzed by another member of the research team for future publication.

In addition to completing questionnaires, participants were given the opportunity to meet with the clinic social worker during one of their clinic visits. During this visit, the social worker collected information on each patients' household makeup, education, current insurance plan, knowledge of their primary care provider and medical supplier, and their ability to identify sources of support and barriers to their care. Information reported during this visit was included in the study's consent.

There was no cost to the subjects and no payment to them for their participation.

Analyses

The TRAQ, Quality of Life questionnaire, and demographics of the participants collected by the social worker were analyzed for this study. This specific study required appropriate coding of participant answers. The latest version of SPSS was used during analysis under the supervision of thesis chair, Dr. Wayne Paris. Existing procedures were appropriate for parametric and nonparametric analyses. Parametric analyses were performed to find correlations between patient demographics and quality of life factors.

CHAPTER IV

RESULTS

A total of 46 patients participated in this study. All of these patients are diagnosed with a form Spina Bifida and some have neurogenic bladder. Ages of participants ranged from 17 years old to 25 years old. Of the 46 participants, 20 (43.5%) were male, and 26 (56.5%) were female. Participant's gender was based off of their natal gender as listed in their medical information. An independent samples *t*-test on the age of males and females was run (data not shown). The average age for male participants was 18.73 years, and the average age for females was 19.35 years. There was no significance in the age between male and female participants.

Frequency tests were run for the rest of the demographics collected during the social work consult. Thirty-nine percent of the 46 participants currently live in a house, 6% live in an apartment, and 4% live in a trailer. Thirty-seven percent lived with one parent while 28% lived with both, and about 7% lived with another person as their guardian. Thirty-seven percent were currently in college, 6.5% were still in high school, 10.9% had either a full-time or part-time job, and 8.7% were unemployed and not currently enrolled in any school. Education and work information was not provided by seven of the 36 participants. There were ten demographic profiles that had not been collected by the time of the analysis. The results of these tests are listed in Table 1.

Table 1

Participant Demographics

Variable	Total Sample	%
<u>Age</u>	17-25 years old	Mean: 18.7 years
<u>Gender</u>	<u>46</u>	<u>100.0</u>
Male	20	43.5
Female	26	56.5
<u>Housing*</u>		
Unknown	12	26.1
Apartment	3	6.5
House	18	39.1
Trailer	2	4.3
<u>Guardians**</u>		
Single Parents	17	37.0
Both Parents	13	28.3
Other	3	6.5
<u>Employment***</u>		
Employed	5	10.9
Unemployed	4	8.7
College	17	37.0
High School	3	6.5

Note. Missing: * $n = 11$; ** $n = 13$; *** $n = 17$. Mean age of participants is 18.7 years old. Range between 17-25 years.

Additional demographic information was collected during the social worker visit: patient's current insurance coverage, adult primary care provider (PCP) information, home health company information, medical supplier information, and size of support system. Insurance coverage was divided into coverage as an adult or coverage as a child. Participants were also asked to identify the name and contact information of their adult PCP, home health company, and medical supplier company if they had one. Frequency tests were performed to analyze the results of these additional questions. The results are listed in Table 2.

Table 2

Participant Characteristics

Variable	Total Sample	%
<u>Adult Insurance*</u>	46	100.0
Has adult coverage	13	28.3
No coverage	18	39.1
<u>Adult PCP**</u>		
No PCP	7	15.2
Does not know PCP	6	13.0
Knows contact of PCP	17	37.0
<u>Home Health Company***</u>		
No home health company	22	47.8
Has a home health company	2	4.3
<u>Medical Supplier***</u>		
No medical supplier	5	10.9
Does not know medical supplier	1	2.2
Knows contact of medical supplier	18	39.1
<u>Support System***</u>		
Identifies fewer than 2 supports	6	13.0
Identifies 2 or more supports	18	39.1

Note. Missing: * $n = 15$; ** $n = 16$; *** $n = 22$.

Twenty-eight percent of participants had already been approved for adult coverage, through either Medicaid or commercial insurance plans that would ideally cover them until at least the age of 26 years old. Thirty-nine percent did not have insurance coverage as an adult. Thirty-seven percent could identify their adult primary care provider and knew their contact information. Thirteen percent knew they had an adult PCP, but did not know their contact information. Fifteen percent did not have an adult PCP at the time of their visit. As for home health services, only 4% were receiving home health services. They could also could identify their contact information. Forty-seven percent did not require home health services. One participant (2%) could not identify their medical supplier company, but 39% could. Ten percent did not need a

medical supplier company. Lastly, participants were asked to identify multiple sources of support, such as family, friends, or groups through their religious institution. Thirty-nine percent could identify at least two people who could provide support with medical care by assisting with needs such as transportation to appointments. Thirteen percent were unable to identify two sources of support.

Additional information collected by the social worker was number of barriers the participant identified that are preventing them from maintain medical-adherence. Twenty-five participants (54.4%) denied any barriers to receiving the medical care needed. Two participants (4.3%) identified two or more barriers to receiving the quality medical care needed. Barriers identified included lack of consistent transportation, receiving incontinence supplies, and financial concerns such as impending loss of insurance coverage. This data is not shown.

Forty-four (97%) of the 46 participants completed the non-validated, 4-item Quality of Life questionnaire. All four questions were open-ended, giving the patients an opportunity to list multiple answers to each question. The first answer listed for each question was analyzed, as this researcher interpreted the first item listed for each question was the most important factor in the patient's perception.

The first question asked the participants to address the current barriers in their daily living. The answers provided were broken into 4 categories: physical barriers, transportation, reactions from others, and other. These were coded as 1-4 respectively. Those who left the answer blank were coded under "0." Examples of "physical barriers" included the limited ability to walk, play in sports, to bear children, dress themselves, limited flexibility, and the reoccurrence of urinary tract infections (UTI) and frequent use

of the bathroom. Answers coded under “transportation” included inability to drive or access buildings without wheelchair ramps. Examples of “reactions from others” included reports of people staring at them or the participant being bullied. Lastly, answers coded as “other” included the difficulty to find clothes that fit, frequent absence from school due to multiple appointments and other medical needs, having to wear diapers and multiple medications to manage, delayed mental capabilities. Thirty-four percent of male participants and 17% of females identified a physical barrier as the primary barrier. Additionally, 10% of females listed the primary barrier as reaction from others, and only 1 (2%) male participant listed reactions from others as a primary barrier. A chi-square analysis was completed, and the data is shown in Table 3.

Table 3

Chi-Square Comparison of Gender and Barriers to QoL

QoL	Physical	Transportation	Reaction from Others	Other	Sig.
<u>Gender</u>					No Sig.
Male	14	3	1	4	
Female	7	5	4	3	

Note. Total $n = 41$ answers reported.

The second question asked participants to identify the treatments, surgeries, procedures and medications that have had a positive effect on their quality of life. The third asked which of these had a negative effect. Surgeries and procedures were combined into one category. This researcher created another category, “medical appointments.” Treatments were coded as “1”. Surgeries and procedures were coded as “2.” Medical appointments were coded as “3.” Medications were coded as “4,” and those coded as “0” representing the patient stating “no/none” or left blank on the questionnaire. Treatments included therapy, catheterizing, and using a walker or leg

braces. Surgeries listed included bladder augmentation, spinal fusion, vesicostomy, and appendicovesicostomy (APV). Appointments consisted of annual check-ups, reminders of their appointments, and their primary doctors as factors. Medications listed included Ditropan, Enemeez, Kepra ER, Enablex, cone enemas, and Senna Prompt. A chi-square could not be performed due to value of zeros present in multiple categories. Thus, a cross-tab was performed to analyze the data for these two questions. Data for each question is shown in Tables 4 and 5 shown below.

Table 4

Comparison of Gender and Positive Medical Treatments on QoL

QoL	Treatments	Surgeries	Appointments	Medications
Gender				
Male	3	14	1	2
Female	3	12	0	1

Note. Total $n = 36$ answers reported.

Table 5

Comparison of Gender and Negative Medical Treatments on QoL

QoL	None	Treatments	Surgeries	Appointments	Medications
Gender					
Male	13	1	2	0	1
Female	9	0	4	1	2

Note. Total $n = 33$ answers reported.

Thirty-six (78%) of the 46 participants reported a treatment, surgery, appointment or medication as having a positive effect on their quality of life. Thirty-three (72%) of the 46 participants listed a treatment, surgery, appointment, or medication as having a negative effect on their quality of life. 22 (48%) of the 33 participants denied any treatment, surgery, procedure or medication as having a negative effect on their quality of

life. Fourteen (30%) males and 12 (26%) female participants listed a type of surgery or procedure first under positive effect on their quality of life.

The last question of the quality of life questionnaire asked the participants to identify ways the transition process could be improved to benefit them. Those that denied any changes were coded as a value of “1,” and those with suggestions for changes were coded as “2.” Suggestions for improvement included the following: assistance in connecting with therapy services, assistance in connecting with agencies to find employment, pediatric doctors sharing patient information and tips with adult providers, continued follow-up with patient after last appointment, using “smaller, non-medical words” during explanations, providing contacts to adult providers, providing assistance to transportation resources, and providing memory tools for the patient to maintain care. Exactly 22 (50%) of the 44 participants that completed the Quality of Life Questionnaire listed a suggestion for improvement with the transition process. Data is not shown.

Forty-two of the 46 participants completed the 29-item TRAQ questionnaire. This questionnaire provided answers in a Likert-scale form ranking from 1-5, asking the participant to rate their skills under each item from “I do not need to do this” to “I always do this” respectively. An independent samples t-test was run to compare the gender and transition skill level identified in this questionnaire. Data are shown in Table 6.

Table 6

Comparison of Gender and Transition Readiness

TRAQ	3*	5***	12**	13*	18**	22***
<u>Gender</u>	<u>M(SD)</u>	<u>M(SD)</u>	<u>M(SD)</u>	<u>M(SD)</u>	<u>M(SD)</u>	<u>M(SD)</u>
Male	1.88(1.329)	2.83(1.685)	2.21(1.560)	2.04(1.367)	2.50(1.588)	1.29(.955)
Female	2.83(1.505)	3.78(1.437)	3.61(1.614)	3.28(1.638)	3.78(1.396)	2.50(1.465)

Note. Male $n = 24$. Female $n = 18$. Missing value is 4. $*p < .05$. $**p < .01$. ^aLevene's test was significant at .003.

There were six questions that approached significance in this comparison: questions numbered 3, 5, 12, 13, 18, and 22. The third question asked “Do you pay or arrange payments for your medications?” The fifth asked, “Do you reorder medications before they run out?” The twelfth question asked, “Do you arrange for your ride to medical appointments?” The thirteenth question asked, “Do you call the doctor about unusual changes in your health (Ex. allergic reactions)?” The eighteenth question asked, “Do you keep a calendar or list of medical and other appointments?” The twenty-second question asked, “Do you make a list of questions before the doctor's visit?” In all of these questions, the female participants self-reported a higher skill level than male participants. At question number 22, the Levene's test approached significance at .003, thus the variance amongst both genders was minimal. This information is shown in Table 6.

A chi-square tests was run to compare the guardian makeup amongst male and females were run to determine if guardian makeup would be a factor in the participants' transition readiness level. Seven females reported to live with single parents, and 5 lived

with both parents. Ten males reported to live with single parents and 8 lived with both parents. The results are listed in Table 7.

Table 7

*Chi-Square Comparison of Gender and Guardians**

Guardians	Male <i>n</i> =	Female <i>n</i> =	Sig.
Single Parents	10	7	
Both Parents	8	5	
Total	18	15	No Sig.

Note. *Missing: *n* = 16.

CHAPTER V

DISCUSSION

Multiple trends were found throughout the analysis. The information gathered by the social worker provided the foundation of demographics and factors used during comparisons of barriers, quality of life and transition readiness. There was a non-significant correlation between the number of barriers identified by participants and compared to their age, gender, or guardian makeup. There was a non-significant relationship between genders and guardian makeup, thus we focused on comparison of the answers provided in the remaining questionnaires to genders.

Although there was no significant relationship found between gender and most significant barrier associated with having Spina Bifida, there was an interesting find in the number of females identifying reactions from others as their primary barrier. A majority of both males and females reported physical barriers as the most significant barrier to their quality of life. More males than females identified physical barriers, but more female than male respondents reported identified reactions from others as their primary barrier. This reflects that females tend to be more relationship oriented while males are more goal oriented during their adolescent stage, which would explain the difference in barriers (Beutel & Marini, 1995; Plunkett, Radmacher, & Moll-Phanara, 2000). This shows what limitations seem most important patients with Spina Bifida while they are young adults.

It is important to note that 23 of these participants listed multiple barriers in the first question. A majority of them identified two barriers, but five participants listed three barriers and three participants listed four or more barriers. This shows that there are multiple psychosocial factors affecting one's quality of life, rather than just their own medical needs.

When asked to identify medical procedures with a positive or negative effect, males and females identify more examples representing all categories as having a positive effect. There was a non-significant relationship between gender and medical treatments reported. Surgeries were the most frequently mentioned as having a positive and negative impact on their quality of life. Additionally, there was a non-significant relationship found between gender and suggestions for a better transition experience. The non-significant relations indicate male and female participants have had similar satisfaction levels with their medical procedures and their transition.

There was one statistically significant relationship found in the analyses of the TRAQ. A significant relationship exists between gender and participants transition readiness among study participants. This study found that females, at the time of their first visit in the transition clinic, confidence in utilizing the skills an independent adult would use to maintain their health than their male counterparts. This relationship also indicates females perceive themselves as more independent than their male counterparts.

Although not statistically significant, there were more females living with a single parent and more males living with both of their parents at the time of their visit. This could be an influential factor in the gender differences in transition readiness. In other words, males may lack in these skills due to continued dependence on others' assistance

with their medical care, as they reported to having more parental support throughout their life than the female participants.

It is important to note there were 38 patients referred to this clinic who were not included in the results of this study as they did not complete their scheduled appointments. Eleven of these patients identified lack of insurance coverage accepted at this hospital as the reason they did not attend their appointment. Eight of them were referred to or already being seen by another adult provider. One exceeded the age limit for participation in this clinic. This clinic was unable to contact and schedule a visit for the other 18 referred patients. Due to these reasons, the patients were listed as inactive and not considered in the analysis of this study

Limitations

These findings should be taken with caution as there were multiple limitations to this study. First, the results of this study are not generalizable to the whole young adults with Spina Bifida population. There was not a breakdown patient's level of physical and mental disability. This study was conducted at one pediatric hospital in the state of Texas. The small sample size provides results which are not generalizable. Future research could seek to analyze how the cognitive delay and level of physical disability impacts the patient's ability to successfully transition to adult care.

Multiple issues can also be pointed out with our questionnaires and response rate. Only one of the questionnaires being used in this study was validated, and thus the other questionnaire had an undetermined reliability and validity. There was also an inconsistent response rate among the questionnaires. Only a portion of the participants filled out the TRAQ, and a smaller portion filled out the quality of life questionnaire.

These questionnaires were also self-reported, which has potential for bias in our results. The time the questionnaires were filled out varied amongst the participants. Ideally, the questionnaires would have been filled out by the participants on their first visit in our clinic, but that was not the case for all of the participants in this study. It was not possible to use the point these participants were in their transition as a control in this study.

Strengths of our study include the use of a validated transitional survey, the prospective nature, and the inclusion of only patients with neurogenic bladder.

Future Implications

This study's findings can suggest adjustments to medical providers' approaches in assisting adolescents through the transition to adult care based on these findings. It is all medical providers' goal to treat patients with the best care and assist them during a transition to ensure they continue to receive quality care. The quality of care can increase as the needs of the Spina Bifida population continues to be studied. As the various types of priorities of young adults with Spina Bifida continue to be identified, this study informs the medical staff of goals that would be considered a priority to their young adult patients. able to target which resources and interventions to address the needs of patients, by considering their gender. Social workers can implement these results in multiple levels.

As presented in the current literature, there is currently no uniform way for medical providers to address the transition into adult cares that has shown to have total success for patients. Although each individual is unique, this study suggest females view themselves as more prepared for transition into adult care than males, but both genders

rated themselves as not successfully utilizing the skills consistently as evaluated in the TRAQ. On a micro level, social workers can communicate this finding to their medical team. Ideally, they could suggest the discussion of transition be initiated at a younger age for the patients to give them more time to develop the behavior of using the TRAQ skills consistently. They can advocate on their patient's behalf to adjust the timeline of the transition process—perhaps depending on the patient's gender. The social worker may have to use interventions that focus on teaching males these skills an earlier age for them. Our study also showed males to be more dependent on others to use the TRAQ skills to assist them. Social worker interventions must be focused on teaching the male patient how to use these skills independently rather than utilizing the skills for them.

Based off of these findings, the social worker may also be encouraged to initiate support groups led by patients with Spina Bifida that have successfully completed the transition. Adolescent males and females could learn from their appropriate adult counter-parts. These groups were identified as a need in a transition program by one study (Dellon et al., 2013). These mentor groups would focus on the development of independent living skills needed to make a successful transition. The lessons may hold a positive impact for the patients when they hear from adults with the same condition, who have already been through the process.

One of the core competencies of a social worker is to utilize and add to evidence-based practice. At the macro level, the clinic social worker could continue this research and pursue additional research ideas on Spina Bifida patients' quality of life. These are preliminary findings, and there is a scarcity of literature on this population. Since the population of patients aging into adult care continues to increase, it is important to

continue research in order to determine the best process for transition. Conducting research with those who have completed the transition will also give an idea of the percentage of patients that are able to maintain their health as an adult after a comprehensive transition process. As the results come about, the social worker should share these findings with other hospitals in order to reach more of this population or conduct multi-site studies to control the influence of the environment and team structure.

Social workers may also advocate for more funding for Spina Bifida research and resources at a macro level. With increased funding and awareness, outside agencies may be willing to donate some of their philanthropic hours to patients with Spina Bifida. Fundraisers may help hospitals create a better informational handout for the patients and families. More awareness may lead to more support groups as well. Peer-led support groups with connections to supportive agencies may assist the patients in completing the transition. The social worker's role as an advocate could help make improvements in the development of a successful transition model in order to maintain or improve the quality of life for patients with Spina Bifida.

Conclusion

This specific study was a preliminary, exploratory design completed to fill the gap in literature on the needs of patients with Spina Bifida transitioning into adult care. Existing literature continues to evaluate other current transition models with hopes of finding a successful transition design, where pediatric patients are successfully sustaining their health and medical compliance as adults. This study supports current literature and suggests a uniform approach for patients with Spina Bifida may not be appropriate due to a significant relationship between gender and level of skills needed for transition. Social

workers can use these findings to implement adjustments to their approaches of the transition process for each gender, then advocate for this population's needs at multiple levels.

As the number of patients with chronic conditions aging into adult care continues to increase, this study's focus will become an increasingly important topic in the medical field. There is a desperate need for more research on transitioning into adult care processes that addresses all psychosocial and medical needs of patients. Social workers and their medical team will use this research to guide their assessments in order to effectively address their patient's needs. The continuation of this study will strive to add to the existing literature, so this hospital and hospitals alike can improve its own approach to transition.

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APPENDIX A

IRB AUTHORIZATION

Version Date: 04/6/2015

Institutional Review Board (IRB) Authorization Agreement

UT Southwestern Medical Center (Institution A):
IRB STU 092013-034 FWA ~~16790~~ (FWA 00005087)

Abilene Christian University (Institution B):

IRB 00009869

The Officials signing below agree that Abilene Christian University may rely on the designated IRB for review and continuing oversight of its human subjects research described below: (check one)

This agreement applies to all human subjects research covered by Institution B's FWA.

This agreement is limited to the following specific protocol(s):

Name of Research Project: Transition Readiness and Quality of Life in Patients with Congenital Urologic Conditions

Name of Principal Investigator: Micah Jacobs

Sponsor or Funding Agency: UT Southwestern Medical Center

Other (describe): _____

The review performed by the designated IRB will meet the human subject protection requirements of Institution A's OHRP-approved FWA. The IRB at Institution A will follow written procedures for reporting its findings and actions to appropriate officials at Institution B. Relevant minutes of IRB meetings will be made available to Institution B upon request. Institution B remains responsible for ensuring compliance with the IRB's determinations and with the Terms of its OHRP-approved FWA. This document must be kept on file by both parties and provided to OHRP upon request.

Signature of Signatory Official (Institution/Organization A):

Angela R. Wishon Date: 3-28-2016

Print Full Name: Angela R. Wishon, J.D. Institutional Title: Vice President for Research Administration

Signature of Signatory Official (Institution B):

Susan Lewis Date: 12/16/15

Print Full Name: Susan Lewis Institutional Title: Vice Provost

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APPENDIX B
INFORMED CONSENT

The University of Texas Southwestern Medical Center
Parkland Health & Hospital System
Children's Medical Center
Retina Foundation of the Southwest
Texas Scottish Rite Hospital for Children
Texas Health Presbyterian Hospital Dallas

CONSENT TO PARTICIPATE IN RESEARCH

Title of Research: Transition Readiness and Quality of Life in Patients with
Congenital Urologic Conditions

Funding Agency/Sponsor: No funds/UT Southwestern Medical Center

Study Doctors: Micah Jacobs M.D.
Bruce J. Schlomer, M.D.
Gwen Grimsby M.D.

Research Personnel: Martinez Hill, LVN
Emma Sanchez
Rachel Burgess, RN
Elissa Moses, RN

You may call these study doctors or research personnel during regular office hours at (214) 456-2444. At other times, you may call them at (214) 456-7000.

Note: If you are a parent or guardian of a minor and have been asked to read and sign this form, the "you" in this document refers to the minor.

Instructions:

Please read this consent form carefully and take your time making a decision about whether to participate. As the researchers discuss this consent form with you, please ask him/her to explain any words or information that you do not clearly understand. The purpose of the study, risks, inconveniences, discomforts, and other important information about the study are listed below. If you decide to participate, you will be given a copy of this form to keep.

Why is this study being done?

This study is being done to evaluate how having a congenital urologic condition, such as spina bifida, affects general well-being and your readiness are for transition to self-care and care by an adult urologist.



Why am I being asked to take part in this research study?

You are being asked to take part in this study because you or your child has a congenital urologic condition, such as spina bifida, and are 16 years or older.

How many people will take part in this study?

About 500 people will take part in this study at Children's Medical Center in Dallas, TX.

What is involved in the study?

If you agree to be in this study, you will be asked to sign this consent form and complete a questionnaire about how your diagnosis, such as spina bifida and how this affects your quality of life and readiness for transition to care of yourself and care from an adult urologist, as well as a questionnaire about your sexual history. In particular, we hope, to assess sexual dysfunction. This will provide study physicians with invaluable information that might help the subject with any such dysfunction. The questionnaires in this study are designed for research and medical purposes to assist the doctor in collecting important information regarding your diagnosis. You and/or your child will be asked to complete these questionnaires behind closed doors. The questionnaires are brief and should only require approximately 20 minutes for completion. You will only be given these once throughout your study participation. The information you provide will be gathered and placed into a database for review.

How long can I expect to be in this study?

All that is required is for you to complete the questionnaires in one visit. There will be no further contact.

What are the risks of the study?

There is little to no risk to you or your child by completing this study. It only involves completing two questionnaires, each only two pages long. You may refuse to answer any of the questions, take a break or stop your participation at any time.

Psychological Stress

Some of the questions we will ask you as part of this study may make you feel uncomfortable. You may refuse to answer any of the questions, take a break or stop your participation in this study at any time.

Loss of Confidentiality

Any time information is collected there is a potential risk of loss of confidentiality. Every effort will be made to keep your information confidential; however, this cannot be guaranteed.

What are the possible benefits of this study?

If you agree to take part in this study there may not be any direct benefits to you. We hope that the information learned from this study will benefit patients with congenital urologic conditions, such as spina bifida, by identifying how your diagnosis affects your



quality of life. In addition, we hope to identify barriers to transitioning of care as you become an adult. With this information we can then focus on how to improve health care and the transition process for future patients.

What options are available if I decide not to take part in this research study?

This is not a treatment study. You do not have to be part of it to receive treatment for your condition.

Will I be paid if I take part in this research study?

No. You will not be paid to take part in this research study.

Can I stop taking part in this research study?

Yes. If you decide to participate and then change your mind, you are free to stop taking part in the research study at any time. Your doctor may be a research investigator in this study. He is interested in both your medical care and the conduct of this research study. At any time, you may discuss your care with another doctor who is not part of this research study. You do not have to take part in any research study offered by your doctor.

Will my information be kept confidential?

Medical information collected during this study will be kept in a confidential database.

Whom do I call if I have questions or problems?

For questions about the study, contact Micah Jacobs M.D at 214.456.2444 during regular business hours and at 214.456.7000 after hours and on weekends and holidays.

For questions about your rights as a research participant, contact the UT Southwestern Institutional Review Board (IRB) Office at 214-648-3060.



SIGNATURES:

YOU WILL BE GIVEN A COPY OF THIS CONSENT FORM TO KEEP.

Your signature below certifies the following:

- You have read (or been read) the information provided above.
- You have received answers to all of your questions and have been told who to call if you have any more questions.
- You have freely decided to participate in this research.
- You understand that you are not giving up any of your legal rights.

 Name of Participant (Printed) _____
 Date of Birth

 Signature of Participant _____ AM / PM
 Date Time

 Legally Authorized Representative's Name (Printed)

 Legally Authorized Representative's Signature _____ AM / PM
 Date Time

 Name of Person Obtaining Consent (Printed)

 Signature of Person Obtaining Consent _____ AM / PM
 Date Time

ASSENT OF A MINOR:

I have discussed this research study with my parent or legal guardian and the researchers, and I agree to participate.

 Participant's Signature (age 10 thorough 17) _____ AM / PM
 Date Time



APPENDIX C
QUESTIONNAIRES

Date: _____ Person Completing Survey: _____

Transition Readiness Assessment Questionnaire 3.0

Directions: We would like to know how you describe your skills in the areas that are important in your care. Your answers will help us provide services and education that will be important in preparing you to transition to adult health care. There are no right or wrong answers and your answers will remain confidential and private. Please check the box that best describes you.

TRAQ DOMAIN 1: Skills for Chronic Condition Self-Management					
	I do not need to do this	I do not know how but I want to learn	I am learning to do this	I have started doing this	I always do this when I need to
1. Do you fill a prescription if you need to?					
2. Do you know the side effects or bad reactions of each medication and what to do if you are having a bad reaction?					
3. Do you pay or arrange payments for your medications?					
4. Do you take medications correctly and on your own?					
5. Do you reorder medications before they run out?					

6. Do you use and take care of medical equipment and supplies?					
7. Do you call the suppliers when there is a problem with the equipment?					
8. Do you order medical equipment before they run out?					
9. Do you arrange payment for the medical equipment and supplies?					
10. Do you call the doctor's office to make an appointment?					
11. Do you follow-up on any referral for tests or check-ups or labs?					
12. Do you arrange for your ride to medical appointments?					
13. Do you call the doctor about unusual changes in your health (Ex. Allergic reactions)?					
14. Do you apply for health insurance if you lose your current coverage?					
15. Do you know what your health					

insurance covers?					
16. Do you manage your money & budget household expenses (Ex. Use checking/debit card)?					



TRAQ DOMAIN 2: Skills for Self-Advocacy and Health Care					
Utilization					
	I do not need to do this	I do not know how but I want to learn	I am learning to do this	I have started doing this	I always do this when I need to
17. Do you fill out the medical history form, including a list of your allergies?					
18. Do you keep a calendar or list of medical and other appointments?					
19. Do you tell the doctor or nurse what you are feeling?					
20. Do you answer questions that are asked by the doctor, nurse or clinic staff?					
21. Do you ask questions of the doctor, nurse or clinic staff (Ex. What medications or treatments are best for you)?					
22. Do you make a list of questions before the doctor's visit?					
23. Do you request and get the accommodations & support you need at school or work?					
24. Do you apply for a job or work or vocational services?					
25. Do you get financial help with school or work?					
26. Do you help plan or prepare meals/food?					
27. Do you keep home/room clean or clean-up after meals?					
28. Do you use neighborhood stores and services (Ex. Grocery stores and pharmacy stores)?					
29. Do you call on and use community support services (Ex. After school programs) and advocacy services (Ex. Legal services) when you need them?					

Spina Bifida Syndrome Quality of Life Questions

Please indicate your:

Age _____ Gender _____

Please answer each question to the best of your ability. Please look back on your entire life when answering the questions. There is no right or wrong answer. This is completely voluntary and will not influence the medical care you receive.

- 1. What are the things about having spina bifida that negatively affect your quality of life? Please list.**

- _____
- _____
- _____
- _____
- _____
- _____
- _____
- _____
- _____
- _____
- _____
- _____
- _____
- _____

- 2. What treatments, surgeries, procedures, medications, etc that your health care providers and/or doctors have recommended have had a POSTIVE impact on your quality of life?**

Please explain.

3. What treatments, surgeries, procedures, medications, etc that your health care providers and/or doctors have recommended have had a NEGATIVE impact on your quality of life or the? Please explain.

4. What can we do, as health care providers, to make it easier for you to transition to caring for yourself as an adult? Please explain.

Young Adult Urology Clinic

_____ seen in clinic with _____

Patient lives in a _____ in _____ with _____

Transportation:

Insurance _____ Child or Adult

When that ends... _____

SSI: Child Pending Adult

School / Employment:

(any accommodation needs)

PCP: _____ Home Health: _____

Support System:

Barriers:

Back-Up help if needed: _____ and _____