

Transition from Pediatric to Adult Care for Youth with Spina Bifida: An Integrative Literature  
Review and Implications for the Clinical Nurse Specialist Role

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### **Abstract**

As a direct result of advances in medicine and surgical interventions, youth with spina bifida are now living well into adulthood (Sandler, 2010). As a result, a new healthcare priority has emerged: facilitating an effective transition from pediatric to adult care. Primary goals for transition preparation includes facilitating increased self-management, independence, and obtaining adequate follow-up services for individuals with chronic health care needs to ensure youth are adequately prepared for the adult health care system, and able to manage their own care (Canadian Pediatric Society, 2007; Blum et al., 1993).

I conducted an integrative review to learn about the transition from pediatric to adult care for youth with spina bifida in order to identify implications for the clinical nurse specialist (CNS) role. As a result, I have learned that while transition programs are in existence, (a) self-management skills, (b) independence, and (c) adult medical follow-up are lacking in young adults with spina bifida, and that (d) general health status decreases from youth to adulthood in this population. The CNS can utilize the theoretical framework of the Chronic Care Model (The MacColl Center, 1996-2003) and Meleis' Middle Range Transition Theory (Meleis, 2000) to create a transition program and plan tailored interventions to facilitate an effective transition from pediatric to adult care for this population. I developed a draft transition program outline that addresses the issues I identified for this population in the review, such as enhancing communication between pediatric and adult services, and utilizing a stepwise approach of increasing self-management skills. Through creating, implementing and evaluate a transition program like the one I designed, the CNS has the ability to improve the care of youth transitioning from pediatric to adult care and impact their health outcomes, independence, and social participation.

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Transition from Pediatric to Adult Care for Youth with Spina Bifida: An Integrative Literature  
Review and Implications for the Clinical Nurse Specialist Role

Advances in both medicine and technology over the past several decades have improved the quality of life and outcomes for youth with chronic health conditions. In the past, the majority of youth with many congenital disorders did not survive until adulthood; with the reported survival rate prior to 1960 being 10 to 12% (Pruitt, 2012). Today, many youth with congenital disorders are living well into adulthood, and they will require lifelong health care from adult health care providers once they are 18 years old (Canadian Pediatric Society, 2007; Blum et al., 1993; Grant & Pan, 2011). Spina bifida is a congenital disease that is consistent with these changes. Previously, the majority of youth with spina bifida did not survive into adulthood, whereas today's survival rate is 75% (Cox et al., 2011). This increased survival rate is mainly due to advances in neurosurgical and urological care that developed in the 1970's, changing how the health of individuals with spina bifida was managed. These advances included the use of ventriculo-peritoneal (VP) shunts to manage hydrocephalus, and clean intermittent catheterization (CIC) to maintain kidney function (Bomalaski, Teague & Brooks; 1995; Cox et al., 2011; Sandler, 2010).

During my second practicum for the Master of Nursing (MN) program at the University of Victoria, I had the opportunity to work with youth diagnosed with spina bifida that will eventually transition to adult care. During a preliminary literature review, I noticed many issues that are common to this population related to this transition that are alarming. Deteriorating health status among young adults with spina bifida is a common trend. Health status of youth with spina bifida is comparable to youth without chronic health illnesses, while health status of

adults with spina bifida compared to the general population is worse (Sawyer & MacNee, 2010). Additionally, poor social outcomes are prevalent in this population, including lack of independence, unemployment, poor quality of life, lower socioeconomic status, dependence on others, lower education, and lack of meaningful relationships (Smith et al., 2010; Bomalaski et al., 1995; Moore, Kogan, & Parekh, 2004; Clayton & Brock, 2004). By searching the literature, and discussions with my practicum field guide and other members of the health care team, I learned that these issues could potentially be addressed through preparing youth for the transition from pediatric to adult care.

To address this issue of transition, I decided to conduct an integrative review of the literature. My two primary goals were to learn about the transition from pediatric to adult care for youth with spina bifida and explore how the role of the Clinical Nurse Specialist (CNS) can contribute to meeting the needs of this population. I believe the CNS is an ideal health care professional to address and find solutions to improving the transition of care for this population. I used Whittemore & Knafle's (2005) approach to an integrative review to guide my review, and incorporated Meleis' middle range transition theory (Meleis, 2000) and the Chronic Care Model (The MacColl Centre, 1996 – 2013) as theoretical frameworks. In this paper I will: (a) review spina bifida from diagnostic, prevention, symptom management, multidisciplinary team support, and transition from pediatric to adult care perspectives, (b) describe the current state of practice and program development related to transition from pediatric to adult care, (c) review the role of the Advanced Practice Nurse (APN), and specifically, the CNS, (d) summarize the literature that is available in this field, and finally (d) discuss how integration of the CNS role into the transition planning process holds great potential for improving the health and social outcomes of this population.

## **Spina Bifida**

Spina bifida is a congenital defect that affects the spine, and occurs during the first trimester of pregnancy. In spina bifida, a neural tube defect occurs where bone of the spine does not close all the way, leaving the spinal cord unprotected. As a result, the spinal cord and nerves become damaged (McDonnell & McCann, 2000). Spina bifida can happen anywhere along the spine, and the severity of the opening can vary, with higher level of lesion resulting in greater deficits (Jandasek et al., 2009). Spina bifida can cause both physical and intellectual disabilities that vary in a range from mild to severe. The severity of the effects of spina bifida depends on the location and size of the spinal opening, and whether the nerves and spinal cord are affected (Centers for Disease Control and Prevention, 2013; Lie, 2006; Liptak, 2012; Barker, Saulino & Caruso; 2002).

Spina bifida is an umbrella term, and there are several different types of spina bifida. Three types of spina bifida are the most common: myelomeningocele, meningocele, and spina bifida occulta. Myelomeningocele is the most severe type of spina bifida, where a sac of fluid protrudes through an opening on an infant's back (Friedman, Holmbeck, DeLucia, Jandasek, & Zebracki, 2009). Within this sac is part of the spinal cord and nerves, and they are damaged. Myelomeningocele results in moderate to severe disabilities. In meningocele, there is a sac of fluid that protrudes through an opening on an infant's back, but the spinal cord and nerves are not in this sac, and only contains CSF. With meningocele, there is usually little or no nerve damage. Minor disabilities are expected for individuals with meningocele. Lastly, spina bifida occulta is the mildest form of spina bifida, where there is a small gap in the spine, but there is no opening or protruding sac on the infant's back (Liptak, 2012; Barker et al., 2002; Centres for

Disease Control and Prevention, 2013). On the back, a midline dimple, altered pigmentation, hairy patch, lump, scar, or other suspicious abnormalities (on the back along the spine) should be investigated as possible spina bifida occulta (Buxton, 2011) Most of the time, the spinal cord and nerves are normal in spina bifida occulta. This type of spina bifida usually does not cause any disabilities, and usually is not diagnosed until late childhood or adulthood, and sometimes may never be discovered (Centers for Disease Control and Prevention, 2013; Liptak, 2012; Barker et al., 2002; Buxton, 2011).

### **Diagnosis**

It is possible for spina bifida to be diagnosed either during pregnancy or after the infant is born. During pregnancy, spina bifida can be discovered through prenatal screening tests that check for birth defects. AFP is an acronym for ‘alpha-fetoprotein’, a protein an unborn baby produces, and is found in a blood test. High levels can mean the fetus has spina bifida (Cohen, 1987; Centers for Disease Control and Prevention, 2013). Ultrasounds can visualize the infant in the uterus, and can detect physical abnormalities, like a protruding sac (Wingate et al., 2004; Boyd et al., 2000; Public Health Agency of Canada, 2008). Allen, McCourt & Lee (2002), in a Health Canada publication, state ultrasound and maternal serum AFP levels will detect spina bifida in 95% of cases. Another diagnostic test for spina bifida is amniocentesis, where a small amount of amniotic fluid is taken as a sample and levels of AFP are tested (Cohen, 1987; Wald et al., 2000; Centers for Disease Control and Prevention, 2013; BCHealthLink, 2011). Amniocentesis can confirm can confirm spina bifida, but has associated risks, such as a chance of miscarriage (HealthLinkBC, 2011; Wald et al., 2000)

## **Causes and Prevention**

The cause of spina bifida is a complex interplay of factors, and exact causes are still somewhat unclear. It is known that there are factors that are involved in causing spina bifida, and include both genes and the environment. Low folic acid levels, obesity, diabetes, high maternal temperature, and maternal fever can cause spina bifida (Centers for Disease Control, 2013, Sandler, 2010; HealthLinkBC, 2011).

Spina bifida and other neural tube defects can be prevented through folic acid supplementation (Centers for Disease, 2013; Roper et al., 1992; Berry et al., 1999; Public Health Agency of Canada, 2008). The Public Health Agency of Canada (2008) recommends all women who could become pregnant take 400 mcg of folic acid daily to prevent neural tube defects. Women who have given birth to children with a neural tube defect, or have a family history may require higher doses of folic acid and should see a doctor. The Public Health Agency of Canada (2008) also recommends women with diabetes, obesity, and epilepsy to see a doctor prior to planning for pregnancy as these women may be at an increased risk of giving birth to a child with a neural tube defect.

## **Incidence**

Since the start of public health services recommending 400 mcg of folic acid daily to reduce the risk of having a pregnancy with a neural tube defect, spina bifida rates decreased (Centers for Disease Control and Prevention, 2011; Werler, Shapiro & Mitchell, 1993; De Wals et al., 2008). In Canada, prior to the start of recommending folic acid fortification, the prevalence of spina bifida was 0.86 per 1,000 live births. Post folic acid fortification, spina bifida prevalence is 0.4 per 1,000 live births (De Wals et al., 2008). The Public Health Agency of Canada (2004) reports prevalence of spina bifida has declined from 6.5 to 2.5 per 10,000 live

births from 1995 to 2004, most likely due to folic acid supplementation. There is regional variation of spina bifida prevalence across Canada, likely due to prenatal screening diagnostic service availability, and pregnancy termination rates, with British Columbia having the highest prevalence of Spina Bifida (Public Health Agency of Canada, 2004). Since recommending folic acid fortification, and some countries, such as the USA and Canada fortifying grain products with folic acid, spina bifida rates have been reported as having declined throughout many parts of the world, such as in Canada, USA, Europe, and Chile (Yi et al., 2011).

### **Spina Bifida Symptoms and Management**

The symptoms presented by individuals with spina bifida and the required management of these symptoms varies depending on the location and severity of the spinal cord lesion (Centers for Disease Control, 2011, 2013; Sandler, 2010). Spina bifida can affect multiple body systems, and require both medical and surgical management. If the spinal cord is exposed, surgery is performed either prior to birth, or within the first few days of life. If the spinal cord is not exposed, such as in spina bifida occulta, this surgery is not required (Sandler, 2010, Barker, Saulino & Caristo, 2002).

There are several possible central nervous system issues. Many babies who have spina bifida develop hydrocephalus, where extra cerebrospinal fluid (CSF) accumulates in the ventricles of the brain, which can cause brain swelling and increased intracranial pressure (ICP) (Sandler, 2010). In individuals with spina bifida, hydrocephalus is caused by a Chiari II malformation (downward cerebellum displacement, upward displacement and elongation of the medulla, and fourth ventricle, corpus callosum dysgenesis, small posterior fossa) (Sandler, 2010). Hydrocephalus needs to be monitored closely, and treated if necessary to prevent head injury and brain damage. Sometimes a shunt is required to drain excess CSF and protect the

brain from increased ICP. Throughout the lifespan, additional surgeries might be required due to shunt clogging or shunt infections (Centers for Disease Control, 2011; Sandler, 2010). Secondly, many individuals with spina bifida have tethered spinal cords, where the spinal cord is attached to the spinal canal instead of floating freely in the canal. This can result in scoliosis, back pain, lower extremity weakness, and problems with bladder and bowel control. Surgery can be performed to treat a tethered cord, but symptoms may not always improve (Sandler, 2010).

In addition to central nervous system effects, spina bifida often affects an individual's mobility. Many people affected with spina bifida have limited mobility and limited use of their lower extremities, and may even be paralyzed (Sandler, 2010; DiCianno, Bellin & Zabel, 2009). Mobility aids may be used including wheelchairs, braces, crutches and walkers (Sandler, 2010; Roach, Short & Saltzmann, 2011). Some individuals with spina bifida may have muscle weakness, but can walk without assistance, and individuals with spina bifida occulta frequently have minor or no mobility limitations (Sandler, 2010; DiCianno, Bellin & Zabel, 2009). Many individuals with spina bifida live sedentary lifestyles in comparison to those without disabilities (DiCianno, Bellin & Zabel, 2009). Individuals who use wheelchairs typically have a lower level of home and community activity levels than ambulators with spina bifida despite having access to high-quality assistive devices (DiCianno et al., 2009). In Roach, Short, & Saltzman's (2011) study, level of lesion was associated with ambulation status among adults with spina bifida. In their study, 100% of individuals with a sacral level of lesion walked full-time without crutches, individuals with a lumbar level of lesion in the study primarily walked with an aid such as crutches, or used a wheelchair at least part-time, and 100% of individuals with a thoracic level of lesion used a wheelchair full-time (Roach et al., 2011).

Bowel and bladder function is frequently altered in individuals with spina bifida. Many of these individuals have urinary incontinence and neurogenic bladder, and can develop frequent urinary tract infections; renal reflux, and even kidney failure (Sandler, 2010; Lemelle et al., 2006; Joseph, 2008). At birth, most children with spina bifida have normal renal function (Joseph, 2008). Neurogenic bladder is caused by damage to the central nervous system, and results in bladder dysfunction, including “lack of coordination between detrusor contraction and sphincter relaxation (Sandler, 2010, p. 883),” causing incomplete emptying and incontinence. If neurogenic bladder, a condition that is caused by damage to remains untreated, Joseph (2008) reports more than 50% of these children will experience serious kidney deterioration due to vesicoureteral reflux (VUR) by five years of age. The gold standard for treatment of bladder incontinence and neurogenic bladder is clean intermittent catheterization (CIC) but can also include surgeries such as urinary diversion, or bladder augmentation (Centers for Disease Control and Prevention, 2011; Sandler, 2010; Lemelle et al., 2006; Joseph, 2008; Clayton, Brock & Joseph, 2010; deJong, Chrzan, Klijn & Dik, 2008). Other treatments to manage neurogenic bladder for individuals with spina bifida include medications, surgeries, and other treatments. For example, medications such as oxybutynin can be used to manage uncontrolled, overactive bladder contractions (Joseph, 2008). Vesicostomy surgery can be performed for infants who are not responding well to CIC and medication (Joseph, 2008). Enterocystoplasty can be done to increase bladder capacity and to restore bladder compliance (Martin & Ritchey, 2009) where gastrointestinal segments, such as stomach or colon are used to augment the bladder (Joseph, 2008, Clayton, Brock & Joseph, 2010). Bowel incontinence can also occur in individuals with spina bifida, and is managed with bowel training, dietary management, and sometimes surgery, such as a cecostomy to help clear the bowel (Clayton, Brock & Joseph, 2010; Joseph, 2008).

Constipation is a common issue among individuals with spina bifida, and dietary management, including a diet that is high in fibre, in addition to a bowel program composed of suppositories, enemas, and rectal stimulation help achieve normal bowel continence (Clayton, Brock & Joseph, 2010). Surgically created catheterizable channels between the abdominal wall and colon (Clayton, Brock & Joseph, 2010; Malone et al., 1990) have also been used to maintain continence, and have been demonstrated to improve self-continence and personal hygiene (Yerkes et al., 2001)

Other effects of spina bifida include decreased sensation, allergies, obesity, and learning disabilities. Individuals with spina bifida often have decreased sensation on certain parts of their body, especially the lower extremities. Therefore, there is a risk for the development of pressure sores. Prevention techniques are strategies to reduce the risk of pressure ulcer development (Centers for Disease Control, 2011; Sandler, 2010). Latex allergies are common among individuals with spina bifida, and should be avoided. Individuals with spina bifida are also at a high risk of obesity, especially those who have decreased mobility (Centers for Disease Control, 2011; Sandler, 2010). Lastly, Sandler (2010) states a mild intellectual disability is common among individuals with spina bifida, although the mechanism is not entirely clear. Barf et al. (2003), however, states the majority of adults with spina bifida have a normal IQ of 70 or greater. Individuals with both spina bifida and hydrocephalus are more likely to have cognitive deficits, but there are also many youth with spina bifida (and without hydrocephalus) that possess an intellectual disability (Sandler, 2010).

### **Social Issues Related to Spina Bifida**

There are many social issues that are affected among individuals with spina bifida. For example, there are specific sexual health and sexuality concerns that may need to be addressed,

such as safe sex practices, and how pregnancy will affect the body for women (Sawyer & Macnee, 2010; Woodhouse, 2005). Individuals with spina bifida are also at an increased risk for depression (Liptak, 2012), and have an increased chance of health risk behaviours (Soe et al., 2012). Healthcare is costly, and access to health insurance is essential, and youth with chronic illness are at risk for being underinsured (Canadian Pediatric Society, 2007). It is important to highlight that despite the medical, physical and social issues individuals with spina bifida may face, many adolescents and young adults affected by spina bifida report they are satisfied with their quality of life (Centers for Disease Control, 2011; Rodriguez et al., 2010).

### **Management of the Effects of Spina Bifida and the Multidisciplinary Team**

After identifying many of the potential health, physical and cognitive effects of spina bifida, it is apparent that management and follow-up for individuals with spina bifida is complex, and that many individuals require time-consuming daily care. Individuals with spina bifida often have to perform daily medical interventions to maintain their health such as catheterizations, enemas, and monitoring for pressure sores (Sandler, 2010; Clayton et al., 2010).

To manage the effects of spina bifida, a number of specialized health professionals are required to optimize health. These include orthopedists, physiatrists, urologists, neurosurgeons, nurses, physiotherapists, and social workers, among others. For example, nurses have a variety of different roles within the multidisciplinary team, depending on their area of practice. Public health nurses would be involved in health promotion activities for individuals with spina bifida, such as promoting safe sexual practices. Nurses involved in inpatient care would provide care to individuals with spina bifida who require nursing care and health teaching for a variety of different reasons, such as hospital admissions for urinary tract infections, pressure sores, sepsis, or postoperatively for planned surgeries. Home care nurses would provide care in the home to

individuals with spina bifida, such as changing dressing, giving antibiotics, and providing health teaching. Clinic nurses would provide outpatient care and health teaching during routine follow-up appointments, and facilitate access to resources (Sandler, 2010, Buxton, 2011; deJong et al., 2008). The use of a multidisciplinary team works both individually and together to manage the effects of spina bifida in order to promote health, and maintain the best health status possible for each individual with spina bifida (Sandler, 2010, Buxton, 2011; deJong et al., 2008).

In summary, limited self-management, deteriorating health status, and poor psychosocial outcomes are common issues among youth with spina bifida. Considering that the majority of youth with spina bifida are now living into adulthood, addressing these issues is a significant health care priority. I believe addressing the transition from pediatric to adult care is a key strategy in resolving these problems, and the Clinical Nurse Specialist (CNS) is an ideal professional to work on this problem.

### **Transition from Pediatric to Adult Care**

Transition has been defined in the Merriam-Webster (2012) dictionary as a “passage from one state, subject or place to another; a movement, development, or evolution from one form, stage or style to another”. Within the context of transition from pediatric to adult care, transition has been defined by Blum et al. (1993) as “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health systems” (p. 570). Transition from adolescence to adulthood is a life phase, and moving from the pediatric to the adult health care system is part of this phase for all youth. This part of the transition is likely more significant for youth with chronic illnesses that require intense management and follow-up. Transition is considered different from the transfer of patients. In

general, transition is a process that occurs over a long period of time, while transfer is the one-time event of handing over from pediatric to adult care (Canadian Pediatric Society, 2007).

Programming to assist in guiding the transition from pediatric to adult care is well documented as being necessary to improve health and associated outcomes such as medication adherence, compliance with treatment, morbidity and mortality, compliance with follow-up visits, and improved self-management and self-confidence (Blum et al., 1993; Canadian Pediatric Society, 2007; Johnston-Fletcher, Marshall & Straatman, 2011; Baines, 2009; Kelly, 2011; Wont et al., 2010). Advances in medicine, technology, and treatment have improved outcomes and increased the lifespan of youth and the quality of life for individuals with chronic health conditions. In the past, most children with chronic illnesses did not survive until adulthood. Now, many individuals with chronic illnesses are living well into adulthood, and will require care from adult health care providers once they turn 18 years old (Canadian Pediatric Society, 2007; Blum et al., 1993; Rosen, 1995; Sawyer et al., 1997; While et al., 2004).

The philosophy and culture of care within pediatric and adult health care systems vary greatly. In pediatrics, health care is family-centered, where the family is significantly involved in care, follow-up appointments, and making decisions, and developmentally appropriate care is a key concern (Canadian Pediatric Society, 2007; Arango, 2011; Committee on Hospital Care, 2013). Within pediatrics, care most often occurs in a multidisciplinary team. In contrast, the adult care system is quite different. The adult system is focused on the individual who is an independent and autonomous being in managing their care and making decisions. Adults are expected to be knowledgeable about their illness, independent in self-management, and able to identify and access appropriate resources when necessary (Canadian Pediatric Society, 2007). In the adult system, family involvement is significantly decreased and multidisciplinary resources

are limited (Canadian Pediatric Society, 2007). When describing the differences in culture and philosophy between the pediatric and adult care systems, it is obvious that transition planning including patient education and practice period of preparation from a young age to gain self-management, advocacy, and accessing health services is required to prepare for the change and an effective support system (Canadian Pediatric Society, 2007; Blum et al., 1993; Betz, 2006; Jalkut & Allen, 2009).

Nurses have been identified as having a role in preparing adolescents for the transition from pediatric to adult care. Baines (2009) calls for policies associated with transition, and education training to prepare youth for the transition. Specifically, nursing roles specific to preparing youth for transitioning to adult care include identifying care needs, utilizing policies, plan and carry out an individually tailored transition program, provide support to patients and families, facilitate communication between pediatric and adult services, and obtain feedback to improve transition care (Baines, 2009).

### **Barriers to a Successful Transition**

Several barriers have been identified in the literature that has prevented successful transition from pediatric to adult care for youth with chronic illnesses. Some of these include lack of trust between pediatric and adult healthcare providers, difficulty letting go, lack of funding, and unwillingness of patients and parents to transition (Sawyer & MacNee, 2010; Wong et al., 2010; Parks, Adam & Irwin, 2011). Key criteria and elements for transition preparation in the literature include starting transition planning early, increasing patient responsibilities incrementally as developmentally appropriate, and having a transition clinic. In addition addressing both medical and nonmedical issues such as self-care and management, patient medical knowledge, self-advocacy, and engaging in career planning, postsecondary education,

sexuality and physical activity was deemed as important (Stewart et al., 2009, Canadian Pediatric Society 2007; Blum et al., 1993). To date, research evidence regarding transition, including elements and barriers to transition, has been mostly limited to anecdotal expert opinion and qualitative studies, and evaluation of outcomes of transition programming has been limited (Johnston-Fletcher et al., 2001; Blum et al., 1993).

### **Spina Bifida and the Transition to Adult Care**

As I have previously stated, the transition from pediatric to adult care for youth with spina bifida is a new health issue that has been created due to increasing survival rates of this population. To assist in framing background information relevant to the review, I will now provide an overview of topics relevant to spina bifida and this transition, including increasing survival rates, follow-up care requirements, gaps in follow-up care and self-management, prevention of death and psychosocial issues.

#### **Increasing Survival for Youth with Spina Bifida**

In the past, individuals with spina bifida often did not survive until adulthood. With advancement in health care, the survival rate for youth with spina bifida to live into adulthood is now 75% in North America (Cox et al., 2011; DiCianno et al., 2008). The increased survival rate is mainly due to neurosurgical and urological care advances that transformed the care of individuals with spina bifida in the 1970s, including the use of the ventriculo-peritoneal (VP) shunt to treat hydrocephalus and prevent increase ICP, and clean intermittent catheterization (CIC) (Bomalaski, Teague & Brooks, 1995; Sandler 2010).

#### **Follow-Up Care for Health Maintenance**

Excellent follow-up of youth and young adults with spina bifida by a multidisciplinary team is required to maintain health and prevent complications. Examples of complications that may occur without routine follow-up include urinary tract infections and renal failure due to the effects of neurogenic bladder (Clayton, Brock & Joseph, 2010; McDonnell & McCann, 2000). Additionally, self-management and compliance with prescribed treatments such as medications and CIC is required for health maintenance (McDonnell & McCann, 2000). Youth and young adults with spina bifida need to possess knowledge and skills to monitor for complications such as UTI's, seek immediate health care when they occur, and access follow-up services appropriately (Smith et al., 2010; Lemelle et al., 2006). These skills and knowledge cannot be developed instantaneously; therefore, youth and members of their support system require education and support to work towards a sufficient knowledge base and self-management skills necessary to manage their condition throughout adulthood (Canadian Pediatric Society, 2007; West et al., 2000).

### **Gaps in Follow-Up Care and Self-Management**

Despite today's awareness of the need for excellent self-management and follow-up care for individuals with spina bifida, gaps still exist. The health status of youth with spina bifida is similar to the general population, but the health status of young adults with spina bifida is considerably worse than the general population of young adults (Sawyer & Macnee, 2010). There could be multiple contributing factors, including several that can be attributed to skills and knowledge, and services that can be achieved through preparing for the transition from pediatric to adult care. These include gaps in self-management skills, knowledge, and lack of follow-up, and some youth and young adults not adhering to the prescribed treatment (Sandler, 2010). It is important to note that lack of follow-up and "adherence" has negative connotations, and places

blame on the individual for not following recommendations from health care professionals when a variety of complex reasons could be to blame (such as gaps in knowledge, lack of supplies, lack of time commitments, financial supports, etc.). While non-compliance or non-adherence is associated with risks, it is paternalistic as the prescriber defines what outcomes are desirable for the patient, with the patient's role being to comply with the prescriber's recommendation. Compliance therefore ignores the patient's own autonomy (Felman, 2012).

In West et al.'s (2000) study, there were significant self-management issues prevalent among young adults with spina bifida, with the majority of adults in the study unable to identify symptoms that required urgent follow-up. A study by Ridosh et al. (2011) showed adults with spina bifida can expect to experience health deteriorations, lack of follow-up and poor adherence with treatment after transitioning to adult care. Lack of follow-up among adults with spina bifida is a common trend in the research (Ridosh et al., 2011; Betz et al., 2010; Mourzinos & Stoffel, 2010; McDonnell & McCann, 2000; West et al., 2000).

Despite awareness of this issue by healthcare providers and publications in the literature about the need for excellent self-management and follow-up care, alarming gaps still exist. For example, West et al.'s (2000) study highlighted self-management issues among young adults with spina bifida, and found that the majority of young adults with spina bifida were unable to identify symptoms that required urgent follow up. Currently, there is much room for improvement within the health care system to enhance the follow-up services, education and skills-teaching of youth with spina bifida to assist them in managing their disease and maintaining their health as they transition to independence and adulthood.

### **Psychosocial Issues Relevant to Transition to Adult Care and Spina Bifida**

There are several psychosocial issues that should be addressed in transition programming in addition to medical issues. Both youth and adults with spina bifida are more likely to have a lower quality of life, and poorer social outcomes such as unemployment, lower socioeconomic status, low education, and lack of meaningful relationships with others than individuals without spina bifida (Smith et al., 2010; Bomalaski et al., 1995; Moore, Kogan & Parekh, 2004; Clayton & Brock, 2010). Spina bifida also affects sexuality and sexual functioning, including fertility, an increased risk of pregnancy complications (such as chronic UTI's, metabolic imbalances, and low birth weight), erectile dysfunction, decreased sensation, and a higher risk of offspring with spina bifida. In addition to regular sexual education, spina bifida patients also need to receive sexual health education specifically related to their illness from health care providers (Dector et al., 1997, Gatti et al., 2009, Cardenas et al., 2008). To enhance transition planning, health care professionals need to address psychosocial issues, which could include health teaching, and referrals to other professionals who could manage issues such as career planning, scholarships and insurance.

### **Determinants of Health**

“The primary factors that shape the health of Canadians are not medical treatments or lifestyle choices, but rather the living conditions they experience (Mikkonen & Raphael, 2010, p. 7).” There is a growing body of literature suggesting there are many key factors that determine an individual's health status beyond medical care. This literature states contributions of medicine and health care are limited in comparison to the contribution of these key factors, and that spending time on improving healthcare may not result in improving population health. The foundation for this literature began in the mid 1800's. This knowledge appeared in Canadian government policy documents in 1974 with the LaLonde report, where a framework was

developed outlining key factors that appeared to determine health status: lifestyle, environment, human biology, and health services (Public Health Agency of Canada, 2013; Mikkonen & Raphael, 2010). The Romanow report, published in 2002, called for a greater emphasis on addressing the determinants of health, including emphasizing prevention and wellness as a strategy to improve primary health care in Canada, and investing in research studying the determinants of health (Romanow, 2002). The Public Health Agency of Canada (2013) identifies twelve key determinants of health. These are (1) income and social status, (2) social support networks, (3) education and literacy, (4) employment/working conditions, (5) social environments, (6) physical environments, (7) personal health practices and coping skills, (8) healthy child development, (9) biology and genetic endowment, 10. health services, 11. gender, and 12. culture. There are several key determinants of health that I believe are likely to impact individuals with spina bifida. These include (a) income and social status, (b) social support networks, (c) education and literacy, (d) employment/working conditions, and (e) personal health practices and coping skills, (f) biology and genetic endowment (Public Health Agency of Canada, 2013). In the paragraphs below, I will discuss how these determinants of health may impact youth with spina bifida.

### **A. Income and Social Status**

Income and social status significantly determines health. Income largely determines living conditions, and the ability to buy healthy food. Individuals who have higher incomes also have more control over their life circumstances. Canadians earning low incomes are reported as more likely to die earlier and suffer more illnesses, and interval improvements in income earnings results in improved health status (Public Health Agency of Canada, 2013). Low-income levels are evident among the population of people with spina bifida due to low levels of

employment, and low wages among those who were employed. For example, in Liptak et al.'s (2010) study, the mean annual income of participants (youth with spina bifida) was \$39,030. I could expect individuals with spina bifida who have low income levels to be at risk of poor health due to their income level and resulting lower socioeconomic status.

### **B. Social Support Networks**

Social support networks, including support from families, friends and communities result in improved health. Increases in social support have been linked with decreases in premature death (Public Health Agency of Canada, 2013). In Antle, Montgomery, & Stapleford's (2009) study, parents and friends were identified as a source of social support for youth with spina bifida. Individuals with spina bifida who did not have social support from family and friends would be at increased risk of poorer health status. Sawin et al (2010) support networks such as education and income supports, and technology supports are not yet well understood and more research is needed. Based on the key determinants of health literature, I would expect that individuals with spina bifida who had access to more social supports, such as family and income support would likely experience improved health.

### **C. Education and literacy**

Higher levels of education are associated with higher health status. Education can contribute to the health of individuals by providing them with the knowledge and skills to solve problems. Education increases an individual's opportunity for employment and income (Public Health Agency of Canada, 2013). Low levels of education are characteristic of the literature studying individuals with spina bifida, including Boudos & Mukherjee (2008), and Bellin et al (2011). Lower levels of education could mean that individuals with spina bifida do not possess the knowledge problem-solving skills to respond to the daily challenges of self-managing their

illness. Individuals with lower levels of education who also have spina bifida may also have lower employment and income potential which is also likely to affect their health status.

#### **D. Employment**

Employment is also related to health status. Individuals who are unemployed, underemployed, or participate in unsafe or stressful work are associated with poorer health statuses (Public Health Agency of Canada, 2013). As previously discussed, individuals with spina bifida commonly experience unemployment, and those who are employed are likely to have low-wage entry-level positions (Roach, 2011; Bellin et al, 2011). Employment status would affect medical-benefit status of individuals, and unemployed individuals who have spina bifida may not have coverage for required medical supplies and medications, such as catheters and anticholinergic medications. I could expect individuals with spina bifida who are unemployed to have a poorer health than those who are employed.

#### **E. Personal Health Practice and Coping Skills**

Personal health practice and coping skills are activities individuals partake in that can prevent diseases, enhance self-care, solve problems, and make choices that improve health. Positive personal health practices and coping skills result in improved health. Individuals with spina bifida often need to participate in daily interventions to maintain health, such as taking medications and intermittent catheterization (Sandler, 2010; McDonnell & McCann, 2000). Youth with spina bifida who participate in personal health practices of self-management, including taking prescribed medications would likely have improved health in comparison to those who did not partake in these practices.

#### **F. Biology and Genetic Endowment**

A person's genetics predisposes them to a variety of responses that affect health status. Spina bifida predisposes individuals to many illnesses, including hydrocephalus, chiari malformation, and neurogenic bladder, and problems with mobility (Sandler, 2010; McDonnell & McCann, 2000). Individuals with spina bifida likely have a lower health status than people without spina bifida due to their genetics.

### **Transition Preparation**

In summary, common issues among youth and young adults with spina bifida during the transition from pediatric to adult care and afterwards include a risk for deteriorating health status, limited self-management skills, poor psychosocial outcomes, and the determinants of health need to be addressed to improve the health of this population. Regular medical follow-up is required to maintain health, yet studies such as Ridosh et al. (2011) report lack of follow-up care among young adults with spina bifida. Self-management skills are essential to maintain bladder continence and prevent urinary tract infections and renal failure. However, West et al.'s (2000) study, among others, reported a lack of self-management skills where the majority of participants in the study could not identify symptoms that required urgent medical attention. Additionally, several key determinants of health impact health status of individuals with spina bifida.

I believe many of the above issues can be addressed through transition preparation. Follow-up services for adulthood can be arranged prior to transition from pediatric to adult care by the transition team. Self-management skills and increasing youth's knowledge about their spina bifida can be promoted, and youth can be encouraged to practice self-management skills and using their knowledge prior to transfer in order to promote health. Psychosocial issues can be addressed through a transition plan by referring to appropriate resources, and planning for adulthood through transition programming (Canadian Pediatric Society, 2007; Rosen et al.,

2003). These preparation activities would also likely address the determinants of health. Overall, facilitating an effective transition from pediatric to adult care has the potential to contribute to addressing the multiple issues affecting today's youth and young adults with spina bifida. I believe the CNS is an ideal healthcare professional to improve the transition from pediatric to adult care and address these issues. Next, I present an overview of the CNS role.

### **An Overview of the Role of the Clinical Nurse Specialist**

As a registered nurse working in the Pediatric Intensive Care Unit (PICU), I have been involved in caring for youth with spina bifida post-operatively and during times of medical crisis such as urosepsis. During my Master's of Nursing (MN) program, I completed a practicum where I worked with youth with spina bifida who will be transitioning to adult care. With my field guide, I recognized gaps in care, including gaps in effectively transitioning these youth from pediatric to adult care. Throughout the MN curriculum, I have been learning about the impact CNS's can have through their role, such as developing and evaluating evidence-based programs to improve the health of patients (Hamric, 2009). My experiences in caring for youth with spina bifida, in both my own work and during my practicum, and my developing knowledge of the CNS led me to question whether the CNS role would be able to improve the transition from pediatric to adult care for this population. Below is a brief description of a) Advanced Practice Nursing and the b) CNS role, and continued growth and challenges in development of this role in Canada.

### **Advanced Practice Nursing**

Health care needs in Canada are constantly changing. Today, the challenges Canadian health care is facing includes rising costs of care, health care professional shortages, an aging population, new technologies, and difficulties accessing care (Canadian Nurse's Association,

2008; Hamric, 2009, McDonald, 2012). This has led to the demand for health care professionals who are innovative and collaborative, and are leaders in transforming and improving health care despite these challenges (Canadian Nurse's Association, 2008; Hamric, 2009; McDonald, 2012). According to the Canadian Nurse's Association (2008), advanced practice nurses (APN's) are well-positioned to respond to health care's needs.

Advanced practice nursing is a practice of nursing that builds upon the knowledge, foundation, and values of the nursing profession and shares many of the same core values with the foundation of nursing (Hamric, 2009). The table below provides an overview of advanced practice nursing, including core values, characterizing features, competencies, and qualifications.

Table 1

*Characteristics of APN Practice*

APN Competencies	Core Values	Characterizing Features of APN Practice	APN Qualifications
<ul style="list-style-type: none"> <li>• Direct Practice</li> <li>• Expert coaching</li> <li>• Expert Guidance</li> <li>• Research</li> <li>• Leadership</li> <li>• Collaboration</li> <li>• Ethical Decision-Making</li> </ul>	<ul style="list-style-type: none"> <li>• Advocacy</li> <li>• Respect</li> <li>• Informed Consent</li> <li>• Holism</li> <li>• Focus on disease prevention, health promotion, and restoration</li> </ul>	<ul style="list-style-type: none"> <li>• Role autonomy</li> <li>• Leadership authority</li> <li>• A significant role for health promotion</li> <li>• Responsibility to diagnose and manage patient issues</li> <li>• Responsibility for more complex decision-making in the clinical setting</li> </ul>	<ul style="list-style-type: none"> <li>• Graduate Education (Minimally a master's degree in Nursing)</li> <li>• Expert clinical knowledge</li> <li>• Professional certification (if applicable)</li> </ul>

(Developed from: Hamric, 2009; Canadian Nurses Association, 2008; McDonald, 2012)

There are several features that characterize advanced practice nurses and their role. Their in-depth nursing knowledge within their particular specialties allows them to positively impact patient care and outcomes in a variety of ways, such as providing direct clinical care, coaching,

and guiding. APN's also use their knowledge of theory and apply this knowledge in a variety of situations. They are able to understand and disseminate evidence-based research and incorporate research into practice. In addition, they are able to participate or lead program evaluation in order to better meet patients' needs (Canadian Nurse's Association, 2008). While this description provides an example of the many ways that APN's can influence healthcare and patient outcomes, it is certainly not all-inclusive, and there are many other ways APN's can influence health care and patient populations.

In Canada, APN's are often classified into two different roles: the CNS, and the nurse practitioner (NP). Each has its own roles and responsibilities, and scope of practice (Canadian Nurses Association, 2008). I believe that the clinical nurse specialist can play a significant role in providing care to the youth with spina bifida who is transitioning from pediatric to adult care. Therefore, I focus throughout this paper on the clinical nurse specialist, and will focus my review of advanced practice nursing on the CNS. I will provide an overview of the clinical nurse specialist role, competencies, and challenges in order to help form a foundation where I can critically engage with the conclusions of my integrative review in order to identify the implications for the CNS role.

### **The Clinical Nurse Specialist**

CNS's first emerged in healthcare in the late 1970's as health care was becoming more complex (Canadian Nurses Association, 2008; Sparacino & Cartwright, 2009). Their role at that time was to provide guidance and leadership to nurses, in order to assist them in managing complex care, improve care quality, and to promote the utilization of evidence in their practice (Canadian Nurses Association, 2008). According to Sparacino & Cartwright (2009), the role was also created to provide direct care to complex patients, to improve patient care (by developing

the clinical judgment and skills of staff nurses), and to retain expert nurses. CNS's are considered to be expert clinicians in their specialty area of nursing practice that can be characterized by a population, a setting, disease, subspecialty, type of care setting, or a particular problem (Sparacino & Cartwright, 2009). For example, a CNS can be an expert in providing urological care for youth with spina bifida in the clinic setting. The CNS works in a large variety of specialties and the role is purposefully broad in order to meet the needs of different areas of practice and patient populations (Sparacino & Cartwright, 2009).

CNS's provide expert care for complex and specialized patient populations. They provide a leading role in promoting evidence-based practice, integrating research into practice, developing clinical guidelines and protocols, providing expert support and consultation, and facilitating organizational changes (Canadian Nurses Association, 2008). The Canadian Nurses Association (2009) identifies the CNS role as having five key components, which are described in the table below.

Table 2:

*The CNS Role*

CNS Role Component	Description or example
Clinician	<ul style="list-style-type: none"> <li>• Provide expert care</li> <li>• Develop a plan of Care</li> <li>• Develop and carry out interventions</li> <li>• Occurs within complex situations</li> </ul>
Consultant	<ul style="list-style-type: none"> <li>• Acts as an expert resource for other healthcare professionals to assist in managing situations</li> </ul>
Educator	<ul style="list-style-type: none"> <li>• Preceptor</li> <li>• Mentor</li> <li>• Teacher</li> <li>• Client Educator</li> <li>• Planner</li> <li>• Evaluator</li> </ul>
Researcher	<ul style="list-style-type: none"> <li>• Participate in research projects (primary or co-investigator or research team member)</li> <li>• Disseminate research findings and translate into practice</li> </ul>

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Leader	• Act as a facilitator, resource, role model, coordinator and advocate to improve quality care.
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(Developed from: Canadian Nurses Association, 2008; Hamric, 2009)

### **Advanced Practice Nursing: A National Framework**

The Canadian Nurses Association (2008) has developed a document that defines advanced practice nursing, clarifies requirements to be classified as an APN, and identifies APN competencies. This document is a guide for all APN's across Canada to assist them in defining their practice, and ensuring they are practicing the required competencies. The competencies required for APN practice includes five main components: clinical, research, leadership, consultation, and collaboration (Canadian Nurses Association, 2008). Direct clinical practice is the central competency of advanced practice nursing, and should be the primary focus of an APN (Canadian Nurses Association, 2008).

### **Challenges to the Clinical Nurse Specialist Role**

There are several challenges that threaten both the visibility and the continued existence of the clinical nurse specialist role. First, standardization of education is a significant challenge. There is significant variability in graduate programs that prepare CNS's (DiCenso & Bryant-Lukosius, 2010; Sparacino & Cartwright, 2009). Second, while the role is purposefully broad to respond to the needs of diverse patient populations, this makes an understanding of the role and contribution of the CNS challenging, making the CNS role subject to retitling (Sparacino & Cartwright, 2009; Bryant & Lukosiosus, 2010). Third, advanced practice nursing positions have historically been subject to cutbacks during times of economic hardships. For example, in the 1980's and 1990's, hospital budget reductions led to the elimination of many CNS positions (Canadian Nurse's Association, 2008; DiCenso & Bryant-Lukosius, 2010). A final challenge that is facing the CNS role in Canada is a lack of title protection and credentialing. Unlike the

nurse practitioner, who is title protected, the CNS is not title-protected and any nurse can identify themselves as a CNS, despite the general consensus in the literature about the advanced credentials required for this role (Bryant-Lukosius, 2010). In the future, these challenges need to be addressed and resolved for the CNS role to continue to exist and evolve to meet the health care needs of specific populations.

### **Theoretical Perspective**

Advanced practice nurses have an advanced theoretical foundation, which they draw upon during their advanced practice (Canadian Nurses Association, 2008). Two theories have guided my perspective in this project: the Chronic Care Model, and the Meleis Middle-Range Transition Theory. The Chronic Care Model contributed to my understanding of the issues associated with transition from pediatric to adult care, while the Transition Theory was the theoretical grounding for the concept and process of transition. Both of these theories were essential in helping me to apply the results of the integrative review and identify implications for the clinical nurse specialist providing care for youth with spina bifida transitioning from pediatric to adult care.

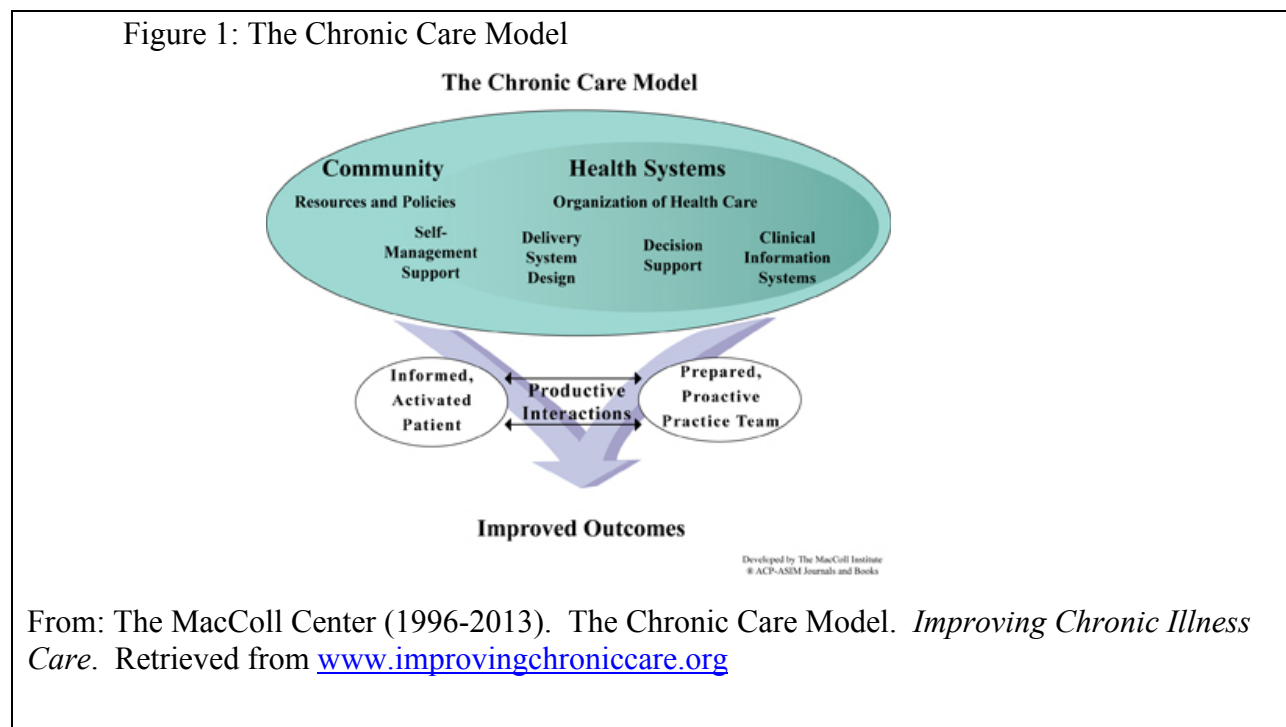
#### **Chronic Care Model**

A chronic illness is defined as “any condition that requires ongoing adjustments by the affected person and interactions with the health care system (The MacColl Center, 1996-2013).” More than half of all individuals living in Canada live with a chronic health condition, and many of these individuals have more than one health condition. As reported by the Canadian Coalition for Public Health (2005), chronic disease costs the economy 77 billion dollars annually, about

half of annual healthcare expenses. The prevalence of chronic illness and the high associated healthcare costs has resulted in improving chronic illness care being an important healthcare concern. Improving chronic illness care as an important healthcare concern. Some gaps in managing chronic illnesses that have been identified include health care professionals not following guidelines (as they are rushed and underfunded), lack of coordination of care, lack of follow-up, and patients who are not adequately educated and supported to self-manage their illness (The MacColl Centre, 1996-2003). This is not a simple issue and solving the problem requires us to address deep-rooted systems challenges such as understaffing, lack of funding, and the complexity of healthcare systems. The MacColl Centre (1996-2003), a group of healthcare professionals and researchers in North America whose goal is to improve health care delivery, states that overcoming these deficiencies in health care requires a transformation of health care, moving from a reactive health care system to a proactive one, focusing on keeping individuals at their optimal health.

The Chronic Care Model has been developed by the MacColl Center for Health Care Innovation and reflects the above-mentioned philosophies. The model was developed in the mid 1990's through utilizing the available literature about chronic illness management strategies, and organizing this literature in an accessible way. In 1997, the model was further refined during a project with support from the Robert Wood Johnson Foundation (an American organization focused on improving the health and healthcare of Americans), and revised based on input from a national expert panel. The model has since been tested in a variety of health care settings, such as with the diabetes population (The MacColl Center, 1996-2013; Wagner et al., 2001; Wagner, 1998).

There are six key elements in the Chronic Care Model: health system, delivery system design, decision support, clinical information systems, self-management support, and the community (see Appendix A). Each model element contributes to positive and productive interactions between patients and health care providers to promote high quality care of individuals with chronic illnesses. I have provided a brief overview of the six model elements below to facilitate understanding of the model concepts.



**Element 1.** The first element is the health system, where there must be motivation for health system change improve chronic illness care. A variety of actions can occur within this element to improve care through a many different systems mechanisms, with senior leadership support identified as a key requirement. These actions include policy and procedure changes, quality improvement, improving healthcare error identification, management and prevention,

open communication, and care coordination (The MacColl Center, 1996-2003; Fiandt, 2006).

An example of improving chronic illness care within this element for youth with spina bifida would be using a quality improvement initiative using Plan-Do-Study-Act cycles to evaluate and improve the care provided at a pediatric spina bifida clinic.

**Element 2.** The second element is delivery system design and involves transforming a reactive system into a proactive system. Specific actions to improve chronic illness care within this element include defining roles and distributing tasks, providing regular patient follow-up, offering case management for patients with complex chronic illnesses, and providing culturally-competent care. (The MacColl Center, 1996-2003; Fandt, 2006). An example of this element within my population of interest is to develop interventions that support regular patient follow-up during the transition from pediatric to adult care.

**Element 3.** The third model element is decision support, which includes promoting care that is based both on evidence-based research and the patient's personal preferences. Actions to improve chronic illness care within this element include integrating evidence-based guidelines and providing health teaching (The MacColl Center, 1996-2003; Fiandt, 2006). An example would be to provide health teaching to youth with spina bifida about self-management, such as clean intermittent catheterization while using evidence-based guidelines informing effective catheterization techniques.

**Element 4.** The fourth model element is clinical information systems. This element is concerned with the organization of patient and population data to provide effective and efficient care. Some actions include sharing information to coordinate care with patients and healthcare providers and providing reminders for patients and healthcare providers (The MacColl Center, 1996-2003; Fiandt, 2006). An example of using this element to improve chronic illness care in

my population is pediatric providers sharing patient-related information to adult healthcare providers during the transfer from pediatric to adult care.

**Element 5.** The fifth element, self-management support, includes empowering patients to manage their own health. Actions can include health teaching and providing support to set goals, priorities, take action and problem solve, organizing resources, and acknowledging the patient as central to managing their own care (The MacColl Center, 1996-2003; Fiandt, 2006). Examples of activities that improving chronic illness care within this element include providing health teaching to youth with spina bifida to manage their bowel and bladder management and to help them develop the skills to manage their own care.

**Element 6.** Lastly, the sixth element is the community. It involved mobilizing resources in the community to meet the needs of individuals with chronic illness. Actions include encouraging individuals to utilize community resources, forming working partnerships with community resources, developing resources and interventions to meet the need for gaps in health care and community services, and advocating for policies that will improve the care of patients with chronic illness (The MacColl Center, 1996-2003; Fiandt, 2006). An example within my population is developing partnerships with community resources such as employment agencies to assist youth and young adults with spina bifida.

Spina bifida is a chronic illness that affects multiple systems, such as the neurological system, urological system, and musculoskeletal systems. Chronic illness management requires regular follow-up from health-care providers, care coordination between providers of different specialties, and patients to manage their illness through activities such as intermittent catheterization. The Chronic Care Model therefore relates well to this population, and paying particular attention to the model elements when organizing, planning and providing care to

patients with spina bifida, and assisting them in becoming self-managers could be beneficial.

Using the Chronic Care Model could transform care from a proactive to a reactive approach, and potentially improve patient health outcomes, including optimizing patient health.

### **Meleis' Middle-Range Transition Theory**

Meleis developed her transition theory to describe the transition process that individuals experience as their health and illness states change. Changes in health and illness status can trigger a process of transition in individuals. Individuals in this process of transition may be more vulnerable to risks that can affect health (Meleis, Sawyer, Im et al., 2000). In Meleis' theory, transition is framed by five components: types and patterns of transitions, properties of transition experiences, transition conditions (facilitators and inhibitors), process indicators, and outcome indicators (see Appendix B for Figure 2) (Meleis et al., 2000; Meleis, 2010). The following is a brief overview of these five components.

**Component 1.** The first component of Meleis' theory is the types and patterns of transition, and there are several recognized in the theory. These include developmental, situational, health/illness, and organizational. Transitions can occur independently (in isolation), interdependently (where two or more transitions are occurring at the same time and are related to each other), and simultaneously (where two or more transitions occur at the same time but are not related) (Meleis et al., 2000; Meleis, 2010; Geary & Schumaker, 2012). When youth with chronic illnesses such as spina bifida are transitioning from pediatric to adult care, all these transitions are possible. Youth may undergo these transitions simultaneously, and they may or may not be related to each other.

**Component 2.** The second component is the properties of transition and includes awareness, engagement, change and difference, time span and critical events (Meleis et al., 2000;

Meleis, 2010). Awareness is related to the recognition of being in transition. Engagement is the level of which an individual is drawn in to the transition process. Change is related to the perceived importance of the changes required to transition and the nature of the change of transition and may disrupt relationships, routines and perceptions. Difference involves confronting any feelings of difference caused by the transition, including feeling or being perceived as different, or seeing the world or others in a different way. Time span includes the time where an individual is in transition, where there are potential feelings of vulnerability, and stress. The end of the time span signals the end of the transition, and a period of stability. Critical points and events are major events or markers that could be associated with transition, such as the transfer to adult care. The properties of transition are not discrete, and can be interrelated or repeated during the same transition as they are part of a complex process (Meleis et al., 2000; Meleis, 2010).

**Component 3.** The third component is the conditions of transition. These conditions may be either facilitators or inhibitors of transition and can relate to a number of factors, including society, community, family, or the individual (Meleis et al., 2000; Geary & Schumaker, 2012, Meleis, 2010). As an example, a hospital community could provide resources and education to facilitate transitioning from pediatric to adult care through referring a patient to appropriate adult specialists and providing teaching. On the other hand, if a hospital did not provide these resources, this would be an inhibitor to transition.

**Components 4 and 5.** The final two components are related to patterns of response, which are the movements through transition. These movements may be identified and assessed as process and outcome indicators. For example, a process indicator for youth with spina bifida could be developing the confidence and skills in self-managing their neurogenic bladder, being

able to identify UTI's, maintaining regular follow-up appointments, and seeking health care when appropriate. An outcome indicator could be the youth mastering self-catheterization techniques, maintains regular follow-up appointments, recognizes complications and seeks health care when appropriate.

In Meleis et al.'s (2000) and Meleis' (2010) work, she identifies why transition is an area of concern for nurses. Meleis et al. (2000) states that "nurses are often the primary caregivers for clients and their families who are undergoing a transition. They attend to the changes and demands that transitions bring into the daily lives and their families (p. 13)." Meleis' Transition Theory is considered a middle range theory, located between grand theories and situation-specific theories. The abstraction level of a middle range theory is more concrete than grand theories, but less concrete than situation-specific theories. This allows a middle-range theory to be applied to a variety of types of nursing practice settings (as opposed to one setting such as pediatric critical care), and can be more easily tested through research in comparison to grand theories (Marris & Lowry, 2009). The Transition Theory was developed through years of research, literature reviews and testing (Meleis, 2010), and has been used in multiple contexts and scenarios such as transition from pediatric to adult care, transition to motherhood, and transition from health to illness for women with rheumatoid arthritis (Meleis, 2010).

### **Congruence Between the Theories and with Transition from Pediatric to Adult Care.**

Utilizing two models as theoretical foundations has strengthened the theoretical framework of my project. The nature of my project included two major components: chronic illness and transitions. Spina bifida is a chronic illness and management of the disease can be complex, involving many different types of healthcare systems and approaches to care. The Chronic Illness Model allows me to explore chronic illness care, including ways to improve the

current state of care. All individuals with spina bifida who survive to adulthood experience a transition when moving progressing towards adulthood. Meleis' Transition Theory allows me to explore the transition experience and how to facilitate an effective transition. Therefore, using both frameworks allowed me to analyze both major components evident in my topic in an integrated fashion, as opposed to studying each one in isolation.

Using both frameworks held the potential to complicate the identification of implications for the role of the CNS after drawing conclusions from my integrative review. It was important that the theory and model had some congruency to assist me in applying both of them to the exploring the transition from pediatric to adult care literature. I have identified some three primary congruencies between the Meleis' Transition Theory and Chronic Care Model that helped me make connections to between the theory, model, and my integrative review conclusions.

**Individuals with chronic illness experience transitions.** One of the philosophical assumptions of Meleis' (2010) model is that "nurses work with people experiencing developmental, situational, health and illness transitions (p. 338)." Nurses work with many people with chronic illnesses, who could be experiencing any or all of the above transitions. For example, a CNS could work with youth with the chronic illness of spina bifida who are experiencing the transition from pediatric to adult care (both developmental and situational) and a health and illness transition if the individual is experiencing a decline in health and an increase in complications.

**Congruence of model elements.** There are elements in the Transition Theory that are similar to the Chronic Care model. In Meleis' theory, nurses assess and plan interventions to promote evidence-based care to facilitate transition (Meleis et al., 2000). Within the Chronic

Care Model, assessing and planning interventions to promote evidence-based care is also a component of the delivery system design element, and the decision support element includes utilizing evidence-based care in everyday practice. Another common element within the model, theory and the transition literature is self-management. Enhancing self-management of individuals within the Chronic Care Model is similar to increasing the patient's responsibility as developmentally appropriate in the transition literature (Canadian Pediatric Society, 2007; Blum et al., 1993), and patterns of response in Meleis' Transition Theory (Meleis et al., 2000).

**Proactive approach.** A third link between the Chronic Care Model, Meleis' Transition Theory, and the transition literature is the proactive instead of reactive approach. Visentin, Koch & Kralik (2010) used Meleis' Transition Theory when working with adolescents with diabetes who were transitioning to adult care. In the study, diet advice was given to provide adolescents with the skills to manage their diabetes prior to transition to adult care and before diet became a problem for the individual. This would be a condition of transition that is a facilitator, where a health care worker is facilitating an effective transition. Similarly, the Chronic Care Model supports a proactive approach to education (The MacColl Center, 1996 - 2013). The Chronic Care Model authors call for a transformation of health care from a reactive approach where health care professionals respond to illness, to one where healthcare is proactive and the focus is on maintaining and optimizing health (The MacColl Center, 1996-2013). In terms of Meleis' Transition Theory, this would translate into health care professionals' actions providing process outcome facilitators to enable effective transition and optimize health. In the transition literature, actions to facilitate a smooth transition can help achieve an overall goal of optimizing health outcomes (Canadian Pediatric Society, 2007), and can be considered a proactive approach.

In summary, there are a number of congruencies between the Chronic Care Model, Meleis' middle range Transition Theory, and the transition literature. The three primary congruencies I have presented contribute to my beliefs that these theories can be effectively used together with the conclusions of my integrative review to identify implications for the role of the CNS when caring for youth with spina bifida as they transition from pediatric to adult care.

### **Project Aim and Approach**

Through the project, my aims were: (a) to learn more about the transition from pediatric to adult care for individuals with spina bifida, and (b) to be able to identify implications for the clinical nurse specialist role. Specifically, my project goals included:

- Increasing my knowledge about the transition from pediatric to adult care for individuals with spina bifida;
- Identifying activities and interventions that contribute to a successful transition;
- Identifying factors that inhibit a successful transition;
- Learning about specific transition programs for youth with spina bifida published in the literature and their outcomes;
- Learning about the perceptions of youth with spina bifida, especially related to transition, and
- Applying the information obtained in the literature review to identifying the role of the clinical nurse specialist in providing care for youth with spina bifida transitioning from pediatric to adult care.

### **The Integrative Literature Review Process**

According to Polit & Tatano-Beck (2004), an integrative literature review is a type or systematic inquiry about a topic or issue of interest, and has a similar methodology to the research process. Integrative reviews “have the potential to build nursing science, informing research, practice and policy initiatives” as they can be applied directly to both nursing and policy development (Whittemore & Knafle, 2005, p. 546). An integrative literature review is a summary of past research that is conducted to create a more comprehensive understanding of a particular topic. This type of review stands out from other review methodologies as diverse methodologies can be included into the same review such as both experimental and non-experimental research, and qualitative studies (Cooper, 1984; Whittemore & Knafle, 2005).

There are several types of integrative literature reviews. For this project, I have chosen Whittemore & Knafle’s (2005) integrative literature review methodology. Combining papers with varying methodologies can result in bias, lack of rigour, and inaccuracy. Whittemore & Knafle’s review includes steps to minimize bias, lack of rigour and inaccuracy, such as using constant comparison and coding in the data analysis stage. Whittemore & Knafle’s (2005) integrative literature review is a five-stage approach, including problem identification, literature search, data evaluation, data analysis and presentation. In the following sections, I will describe both the stages of the integrative literature review, and present the integrative literature review on my chosen topic.

#### **Stage 1: Problem Identification**

The first step of Whittemore & Knafle’s (2005) literature review involves clearly identifying the problem and purpose of the review. After the problem and purpose are identified,

the variables of interest, including concepts, the population and health care problem, and sampling (types of studies) can be identified (Whittemore & Knafle, 2005).

In this literature review, the purpose was to conceptualize what elements, activities and programs contribute to a successful transition for youth with spina bifida from pediatric to adult care. After I identified what contributed to successful transition, and what did not, I was able to identify implications for the role of the clinical nurse specialist caring for these youth. The research question for this review was “What elements, programs or activities, policies and community resources facilitate a successful transition from pediatric to adult care for youth with spina bifida?”

### **Stage 2: The Literature Search**

A literature search strategy that is both comprehensive and well-defined enhances integrative literature review rigour by preventing biased and incomplete results from an insufficient literature database (Whittemore & Knafle, 2005). The literature search I used included two specific search strategies: an on-line search of electronic databases, and an ancestral search of the references in retrieved articles. My inclusion criteria were: articles published from the year 2000 to present, primary studies, articles studying transition from pediatric to adult care for youth with spina bifida (or elements of transition). I decided to include only articles published after the year 2000 to reflect when the main advances in neurosurgical and urological care (VP shunts and CIC's) would have been established at infancy for the youth transitioning around the year 2000. I chose primary studies to narrow the focus to published studies as opposed to theoretical literature as I believed these publications would be more directly related to my project goals and analysis would be more targeted. My exclusion criteria were: articles published before the year 2000, non-English language articles, theoretical

literature, secondary articles, and articles that studied additional chronic illnesses (i.e. cystic fibrosis, cerebral palsy, etc.). While articles that studied additional chronic illnesses likely would have had relevant information for my project, including these studies would have extended the scope of the analysis, and excluding these studies helped to ensure a manageable number of articles in the review. I searched the CINAHL, PsychInfo and Medline databases using the following search terms: “transition”, “pediatric or child\*”, “adult\*”, “spina bifida OR myelomeningocele OR menongocele”, “continuity of patient care, “transitional programs”, “health transition”, “lifelong”, and “life course.” The retrieved articles were assessed for inclusion in the integrative literature review (meeting inclusion criteria), and references of included articles were searched to identify more potential articles for inclusion. The University of Victoria Distance Education Librarian was utilized for assistance when developing the search strategy and identifying search terms. Eight articles were identified that met inclusion criteria to be included in the review. Multiple articles were not eligible for review, as they did not meet my inclusion criteria. There were two main reasons for excluding articles from inclusion in my review. The first was the publication being a secondary article, such as theoretical literature. The second was the article examined transition from pediatric to adult care for multiple illnesses, such as spina bifida, cerebral palsy, and diabetes.

Table 3

*Literature Review Article Chart*

Database	Medline	CINAHL	PsychInfo
Articles Retrieved	23	34	6
Articles Eliminated after Reading Abstract	21	29	5
Articles Included in Review	2	5	1

Cooper (1984) recommends using a data collection tool to facilitate organizing and making sense of the retrieved data. I used a data collection sheet that I created to record key study characteristics including the following headings: Citation, Research Design, Research Purpose, Theoretical Approach, Sampling, Participant Characteristics, Data Collection Method, Data Analysis, Results, and Summary Conclusions.

### **Stage 3: Data Evaluation**

Evaluating data in an integrative literature review is complex when the included studies have diverse methodologies. (Whittemore & Knafle, 2005). Kirkevold (1997) suggests that in an integrative literature review where the included studies range in types of methodologies, an approach to evaluating quality should include the authenticity, methodological quality, informational value, and representativeness of available primary sources. Whittemore & Knafle (2005) suggest creating a scoring system to assist with evaluating methodological quality. Due to the diverse types of studies it is possible to include in an integrative literature review, Whittemore & Knafle (2005) recommend creating a 2-point scale to assess methodological quality, where 2-points represents high quality, and 1-point represents low-quality.

I developed a scoring system for this review based on Whittemore & Knafle's (2005) 2-point scale, Polit & Beck's four major decision points, and the research textbook by Lobiondo-Wood & Haber's (2009) that I utilized throughout the MN program. I used this scoring system to evaluate the retrieved articles (See Appendix A for the scoring system and an example evaluation). Polit & Beck's (2004) four major decision points to critique a study's methodological quality (for both quantitative and qualitative studies) are: (1) design, (2) setting and participants, (3) data collection, and (4) analysis. I used these headings to organize my scoring system, and added "findings" as one additional section, based on LoBiondo & Haber's

(2009) where I learned that evaluation of the findings is critical when critiquing research studies. I created questions under each heading based on Lobiondo-Wood & Haber's (2009) and Polit & Beck's (2004) critical appraisal guidelines. Finally, I assigned a corresponding score that I believed would allow me to effectively evaluate each article. I could not find a critical appraisal scoring instrument that evaluated both qualitative and quantitative articles that would have appropriately evaluated articles in this review, which resulted in a need to create my own. Disadvantages of using my own scoring system are that: (a) the scoring system has not been previously tested for reliability and (b) important data evaluation components may not have been included that would have strengthened the review.

#### **Stage 4: Data Reduction**

The stage of data reduction organizes and simplifies the data into a framework that is more manageable. During the data reduction stage, I reduced the data from each article to one page and used a constant comparative process to make connections. I decided to focus on several headings: study type, purpose, sampling process, number of participants, participant characteristics, data collection, data analysis, results, and limitations as I believed these to be central aspects of analyzing data from studies that are very different in methodology and purpose. Following evaluation, the results were organized within the categories of education, employment, independent living, self-management, adolescent and young adult experience, social outcomes, transition programs, and transition outcomes. These key result categories were utilized as they emerged from the background literature review and from the two theoretical approaches (chronic care model and transition theory).

#### **Stage 5: Presentation of results**

The final step of Whittemore & Knafl's (2005) integrative literature review framework is presentation of the results. In the final section of this paper I will first summarize the methodologies that were used in the studies. I will then follow with a brief summary of each study included in the review, discussion of the themes that emerged from the review, limitations to the review, and recommendations for clinical nurse specialist practice.

## **Results**

### **Summary of methodology elements**

**Study type.** The research designs varied among the eight articles in this review. Three articles were qualitative studies (Sawin et al., 2009; Ridosh et al., 2011; Osterlund et al., 2005), and five were quantitative studies (Bellin et al., 2011; Liptak et al., 2010; Betz et al., 2010; Cox et al., 2011; & Ruck & Dahan-Oliel, 2010). The three qualitative articles had varied types of design, including exploratory descriptive (Sawin et al., 2009); narrative inquiry (Ridosh et al., 2011); and grounded theory (Osterlund et al., 2005). The five quantitative studies also had varied designs, including a prospective cohort study (Liptak et al., 2010), cross-sectional studies (Bellin et al., 2011; Ruck & Dahan-Oliel, 2010), a randomized controlled trial (Betz et al., 2010), and a non-experimental survey study (Cox et al., 2011).

In addition, three articles were secondary analyses of larger studies (Sawin et al., 2009; Liptak et al., 2010 & Betz et al., 2010). These secondary analyses studies were separate from the larger studies referenced in each article, and these articles did not evaluate the same data included in the larger study. I expected the study types to be primarily qualitative and non-experimental as my initial literature search showed a lack of research in this area.

**Research purpose.** There were several different types of research purposes, as I expected due to the varied research designs. Overall, the main purpose of several articles were to

explore transition experiences (Sawin et al., 2009; Ridosh et al., 2011; Osterlund et al., 2005; and Cox et al., 2011), or to evaluate outcomes, such as transition program outcomes, or outcomes of adults with spina bifida (Bellin et al., 2011; Liptak et al., 2010; Betz et al., 2010; Cox et al., 2011; Ruck & Dahan-Oliel, 2010). For example, Cox et al (2011) evaluated patient perspectives and medical outcomes. Variables that appeared in the research purpose included self-management (Sawin et al., 2009; Ridosh et al., 2011; Bellin et al., 2011, Osterlund et al., 2005), independence (Ridosh et al., 2011, Bellin et al., 2011), medical records (Osterlund et al., 2005), employment (Bellin et al., 2011), quality of life or well-being (Bellin et al., 2011; Cox et al., 2011), social participation (Liptak et al., 2010); transition preparation training (Betz et al., 2010); transition experience (Cox et al., 2011), readiness for adulthood (Ruck & Dahan-Oliel, 2010); teen-centeredness (Ruck & Dahan-Oliel), information management (Osterlund et al., 2005); and care satisfaction (Sawin et al., 2009). The variables identified in the research purposes, such as transition programs, information management, transition preparation training, employment, independence, and self-management, are all important variables related to transition that were identified in the literature, such as the Canadian Pediatric Society's (2007) article. The wide number of variables in the research purpose is reflective of the diversity of research methodologies and purposes.

**Sampling.** Sampling among all studies was stated to be a convenience sample, or when not stated, was presumed to be a convenience sample based on the description of sampling procedures. The one exception was Liptak et al.'s (2010) study, where sampling methods were a randomly selected sample, stratified by geography, district site and community wealth. In Betz et al.'s (2010) study, the convenience sample was also randomly stratified by gender.

**Number of participants.** The number of participants varied from 10 participants in Ridosh et al. (2011) to 130 participants in Liptak et al. (2010). Small sample sizes characterized the studies in this integrative literature review, with the qualitative studies having the smallest sample sizes, and quantitative studies having larger sample sizes. The studies did not explain reasoning for the sample size numbers, except one study (Ridosh et al., 2011), who stated data saturation was reached at 10 participants. The quantitative articles did not report a power analysis, which would have been useful to identify the appropriate sample size for the studies. The sample sizes were small, which may be appropriate in qualitative studies, but may have been too small for the quantitative studies, and were identified as a limitation in a number of studies such as (Cox et al., 2011), who identified a low response rate and therefore sample size, and Osterlund et al., 2005. It is likely that sample sizes were restricted in the studies due to the small population of youth and young adults with spina bifida.

**Participant characteristics.** Participant characteristics that were reported varied among the literature. Culturally, in the majority of studies where ethnicity was reported, Caucasian individuals made up the majority of the population (Sawin et al., 2009; Ridosh et al., 2011; Bellin et al., 2011; Liptak et al., 2010). In Betz et al.'s study (2010), the majority of patients were Latino. In the rest of the published literature about individuals with spina bifida, such as McDonnell & McCann's (2000) study, participants were primarily Caucasian.

Age also varied among studies, with four studies including exclusively adult participants (Ridosh et al., 2011; Osterlund et al., 2005; Bellin et al., 2011; Cox et al., 2011), two studies including youth up to the age of 18 as participants (Liptak et al., 2010, Betz et al., 2010), and the remaining studies including a range of participants that included both youth and young adults (Sawin et al., 2009); Ruck & Dahan-Oliel, 2010). When I compared studies for variables such as

self-management, I needed to be careful to ensure that the ages of participants were comparable, as one would expect self-management skills of youth with spina bifida to be less developed than an adult. In most clinics in Canada, patients are transitioned to adult care at 18, regardless of transition readiness. This is not reflected in some of the studies, such as Ruck & Dahan-Oliel (2010), where transition is more flexible and patients can remain in pediatric care up to age 25. If trying to compare pre and post transition, I would need to be aware of the patient ages in the sample, in comparison to the population for which I am considering a specific intervention.

Several studies reported the type of spina bifida, or level of lesion. In Ridosh et al.'s (2011) study, 70% of participants had a myelomeningocele, and 30% had a lipomeingocele. 30% of participants in the study had a high lumbar, 20% had a mid-lumbar, 20% had a low lumbar, and 30% had a sacral level of lesion. The type of spina bifida and level of lesion was reported in Sawin et al. (2009; Ridosh et al., 2011; Bellin et al., 2011, and Cox et al., 2011). The only study where all participants had a myelomeningocele (the most severe form of spina bifida) was Bellin et al., 2011). It is important for me to be aware of the reported level of lesion and type of spina bifida, as severity of medical outcomes vary, and could significantly impact data retrieved in the study in aspects such as medical outcomes, quality of life, and independence. For example, I would expect Bellin et al.'s (2011) participants to have worse outcomes than Ridosh et al. (2011), as all the participants in Bellin et al.'s (2011) study was classified as having a myelomeningocele, compared to 70% in Ridosh et al.'s (2011) study.

**Data collection.** There were common themes among data collection techniques. Qualitative studies used interviews to collect data (Osterlund et al., 2005; Ridosh et al., 2011; Sawin et al., 2009). One article, Osterlund et al. (2005), also used focus groups. Quantitative studies used surveys (Liptak et al., 2010; Cox et al., 2011), questionnaires (Betz et al., 2010;

Ruck & Dahan-Oliel, 2010), and chart reviews (Ruck & Dahan-Oliel, 2010). Qualitative articles did not use data collection tools, which would be appropriate to this type of methodology. The particular instruments for data collection used in the quantitative articles varied. These included the use of both validated and reliable tools (such as the SF-36 in Cox et al. (2011), and the Community Life Skills Checklist in Betz et al. (2010). In addition, there were instruments used that were created specifically for a particular study, such as the TDQ transition questionnaire in Betz, 2010). For the quantitative studies, I could place more confidence in results from studies that employed validated data collection instruments than studies who used instruments that had not been tested, or had lower validity and reliability.

**Data analysis.** Data analysis was undertaken in a variety of different ways in the studies. The qualitative studies (Sawin et al., 2009; Ridosh et al., 2011; Osterlund et al., 2005) involved different types of analyses based on their unique methodologies. For example, in Ridosh et al.'s (2011) study, two authors read and re-read transcripts to identify commonalities and unique experience, and to identify themes. Afterwards, the three additional researchers contributed to the analysis and validated themes. All three qualitative studies used appropriate data analysis methods. In the quantitative studies, data analysis methods varied, including descriptive statistics (Bellin et al., 2011; Cox et al., 2011; Betz et al., 2011; Liptak et al., 2010), logistic regression or linear regression (Bellin et al., 2011; Liptak et al., 2010, Betz et al., 2011), and analysis of variance or covariance (Bellin et al., 2011; Liptak et al., 2010, Cox et al., 2011). Regression and analysis of variance and covariance typically requires larger sample sizes. While the type these types of analysis may have been appropriate, the small sample sizes characteristic of the studies in the review decreases the appropriateness of this type of analysis.

**Summary of key variables.**

**Education.** Lower levels of education were reported in many of the studies, which is consistent with the literature (Betz et al., 2011; Boudos & Mukherjee, 2008). For example, in Bellin et al.'s (2011) article, 51% of participants had a high school diploma or GED, and 10% were college students. Support services from school were reported to be lacking in some studies. Liptak et al. (2010) reported that 26% of parents either disagreed or strongly disagreed their youth was receiving the needed support and services from their school. Ruck & Daham-Oliel's (2010) study reported 77% of participants had the time and space that their health care needs required at school, 39% of participants had IEP's and transition services available, and 55% of participants had knowledge about post-secondary education. Youth in the study reported wanting to learn more about post-secondary education and assistance programs (Ruck & Daham-Oliel, 2010). Overall, education levels among youth with spina bifida are low, especially in comparison with the general population, and youth with spina bifida may not have access to required services such as IEP's, and post-secondary education information.

**Employment.** Employment rates were generally low among the studies where employment was reported. In Bellin et al.'s (2011) study, 55% of participants were unemployed. Those who were employed held low-wage entry-level positions such as a grocery clerk or a store greeter, and more men were employed than women. In Cox et al.'s (2011) study, 67.7% were unemployed. In Ruck & Daham-Oliel's (2010) study, 50% of participants were employed or volunteered. In Liptak et al.'s (2010) study, where 76% were either competitively employed (or at postsecondary school) within the previous 2 years, and 36% had a job within the previous 12 months. It is difficult to compare Liptak et al.'s (2010) sample with the other studies that reported education levels, as it was measured differently (employment within the last 2 years or 12 months as opposed to currently employed). It was difficult to analyze the significance of

employment data, especially comparing between studies. The age ranges of participants varied amongst studies, and many of the participants could be high school or postsecondary students, and therefore being unemployed could be justifiable. Rates of employment among individuals with spina bifida have been reported as low in other published literature, including unemployment rates 60% or greater as cited by Betz et al. (2010) from Boudos & Mukherjee (2008), McDonnell & McCann (2000), and Hunt et al.'s (1999) studies. Employment is critical for individuals with spina bifida, who have costly and complex medical and equipment needs. Without a job, an individual might have limited access to insurance or financial resources to cover medical expenses. They would also likely be financially dependent on their parents.

***Independent Living.*** Several studies reported the incidence of independent living. In Bellin et al. (2011), 74% lived at home with parents in a supervised setting. 24% lived in an independent setting, and 92% of those who lived independently were female (Bellin et al., 2011). In Liptak et al.'s (2010) study, during wave 3 (when the mean age was 19.3 years), 79% of participants lived with their parents. In Cox et al.'s (2011) study, 29.2% lived independently, while 70.8% lived in a group home. Cox et al. (2011) also reported participants who lived alone experienced decreased emotional well-being and mental health. Overall, these independent living rates are low. Bellin et al. (2011) reported that independent living rates among young adults with spina bifida are lower than individuals with other chronic health conditions. Low independent living rates could be related to a number of factors such as poor self-management skills, unemployment, and financial dependence on parents that prevent an individual's ability to live independently. Low rates of independence could also be potentially related to changing a changing social climate, with the "emerging adulthood phase" extending between 18 and 25 years, or maybe even into the early 30's (Ruck & Dahan-Oliel, 2010) which could potential

delay transition to independent living. Independent living is a key variable to transition planning according to sources such as Blum et al. (1993), and the Canadian Pediatric Society (2007).

***Self-Management.*** Self-management was discussed in many of the articles. Sawin et al. (2009) described the experiences of adolescent women with spina bifida with self-management. They identified three and seven subthemes. Overall, self-management was recognized as important among the participants to gain independence. Additionally, parents have a role in promoting self-management through a balancing act of protecting and promoting independence, and facilitating shared decision-making. In addition, advocacy was identified as a theme to confront discrimination and stigma. Self-management preparation was identified as needing to start early (Sawin et al., 2009). In Ridosh et al.'s (2011) article, a theme included participants struggling for independence, and the feeling that their parents should have made them self manage their care sooner. Participants in Ridosh et al.'s (2011) study also believed they can accomplish most things. In contrast, participants in Osterlund et al.'s (2005) study disregarded self management with respect to managing medical records, and delegated this activity to their parents. In Bellin et al.'s (2010) article, it was shown that self-management skills increased in participants with lower levels of lesion. This would be expected as lower levels of lesion are associated with decreased severity of disability and medical issues. Ruck & Dahan-Oliel's study described a concerning lack of self management among their participants. Many participants in Ruck & Dahan-Oliel's (2011) study were not able to describe their health condition and speak with their medical doctor. Many were also not able to manage their care independently, including taking medications, and were not responsible for making medical appointments or maintaining their home medical records. Self-management includes being able to describe one's illness and medical needs, manage their own care, and seek medical follow-up when necessary

and these skills are expected among adults utilizing the health care system (Canadian Pediatric Society, 2007; Blum et al., 1993). The studies included in this review show that while the importance of self-management is recognized, there is a lack of self-management in this population.

***Adolescent and young adult experiences.*** Experiences of adolescents and young adults varied among the articles included in the review, including some experiences with “overprotective parents” in Ridosh et al.’s (2011) article, experiences managing medical records such as limited medical record information being given from healthcare providers to participants in Osterlund et al.’s (2005) article. One common experience identified in several articles was stigma and bullying. In Ridosh et al.’s (2011) article, stigmatization was a common experience, including feelings of being a different, and kids making fun of them. In Sawin et al.’s (2009) article, participants described being on the receiving end of teasing, staring, and hurtful comments. In this article, the importance of friends and family to fight discrimination was common, such as friends advocating for participants and standing up against bullying. In Liptak et al.’s (2010) article, participants reported being teased (47%) and bullied (27%). Other reported literature, such as Sawyer & MacNee (2010) also recognizes the prevalence and impact of bullying, teasing and stigma among adolescents and young adults with chronic illnesses, including spina bifida, which can be addressed through a transition program with a broad transition planning definition.

***Social Outcomes.*** Several types of social outcomes were reported by two studies included in the review. Liptak et al. (2010) reported computer use as a hobby among many participants for accessing the Internet, playing games, email and chatting, and completing homework. Ruck & Dahan-Oliel (2011) reported many participants having a confidante and

seeing friends at least once a week including peers at school, and participating in recreational activities. Other articles in the review did not report social outcomes other than independent living and employment. Thibadeau et al. (2011) stated individuals with spina bifida often have challenges in achieving social participation, and transition planning and preparation for social participation should begin early.

Liptak et al. (2010) reported data about health-risk behaviours. In their study, 6% of participants had smoked a cigarette, and 20% had used alcohol in the past 30 days. Health risk behaviours have been reported to be higher among individuals with spina bifida in comparison to the general population, but this was not reflective in Liptak et al.'s (2010) study.

***Transition Programs.*** Several of the articles included youth and young adults who participated in transition programs. For example, in Betz et al.'s (2010) article, the intervention was a transition program. The program was a 3-module, 8 session program in a 2-day workshop which involved assessment of goals, and creating a plan to achieve the goals, and identifying community resources. In Cox et al.'s (2011) article, participants were part of a transition program at the centre where the study took place, and participant's experiences were evaluated. The transition program in Cox et al.'s (2011) study was not described. In Ruck & Daham-Oliel's (2010) article, the transition program at Shriner's Hospital for Children was evaluated, but their transition program was also not described. In the one article that described the transition program (Betz et al., 2011), aspects of the transition program were consistent with important components of transition program in the literature, including goal setting, individual assessments, and identifying community resources, but some other important components of transition programming were missed, such as patient education about their disease, self-management, and practicing self management in increasing steps, but these could have been included in each

individual's self-identified goals during the study. Since two of the three transition programs were not described, I was not able to compare them.

***Transition Outcomes.*** Transition outcomes varied across studies. In Liptak et al.'s (2010) study, health decreased over time, and Latino health deteriorated fastest. This is consistent with other reported literature. For example, in Sawyer & MacNee's (2010) article, while youth with spina bifida's health status was similar to the general population; young adults with spina bifida health status was considerably worse than the general population.

In Betz et al.'s (2011) article, a randomized trial assessing a transition program, there was no significant difference between the control and experimental groups. There were at least four possible reasons for the lack of significance between the two groups. First, the intervention dose was small, including use of a short work shop. The sample size was also very small, and considered a possible contributing factor. The sample size was also not reflective of the general population of youth with spina bifida, as the majority of the sample's cultural background was Latino. Lastly, the mean age was 16.19 years, which the majority of transition literature (such as the Canadian Pediatric Society, 2007 article) would consider this late to start a transition program.

In Cox et al.'s (2011) study, patients and parents were more satisfied with pediatric care than adult care. Barriers to transition were identified in the study. These included the clinic not adequately addressing financial and employment issues, and not visiting the adult clinic before transition (Cox et al., 2011). In Ruck & Daham-Oliel's (2010) study, several transition outcomes were reported. For example, 89% had a family doctor, and a similar number had knowledge about risky behaviours. 65% were able to describe their condition, speak with their doctor, and manage their health care independently. Other reported outcomes included 53% of participants

being responsible for making medical appointments and keeping medical records, and 94% being at least partially independent with care. More than half of participants did not have an adult health care provider, and one-third of participants did not have a way to pay for medical supplies when transitioned to adulthood (Ruck & Daham-Oliel, 2010). Youth in the study wanted more information about employment, careers, postsecondary education, independent living, and assistance programs (Ruck & Dahan-Oliel, 2010). The issues identified in the articles were consistent with the literature, including self-management, knowledge of participant's conditions, obtaining a primary care physician, independent living, employment, and high-risk behaviours.

### **Brief summary of each study**

**Ridosh, M., Braun, P., Roux, G., Bellin, M., & Sawin, K. (2011). Transition in young adults with spina bifida: a qualitative study. *Child: Care, Health and Development*, 37(6), 866-874. DOI: 10.1111/j.1365-2214.2011.01329.x**

Ridosh et al. (2011) conducted a narrative inquiry study. The narrative inquiry design was selected due to the intention of “to focus on the relationship between individual’s life stories (Ridosh et al., 2011; p. 867)”. Narrative inquiry guides the synthesis of data to represent the participant’s stories as a whole (Ridosh et al., 2011). The research purpose was to explore three specific dimensions of the transition experience. These include: 1. self management, 2. independence, and 3. the role of inner strength in the pursuit of independence. The theoretical frameworks guiding the study were the Ecological Model of Secondary Conditions and Adaptation and the Theory of Inner Strength, and these frameworks were appropriate for the study. Participants in the study were recruited during their clinic appointments at a large teaching hospital in a Midwest metropolitan city in the USA, presumably a convenience sample.

There were 10 participants included in the study. Several patient characteristics were reported in the study. These participants had varying types of spina bifida and functional motor levels. In addition to spina bifida, other chronic conditions were present in some participants including Arnold Chiari malformation, and hydrocephalus (with some requiring shunts). The age of participants ranged between 18 and 25 years of age, with the majority between 22 and 24 years old. Several social outcomes were reported, including marital status, living arrangements, employment, and education. All participants were single; the majority of participants lived with parents or friends, and 1 participant reported living alone. Employment status varied, with five participants employed part-time, one participant employed full time, and four participants were unemployed. All participants had completed high school education; two participants were in vocational school, and two were attending college. Two participants had a driver's license. Five participants used a wheelchair for mobility, and five required orthotics. These characteristics appeared to be consistent with other published studies. While the sample size was small, the authors reported data saturation was reached. The data collection method included semi-structured interviews with the questions derived from concepts relating the theoretical framework. In particular, self-management, relationships with others, satisfaction with bowel and bladder management, and reflection about building inner strength were discussed in interviews. Initial data analysis was conducted collaboratively by the first 2 authors (Ridosh & Braun). This included reading and re-reading transcripts to identify unique experiences and commonalities through narrative analysis. Next, the researchers met to discuss findings and themes, and three additional investigators contributed to the final analysis and validated the study findings. This data analysis was appropriate for the study methodology. There were three major themes within the study. These were: 1. Struggling for independence: 'my parents should have

made me do it sooner’, 2. Limiting social interaction and experiences with stigma – ‘the looks’, and 3. Building inner strength – ‘I believe I can accomplish most things’. Other important information gathered from the study was that not including a visit to the adult clinic prior to transitioning to adult care was identified as a transition barrier; participants in the study wanted to make more decisions regarding care, and youth did not think their parents were unable to give up control of their care. Additionally, participants believed pediatric caregivers let go of care appropriately, adult caregivers were knowledgeable, and the pediatric and adult teams communicated well. The study authors identified implications for practice, including interventions designed to education families to promote social and peer relationships, building job skills, and care models to promote self-management in addition to conducting further research. Reported limitations of the study included recruiting participants from only one site, using a semi-structured interview could have limited themes, and that each participant would respond based on their own definition of inner strength.

**Osterlund, C., Dosa, N.P., & Smith, C.A. (2005). Mother knows best: Medical record management for patients with spina bifida during the transition from pediatric to adult care. *AMIA 2005 Symposium Proceedings*, 580-584.**

Osterlund et al. (2005) conducted a grounded theory study to assess how young adults and their parents interact with their medical records during the transition from pediatric to adult care. In particular, they were interested in “who”, “how”, “what”, and “when” questions (i.e. when is the information needed by parents or patients?). A convenience sampling method was utilized to recruit participants from a regional referring centre. Ten patients, six parents and one caregiver were recruited to participate from a total of 34 patients. Reported participant characteristics included four men and six women with spina bifida, with an age range between 18

and 21 years, four mothers, two fathers, and one private duty home nurse. The data collection methods included focus groups and structured interviews in order to learn the interactions young adults had with their medical records during the transition from pediatric to adult care. Data analysis included transcribing focus group discussions verbatim, and the grounded theory inductive research technique. NVIVO qualitative software was used for data coding and analysis to identify dominant themes. Two phases of analysis occurred: condensation and categorization, and were appropriate to the research method. Thematic analysis was centered on ‘who,’ ‘how,’ ‘what,’ and ‘when’ questions. An overall theoretical diagram was created to explain the themes. It showed family, health care providers, and youth with spina bifida being responsible for medical records, with more information sharing occurring in the direction of parent to provider as opposed to the opposite direction. Limited record sharing occurred between healthcare providers. Medical records were maintained chronologically, and parents were essential in maintaining medical records and remembered the most details in comparison to patients. This type of theme identification and overall theory creation was appropriate to the research method. Overall, summary conclusions were the participants in the study were not as concerned about the transition from pediatric to adult care as they were concerned about youth taking over healthcare information management. In addition, work needs to be done to assist the transition of the health information management role from parents to youth. Limitations identified included the small sample, the qualitative nature of the study, and overrepresentation of highly motivated parents and high-functioning patients, in addition to the flow of the focus group discussion possibly leaving out some participant’s perspectives.

**Sawin, K.J., Bellin, M.H., Roux, G., Buran, C.F. & Brei, T.J. (2009). The experiences of self-management in adolescent women with spina bifida. *Rehabilitation Nursing*. 34 (1), 25-38. DOI 10.1002/J.2048-7940.2009.tb00245.x**

Sawin et al.'s (2009) article was an exploratory descriptive qualitative study, and was part of a large mixed-method study. The study's purpose was to explore the experience of self-management in adolescent women living with spina bifida, and to better understand the challenges facing these women. The theoretical framework of the study was the Ecological Model of Adaptation in Spina Bifida. This framework integrates developmental and systems theories, and situational perspectives in order to describe adaptation in adolescents living with spina bifida. The study was also influenced by the Independent Living Model and the Internal Classification of Functioning, Disability and Health. All three models were appropriate for the research purpose. The sampling method included a convenience sample of 31 adolescent women, which I believe was an appropriate sample size for a qualitative study. Participant characteristics included an age range of 12 – 21 years (mean 15.84), English-speaking, functioning at their grade level in school, and the majority being non-Hispanic white ethnicity. Their level of lesion varied, as youth with thoracic, lumbar, lumbrosacral, and sacral level of lesions represented. The most common level of lesion was lumbar (32%). I questioned whether the participants would be representative of all youth with spina bifida, due to the prevalence of cognitive deficits among individuals with spina bifida. Some women with spina bifida might be functioning at a lower than regular grade level for their age due to cognitive deficits. Data collection included semi-structured interviews, and this was appropriate to the research design. Data analysis was done through content analysis where the first three authors (Sawin, Bellin, and Roux) coded the data, and the data was analyzed for themes. The last two authors (Buran and

Brei) reviewed the analysis for confirmation. The authors used exact words spoken by the adolescents in the themes. While level of lesion was initially used to classify and distinguish themes, it was removed to maintain confidentiality. This was an appropriate method of data analysis for the research method. Three themes and seven subthemes emerged (see below table)

Table 4:

*Themes and SubThemes in Sawin et al.'s (2009) article*

<b>Theme</b>	<b>Subtheme</b>
1. Opportunities to engage in self-management activities – knowledge, skills and aspirations	<p>a. Specialized knowledge and skills related to management SB: ‘I feel it should be my responsibility’</p> <p>b. The journey of skill-building tasks to achieve independence – ‘I need to learn to take care of myself’</p>
2. Dance of individuation – Parental impact on self-management	<p>a. Restricted parenting – parenting delays skill-building to achieve independence – ‘She’s overprotective’</p> <p>b. Balanced parenting – parenting balances protection and promotion of independence: ‘Difficult with certain situations’</p> <p>c. The process of shared decision making to enhance optimal outcomes – ‘In case I do need help’</p>
3. Advocacy within self-management – Confronting discrimination and stigma	<p>a. Self-advocacy: ‘I want to be treated like I’m a person’</p> <p>b. Peer and adult advocacy: “He’ll stick up for me”</p>

Developed from: Sawin, K.J., Bellin, M.H., Roux, G., Buran, C.F. & Brei, T.J. (2009). The experiences of self-management in adolescent women with spina bifida. *Rehabilitation Nursing*. 34 (1), 25-38. DOI 10.1002/J.2048-7940.2009.tb00245.x

The authors concluded conclusions that interventions to assess and enhance self-management are essential to providing optimal health care for these patients. Also they concluded that failure to address self-management could send the message that the young adults might not be able to take care of themselves or transfer to adult care. These themes and

conclusions were appropriate to the data presented. Reported limitations were the limited diversity of the participants, including primarily Caucasian ethnicity. The authors identified a need for further research, including testing interventions for its effect on self-management.

**Betz, C.L., Smith, K., & Macias, K. (2010). Testing the transition preparation training program: A randomized controlled trial. *International Journal of Child and Adolescent Health*, 3(4), 595-607.**

Betz et al.'s (2010) study was a randomized controlled trial that tested if a cognitive-behavioural program of transition-preparation training (TPT) in combination with spina bifida management results in improved transition subjective well-being, role mastery, and self-care. The sampling method included a convenience sample with randomized sampling stratified by gender for 65 patient participants. The sample size was small for the study method, but was likely limited due to the small number of youth with spina bifida. Inclusion criteria were youth whose age ranged between 14 and 18 years, spoke English, and had no history of intellectual disability. Inclusion criteria for parents (participated by filling out questionnaires) were their child was enrolled in the study, and spoke English or Spanish. The experimental and control groups had similar patient characteristics. The majority of participants were attending or had completed high school, with few attending college (4). The majority of participants ethnicity was latino (87% in the experimental group and 91% in the control group). The majority of parents had latino ethnicity, and had completed a high school education. The mean age of parents in the control group was 40, and 43.25 in the experimental group. Through studying the participant characteristics I noticed the patient demographics differ from previously reported studies. These included participants' ethnicity being primarily Latino, and youth participant's having no intellectual disabilities. While having no history of an intellectual disability may not be

characteristic of the typical spina bifida patient, I thought this was appropriate to maintain control in a randomized controlled trial. The intervention was a transition-training program: a 3 module, 8 session program offered through a 2-day workshop. It involved developing a transition plan that was adolescent centered and based on an assessment of the adolescent's goals for the future. The program also included developing strategies to achieve goals, identifying service needs, referrals and contact information, and strategies to obtain required services. The experimental group received the program, and the control group did not. Data collection included pre (baseline) and post (four months later) outcome data collected from both youth and parents, and surveys measuring subjective well-being (PARS III filled out by youth with SB and parents), role mastery (CLSS completed by youth with SB), self-care practice (DSCPI-90 completed by youth with SB), and demographic questionnaires filled out by youth with SB and parents. The PARS III had coefficient alpha estimates ranging from 0.7 and 0.8, and internal consistency of 0.88 to 0.9 indicating good reliability. The CLSS had a cronbach alpha of 0.69 at initial administration and 0.63 at 1 and 2 years, indicating a moderate reliability. The DSCPI-90 had a test-retest reliability of 0.84 to 0.92, indicating good reliability. Analysis included descriptive statistics to compare the two groups, and a linear regression random effects model to compare summary scores, and a main effects model applied separately to each outcome measurement of interest. Overall, there was no significant difference between the two groups. The lack of significant difference could have been caused by several limitations including insufficient intervention dose strength, the youth's knowledge being lower than the researcher's anticipated, and lack of adherence to the protocol (poor attendance, not following through with transition plan), and insufficient time frame.

**Cox, A., Breau, L., Connor, L. McNeely, P.D., & Anderson, P.A. (2011). Transition of care to an adult spina bifida clinic: Patient perspectives and medical outcomes. *The journal of urology*. DOI: 10/1016/j.juro/2011.04.011**

The purpose of Cox et al.'s (2011) study was to find patient and parent perspectives on the transition process at the authors' healthcare center and correlate the perspectives with patient's medical outcomes. The research design was not clearly stated, but could be a non-experimental telephone survey study with a chart audit, or program evaluation or quality improvement. Patients who attended the adult spina bifida clinic at the study's centre were invited to participate, therefore the sample appeared to be a convenience sample. There were twenty-four participants in the study. The response rate was 22.8%, which is low but expected for a telephone survey. Reported participant characteristics were mean age, level of lesion, living arrangements, mobility, employment, and education. Participants had a mean age of 26.8 years, the majority of participants had myelomeningocele (lipomeningocele and sacral agenesis was also represented in the sample in small numbers), and lived with a parent or in a group home (70.8%). The majority of participants were wheelchair dependent or walked with an aid. Among all participants, 33.3% were employed, about 50% had completed high school, and 50% had completed some college or university. These characteristics appear consistent with other reported studies in the literature, except this population appears to be better educated. Data collection procedures included three telephone surveys: SF-36, ACES, and TCS. Surveys were completed by the participants, (young adults with spina bifida) or parents could complete then if the participant was not able due to a disability. The parents could complete a parent version of the TCS. The SF-36 is a measurement of functional health and well-being, and has been well-used in research and previously validated. The ACES survey evaluates patient experiences with

healthcare professionals, and has also been previously validated. The TCS evaluated patient and caregiver perspectives; it was created for this study and was not validated. A validated measurement tool would have been more appropriate, or it also would have been appropriate to validate this tool. A retrospective chart review included recording urological, nephrological and neurosurgical outcomes.

Data analysis was done using statistical software; SPSS version 16.0. MANOVA and MANCOVA tests were used to judge significance for the surveys. In addition, descriptive statistics were calculated. MANCOVA's were also used to determine whether medical outcomes were related to the SF-36. Overall, the results were that young adult's perspectives were independent of health outcomes. Young adults and parents were satisfied with both the adult and pediatric clinics, but preferred the pediatric center. Participants felt transition care failed to address financial and employment issues, and that it would have been helpful to visit the adult clinic prior to transitioning to adult care. They also felt they should be allowed to make more decisions regarding their care. Participants believed communication between the pediatric and adult centers was adequate (although many healthcare providers worked at both centers). Medical outcomes in this study included poorer neurosurgical outcomes (higher incidents of hydrocephalus and VP shunts), and better urological and nephrological outcomes. Limitations included a poor response rate, small sample size, and including patients with less severe forms of spina bifida (lipomyelomeningocele, and sacral agenesis) may have improved medical outcomes.

**Bellin, M.H., DiCianno, B.E., Levey, E., Dosa, N., Roux, G., Marben, K., & Zabel, T.A. (2011). Interrelationships of sex, level of lesion and transition outcomes among young adults with myelomeningocele. *Developmental Medicine & Child Neurology*, 53; 647-652. DOI: 10.1111/j.1469-8749.2011.03938.x**

Bellin et al. (2011) conducted a study to evaluate self-management, employment, independent living and quality of life for individuals with myelomeningocele who had transitioned to adult care. The design was not stated, but appears to be non-experimental cross-sectional study with a structured interview and self-report questionnaire. The study was part of a larger longitudinal study assessing psychosocial adaptation in the population. Study participants were recruited from five multidisciplinary clinic sites in the USA. Sampling appears to have been done by a convenience sample, but this was not explicitly stated. Eligibility criteria included diagnosis of myelomeningocele, age between 18 and 25, residing in one of the five of the study site's catchment area, and the ability to understand the study instruments. The sample size included fifty participants (38% response rate). The mean age was 21 years and 5 months, and participant ethnicity was mostly Caucasian. The majority of participants had hydrocephalus requiring a shunt, with 3.03 mean shunt revisions. A lumbar level of lesion was most frequently reported among participants. Half of respondents had completed high school, 8% had completed college, and 10% of respondents were college students. Fifty-eight percent of participants were unemployed, and those who had obtained employment had low-wage, entry-level jobs. Most participants lived in a supervised environment (74%), and the majority of those who lived independently were female. Data collection included a structured interview of the Adolescent Self Management and Independence Scale (AMIS III) that gathers information about "knowledge and behaviours in myelomeningocele management activities and general activities of daily living (p. 648)." Reliability ranged between 0.72 to 0.89, and the interrater reliability of 0.9, both good reliabilities. Community integration was measured through employment and living status. Quality of life was measured by the World Health Organization Instrument (WHOQOL). The WHOQOL has good internal consistency, and discriminant and construct

validity. Cronbach's alpha ranged from 0.62 to 0.78, showing moderate to good reliability. Data analysis included a statistical analysis, including two-tailed tests, multivariate analysis of variance and covariance, and logistic regressions. This was appropriate for the data collection methods, but was not appropriate for the small sample size. Overall conclusions included no differences in self-management by gender, and significant differences in self-management for level of lesion (lower level of lesion resulted in increased self-management). For community integration, lower level of lesion was associated with greater likelihood of independent living and employment. Gender and self-management were predictors for employment and independent living. More women lived independently, and more men were employed. Level of lesion was a predictor for quality of life, where lower level of lesion resulted in a higher quality of life. Reported limitations were the small sample size (limited statistical analysis), recruitment from only multidisciplinary clinics, the cross-sectional nature of data, and reliance on self-report. Areas for further research identified by the authors included comparing samples of populations with different disabilities to the population with spina bifida.

**Ruck, J., & Dahan-Oliel, N. (2010). Adolescence and young adulthood in spina bifida: Self-report on care received and readiness for the future. *Topics in Spinal Cord Injury Rehabilitation*, 16(1), 26-37. DOI: 10.1310/sci1601-26.**

The purpose of this study was to evaluate the transition program at Shriner's Hospital for Children in Montreal. This included evaluating youth with SB's level of readiness for adulthood, measuring their perception of the teen-centeredness of care at SHC, and determining the transition program's areas of improvement. The type of study was not stated, but appears to be a non-experimental cross-sectional study, or it could also be a program evaluation. The study included two questionnaires and a chart review. Adolescents between the ages of 14 and 21 who

attended the SHC spina bifida clinic between 2004 and 2009 were included in the study (36 patients), and surveys were administered as part of routine transition care. Participants mean age was 17.8 years and they lived across Canada, with the most living in Nova Scotia. The questionnaires administered included the Young Adult Transition Assessment and The Giving Youth a Voice Survey. The Young Adult Transition Assessment collected information to assist patients and their families plan for adult life, and assisted the healthcare team in developing patient-tailored transition services. Validity and reliability of the Young Adult Transition Assessment was not reported. The Giving Youth a Voice Survey evaluated satisfaction with services from a young adult or youth perspective. The original version was shortened to 20 items, with the original version having a Cronbach's alpha of 0.88 to 0.97, and test re-test reliability of 0.7 to 0.87. Convergent validity was estimated to be 0.399 to 0.61 (correlation with Client Satisfaction Questionnaire), showing a good reliability, and moderate validity. Analysis was done using descriptive statistics including means with an excel spreadsheet. Strengths and weaknesses of the program were identified based on mean survey responses. Results included many participants in the study not being responsible for many areas of self-management such as making clinic appointments, and they were not sufficiently educated in their illness. Among the participants, 50% did not have a way to pay for their supplies and therapies when they were adults. Many participants did not have a driver's license, have access to a vehicle, or knew how to use public transportation. Many participants reported they have friends they saw once a week, had regular attendance school, and had their health care needs while at school met. About half of the participants volunteered or had a paying job, and 55% had knowledge of postsecondary education. Many participants (22) had not yet found an adult health care provider. Information participants wanted to learn more about were the most were careers, disability information,

independent living, adult care providers, college and scholarships, assistance programs, and health insurance. Weaknesses of the program included failing to treat the youth as young adult as opposed to a child, looking at all the teen's needs, and being aware that a child's needs change with growth. Limitations were not reported but I believed limitations were the small sample size, the cross-sectional nature of data, the age range of transition was different from many other models of care (normally youth are transitioned to adult care at 18 years old), and limited generalizability of findings (only to youth and young adults with SB and myelodysplasia attending this clinic). Implications of the research include enhancing education and interventions to enhance self-management, broadening transition planning to include more information about youth's identified needs, and increased communication and planning for the transition to adult health services.

**Liptak, G.S., Kennedy, J.A., Nienke, P.D. (2010). Youth with spina bifida and transitions: Health and social participation in a nationally represented sample. *The Journal of Pediatrics*, 157(4), 584-588. DOI: 10.1016/j.jpeds.2010.04.004**

The purpose of this prospective cohort study was “to describe outcomes and identify factors that affect social participation in youth and young adults with spina bifida (p. 584).” The long term goal was to gain knowledge that can develop and guide interventions for individuals with spina bifida transitioning from pediatric to adult care in order to maximize social participation. The guiding framework was the World Health Organization's International Classification of function, disability and health. The study was part of a large national cohort study (“The National Longitudinal Transition Study 2”) and consisted of a prospective cohort study. Youth were followed for four years over three waves (three data collection points with data collected from waves one and three were included in the study). Stratified random sampling

was used to obtain a nationally representative sample of 130 youth with spina bifida through local education agencies. The sample was stratified by geography, district site, and community wealth. The mean age of participants at the time of enrollment was fifteen, and their mean income was \$39,030. There were more males (66%) than females, and the majority of participants were of Caucasian ethnicity (62%). Among all participants, 26% were below the poverty line. Data for the study was stated to be obtained from the larger study, and the specific questionnaires used were not stated. The article states reliability of data collection instruments was verified through pretesting, and validated questions from national surveys and from the first NLTS were used, but more specific details were not provided. I would have benefitted from more details about data collection methods, tools, and rigour to conduct an accurate data evaluation. Data analysis included descriptive statistics, chi-square tests, and analysis of variance. Structural equation modeling was the method of choice but was not used due to the small sample size. Conclusions included the general health status of participants declining from adolescence to early adulthood. Many participants reported being teased or bullied (47% and 24% respectively), and having at least one other disability. The majority lived with their parents (79%), and were either employed or had attended a post-secondary school within the previous two years (76%). Few participants reported having sexual intercourse, smoking, or alcohol use. Overall, the authors concluded interventions to improve health, well-being and social participation among youth and young adults with spina bifida are needed. Limitations included the small sample size, and relying on a spina bifida diagnosis confirmation by the school district.

### **Discussion of Themes**

Through the integrative literature review, I have learned a great deal of valuable information about transition from pediatric to adult care for youth with spina bifida that can be

applied to the role of the CNS. The final step is to now take the knowledge I have gained and apply what I have learned to the role of the clinical nurse specialist moving forward, taking into consideration my theoretical viewpoint of the chronic care model and Meleis' Middle Range Transition Theory. While initially, I wanted to learn what aspects facilitated an effective transition from pediatric to adult care, I realized during my literature review that this has still not been clearly answered with the limited research available. Instead, I have decided to focus on self-management, independence, level of lesion, transition programs and their implications to the clinical nurse specialist role caring for youth with spina bifida who will transition from pediatric to adult care.

### **Self-Management**

Self management was a central theme in many of the review articles (Ridosh et al., 2011; Osterlund et al., 2005; Sawin et al., 2009; Betz et al. 2010; Ruck & Dahan-Oliel, 2010). This was unsurprising due to the focus of self-management in the transition literature, such as in the Canadian Pediatric Society (2007) and Blum et al.'s (1993)'s classic articles. By analyzing articles included in the review, it is evident that adequate self-management skills are lacking among youth and young adults with spina bifida, despite the recognition that self-management skills are important. For example, Ruck & Dahan-Oliel (2010) stated that many participants in their study were not responsible for self-management activities such as making appointments. There were several recommendations for improving self-management throughout the review. These included starting self-management early, providing education, and allowing youth to practice self management skills prior to transitioning to adult care. This is consistent with other

published literature (Canadian Pediatric Society, 2007; Blum et al., 2003; Johnston-Fletcher et al., 2011). Liptak et al. (2010) reported a general decrease in health status over time, which while not proven in the literature, could be partially a result of inadequate self-management. One element of the Chronic Care Model is self-management. In order to empower patients to manage their health care, the chronic care model recommends emphasizing their role to managing their health, utilizing self-management support strategies: “goal-setting, action planning, problem-solving, follow-up (The MacColl Center, 1996-2013).” In Meleis’ transition theory (Meleis, 2010), enhancing self-management is a developmental pattern of transition. During this transition, youth need the awareness that a transition is occurring, and need to be engaged through activities such as seeking information, and purposely changing actions. Youth also would need to recognize that a change is occurring in order to recognize how change could disrupt established patterns, routines and relationships, and to confront feelings of being different. Lastly, the youth would recognize the end point of the transition, where self-management skills become a normal routine. As a CNS caring for this population, a major responsibility would be assisting youth in developing self-management skills. Based on the results of the review, I would start preparing patients for self-management early, and increase responsibilities for self-management incrementally. For example, I could start by encouraging patients to be responsible for taking their medications, and next, encourage them to become responsible for self-catheterizations. I would utilize both the Chronic Care Model as a framework for assessing, planning and evaluating my actions, and utilize the Meleis’ theory to assist youth in recognizing the transition.

### **Independence**

Through my integrative literature review, I noticed that a lack of independence, including independent living, is characteristic of young adults with spina bifida. Several of the articles in the review (Bellin et al., 2011; Cox et al., 2011; Liptak et al., 2010) reported the majority of their participants lived in a supervised setting such as with their parents. Cox et al. (2011) reported those who lived alone had decreased emotional well-being and mental health, though this was not reported in the other two studies. Other issues related to independence were identified in Ruck & Dahan-Oliel's (2010) study, where limited participants had a driver's license, had access to a vehicle or knew how to use public transit, and only about half of participants were able to participate in chores around the house. This could be related to a number of factors. For example, if an individual was unable to self-manage their medical needs, such as taking medications and self-catheterizations independently, they would be unable to live independently. Also, young adults who are unemployed (high rates of unemployment among youth and young adults with spina bifida was a characteristic of this integrative literature review) would have difficulty affording independent living. However, many of the youth and young adults in the review articles may still be completing high school and postsecondary education and not yet be financially independent or employed, and this could be similar to the general population. Low independent rates could actually be a result of a change in social climate, including the emergence of a young adulthood phase between the ages of 18 to 25, and up to 30 years (Arnett, 2000; Ruck & Dahan-Oliel, 2010). I believe independence also relates to the self-management element of the Chronic Care Model in addition to the community element, and Meleis' transition theory. As a CNS, I would conduct an assessment of a youth's progression towards independence (such as asking them about their independence-related goals, and their current status in the transition towards independence). I would tailor interventions towards enhancing

independence, such as social work and community resource referrals, and evaluate the results. I would also assist the youth in recognizing where they are in the transition process, according to Meleis' middle-range transition theory, and guide them through the transition from awareness that a change is occurring to the end point.

### **Level of lesion**

An outcome of my review that I expected was to learn that the level of lesion can effect transition outcomes such as self-management and independence. The higher the level of lesion, the more severe the spina bifida symptoms can be (Centers for Disease Control and Prevention, 2013). In Bellin et al.'s (2011) study, the level of lesion was a significant predictor for self-management, independence and employment. A lower level of lesion was associated with higher self-management, independence and employment rates, whereas a higher level of lesion was associated with lower self-management, independence, and employment rates. As a clinical nurse specialist, I would recognize that youth with a higher level of lesion might not be able to achieve the same levels of self-management, independence and employment than individuals with lower levels of lesion. Another possibility is that as a CNS I would need to have greater contact with youth, plan more interventions, and facilitate greater access to supports and resources for youth with a higher level of lesion to achieve the same level of independence, self-management and employment.

With respect to Meleis' Transition Theory, I believe that my involvement as a CNS would be relatively unchanged for patients of different levels of lesion, except that I may advocate for more regular follow-up to assist in facilitating the transition for individuals with higher levels of lesion and a poorer health status and functional ability as it may be more difficult for these youth to become independent. In addition, I would recognize that it may take more

time for youth with a higher level of lesion to become independent. In the Chronic Illness Model, the self-management support element is relevant, as despite the level of lesion and the ease or difficulty of transition from pediatric to adult care, a collaborative approach to solving problems, identifying priorities and completing goal setting is important.

### **Transition Programs**

Transition programs to assist in preparing youth to transition from pediatric to adult care has been prevalent in the literature as an integral service for youth with chronic health care needs (Canadian Pediatric Society, 2007; Blum, 1993; Johnston-Fletcher et al., 2011). There were articles in my review were conducted at sites where transition programs took place (Cox et al., 2011; Ruck & Dahan-Oliel, 2010). While these articles evaluated satisfaction and patient and parent experiences of the transition programs, the transition programs were not described, nor evaluated in other ways, such as medical outcomes, and effectiveness in preparing youth to be independent and self-management their care. Betz et al.'s (2010) article where a transition program was evaluated did not produce significant results, though the strength of the intervention dose was low. The transition program included a three-module transition preparation training program focusing on an assessment of the individual's future goals, and creating a transition plan to achieve the goals.

As a potential future CNS preparing youth with spina bifida from pediatric to adult care, I recognize the importance of transition programs to prepare youth for adulthood, and the importance is prevalent in the literature (Canadian Pediatric Society, 2007; Blum et al., 1993; Johnson-Fletcher et al., 2011). I would develop a transition program based on the existing literature to assist youth to be adults who are independent, self-manage their illness, and participate in society through individualized interventions to enhance independence, and self-

management, and resource referrals (Canadian Pediatric Society, 2007; Blum et al., 1993; Johnston-Fletcher et al., 2011). As an example, through the literature, I have recognized that many young adults with spina bifida lack access to primary health care, or multidisciplinary specialists (Ruck & Dahan-Oliel, 2010; Canadian Pediatric Society, 2007). Also, in Cox et al.'s (2011) article, participants thought visiting the adult clinic prior to transitioning would be helpful for their transition from pediatric to adult care. When developing my transition program, I would incorporate collaboration with other healthcare professionals and community resources, in addition to identifying appropriate adult health care providers, and referring patients prior to the transition to adult care, and also organize an adult clinic visit prior to the transition based on the evidence. This corresponds with the Chronic Care Model's Decision Support Element to embed evidence-based guidelines into practice, share evidence-based practice with patients, use proven teaching methods, and integrate the expertise of specialists and primary care. It would also support the Health System element of the Chronic Care Model by promoting improvement strategies to change systems, and facilitate care coordination. The Meleis' middle range theory of transition would provide a framework for health teaching, and assisting youth in recognizing transitions, their location within a particular transition, and strategies to help facilitate an effective transition.

### **Youth Experiences**

Several articles contributed to knowledge about the experiences of youth with spina bifida. In Sawin et al.'s (2009) article, some adolescents recognized that self-management should be their responsibility, but that becoming independent is difficult process. Parents were also identified to impact self-management, and parents can be restrictive through being overprotective, or they can promote self-management through skill-building. There is a balance

between protection and promotion of self-management. In Sawin et al.'s (2009) study, participants also recognized shared decision making as important to enhance transition outcomes. Many participants in this study felt they could accomplish their goals, but recognized a delayed transition to adulthood and financial independence. Both Sawin et al. (2011) and Ridosh et al. (2011) reported experiences with stigma and bullying. Ridosh et al. (2011) also reported a lack of support and peer relationships.

It is important for the CNS to take into account each youth's experiences and perceptions and use this knowledge when planning health care. The Self-Management element of the Chronic Care Model recognizes collaboration between the healthcare provider, and patient. Effective collaboration involves an understanding of the individual's perspective in order to tailor appropriate interventions (The MacColl Centre, 1996-2013). In Meleis' transition theory, understanding the youth's experiences and perspectives would assist the CNS with assessing the youth's level of awareness and engagement in transition, and identify joint interventions that could facilitate an effective transition. For example, interventions could include counseling on how to manage bullying and stigmas.

### **Role of the Clinical Nurse Specialist**

Throughout my discussion, I have identified implications for the role of the clinical nurse specialist based on the results of my review. Overall, I would develop a transition program based on evidence-based literature that incorporates preparation for self-management, independence, access to community resources, and access to adult care providers post transition. I would also utilize the Chronic Care Model and Meleis' Middle Range Transition Theory as outlined above to frame my program. A draft program outline is included in Appendix C.

### **Limitations**

There were several limitations to this review. First, while the inclusion and exclusion criteria were helpful to keep the scope of the review manageable and specific to youth with spina bifida, it resulted in the elimination of articles that may have been useful to gain knowledge about my topic. One example of this is that articles were excluded that focused on transition from pediatric to adult care for youth with multiple chronic illnesses in addition to spina bifida. Second, a significant proportion of the literature published in this field was excluded due to being secondary articles, reports, or theoretical literature, which were part of my exclusion criteria. The results of my review need to be considered with the understanding that this literature was excluded. Third, one reviewer conducted the literature search, data collection, and critical appraisals, while Whitemore & Knafle (2005) suggests two reviewers. Fourth, I conducted the literature search using only two methods, an electronic database search and an ancestry search of the reference lists of retrieved articles. It is possible that relevant articles were missed that could have been retrieved if additional search methods were used, such as additional electronic search engines. Finally, three of the articles (Ridosh et al., 2011; Sawin et al., 2009; & Bellin et al., 2011) had common authors from the same research group. This could have resulted in biased or overrepresented results if the studies were conducted in the same geographical area or same center.

### **Conclusion**

The transition from pediatric to adult health care services is a significant health care issue today due to many more youth with chronic illnesses surviving to adulthood. Due to advances in medical and surgical care, individuals with spina bifida are now living well into adulthood and will require care from adult health care systems to participate fully in adult society. I conducted an integrative literature review of transition from pediatric to adult care for youth with spina

bifida and identified a number of key findings: (a) self-management and independence skills are lacking in this population, (b) young adults lack follow-up care, (c) transition programs are in existence but are often poorly described in the literature, (c) evaluation of transition mostly focuses on patient satisfaction and (d) health status of youth with spina bifida decreased over time, and (e) many young adults with spina bifida have difficulty accessing adult health care services.

Specific roles for the CNS that were identified in this literature review include developing a transition program that addresses the needs of youth with spina bifida, (including enhancing self-management and independence and preparing for adulthood), setting up adult services, collaborating with primary care providers and interprofessional teams, conducting research, evaluating programs, and conducting quality improvement work. The CNS role can provide the opportunity to greatly improve the quality of life of young adults with spina bifida, and potentially other chronic illnesses through developing, running, and evaluating transition programs that prepare youth with spina bifida for an adult life that includes (a) managing their illness, (b) maintaining good health, (c) independence, and (d) social participation.

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### Appendix A: Example of Data Evaluation

Citation	Ridosh, M., Braun, P., Roux, G., Bellin, M., & Sawin, K. (2011). Transition in young adults with spina bifida: a qualitative study. <i>Child: Care, Health and Development</i> , 37(6), 866-874. DOI: 10.1111/j.1365-2214.2011.01329.x	
Decision Point	Criteria	Score
1. Design	<p>1. Is the research purpose/problem clearly identified? The purpose of the study is clearly identified: “To explore three dimensions of the transition experience: 1. Self-management; 2. Independence; and 3. The role of inner strength in the pursuit of independence (p. 867).</p> <p>2. Is a clear study design identified? Is it well described? Narrative inquiry is the study design identified. It was briefly described, but references for more information on the design were provided.</p> <p>3. Is the research design suitable for the research question? The research design is suitable for the research purpose. Exploring the experience of individuals transitioning from pediatric to adult care would be well-suited to qualitative study, including narrative inquiry.</p> <p>4. Is the research design the most rigorous or best-suited method to address the research question? Qualitative design is the best-suited method to address this type of research purpose. Another type of qualitative design other than narrative inquiry that could have been used is phenomenology, which is well-suited for describing individual’s experiences. The type of narrative inquiry used for the study is not specified.</p> <p>5. Is the literature-review comprehensive and draw upon the available literature? The literature review draws upon available literature about transition for pediatric to adult care for individuals with spina bifida, and correctly states there is limited relevant literature, and this population is understudied.</p>	5/5
2. Setting and Participants	<p>1. What sampling methods were used? The sampling method was not explicitly stated but appears to be convenience sampling. Participants were recruited from one site at clinic appointments in a Midwest metropolitan city in the USA at a large teaching hospital. “Convenience sampling is the use of the most readily accessible persons or objects as subjects in a study (Haber &amp; Singh, 2009, p. 256)”. The main disadvantage of</p>	2/4

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convenience sampling is the increased risk of bias in comparison to other types of sampling. Recruiting participants who feel strongly about the issue of interest increases, and could result in biased outcomes in favour of the topic of interest (Haber & Singh, 2009). Narrative inquiry is interested in telling the story of individuals having a particular experience, such as those living with a particular disease (Hardy, Gregory & Ramjeet, 2009). Purposive sampling is a sampling strategy where the researcher can hand-pick participants to be included in a research study who are considered representative of a phenomenon of interest. It is appropriate when an unusual group is being studied. Purposive sampling is appropriate for the collection of exploratory data, descriptive data, and focusing on a population with a specific diagnosis (Haber & Singh, 2009). Therefore, purposive sampling would have been the most appropriate sampling method. However, utilizing convenience sampling within a spina bifida clinic would also have yielded an appropriate population, but the resulted data may not be as rich. I would have benefitted from more information about the sampling methods used.

2. Were the inclusion and exclusion criteria appropriate?

Inclusion and exclusion criteria were not explicitly stated, but it appears that inclusion criteria were adults with spina bifida who received care at the recruitment site. I would have benefitted if inclusion and exclusion criteria were clearly stated in the article.

3. Is the sample size adequate?

10 participants were included in the study. Decisions regarding sample size were not included. In qualitative research, small sample sizes are common. However, due to the complexity of spina bifida, and the varied possibilities for physical status, medical outcomes, social outcomes, and personal experiences for individuals with spina bifida, I do not believe 10 participants would be a large enough sample size to accurately describe the research purpose. The study also states data saturation was reached at 10 participants.

4. What are the characteristics of the participants? Were they appropriate to answer the research question?

The 10 participants were 18 – 25 years of age and had either myelomeningocele or lipo-myelomeningocele. All participants lived in a Midwest metropolitan city in the USA and receiving care at a large teaching hospital. The participants varied in ethnicity, with the majority (6) being Caucasian, and had varied levels of lesion. Many participants had other chronic conditions diagnosed (i.e. chiari malformation, hydrocephalus). There were six males and 4 females in the study. These participants were appropriate to answer the research question. In particular, the age of the participants is

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3. Data Collection	<p>appropriate, as individuals 18 to 25 would have already transitioned from pediatric to adult care, and would be able to provide narratives about their transition experience.</p> <p>1. What were the data collection methods? Data collection methods were semi-structured interviews to “elicit sharing of participant’s stories (p. 868)”.</p> <p>2. Were the data collection measures appropriate? Interviews to elicit sharing of the participant’s stories about the variables of interest, including self management, independence, and the role of inner strength in the pursuit of independence would be appropriate, the use of semi-structured interviews is likely not the most appropriate data collect method for narrative inquiry. Stemming the flow of the subject’s talk so that the narrative is fractured” is a common problem of interviewing technique identified in Bleakley’s (2005) article about narrative inquiry. Therefore, unstructured interviews would have been a more appropriate data collection method. I believe unstructured interview would have provided enhance richness to the data and be more consistent with narrative inquiry methodology.</p> <p>3. Who collected the data? The individual who collected the data was referred to as “the researcher”. It appears as if one researcher conducted all 10 interviews with the use of the term “the researcher” but this is not explicitly stated.</p> <p>4. Where and under what circumstances were data gathered? Was the setting for data collection appropriate? The data was collected during a scheduled interview time at the research hospital. A hospital classroom or conference room were used, and they were private and wheelchair accessible. Transportation and accessibility issues were important to this population most participants relied on public transportation or transportation with a parent, and some participants required a wheelchair to get around. It may have been more appropriate to collect data at participant’s homes since accessibility and transportation issues were prevalent among participants.</p> <p>5. Did the collection of data place any undue burdens on participants? Could this have affected data quality? The location of data collection was the teaching hospital which would have been familiar to the participant. There is a possibility that data collection at the clinic setting could have created a power-over dynamic, where the participant felt they had to say nice things about the spina bifida program. It is not stated whether the</p>	3/5
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4. Data Analysis	<p>researcher or the individual collecting the data worked in providing care to spina bifida patients at the clinic. However, with transportation issues common among the participants common, it could have placed burden on the participants. A power-over dynamic could have affected data quality through false-positive statements by the participants.</p> <p>1. What were the data analysis procedures? Were they appropriate to answer the research question? <span style="float: right;">2/5</span></p> <p>The first 2 authors conducted the initial analysis, where transcripts were read and re-read to identify commonalities and unique experiences of each participant, did the initial analysis collaboratively. The narrative strategy used for analysis was “to listen to the particular responses related to self-management, independence and inner strength. Specifically, what was said and how it was expressed were examined. Particular attention to the participant use of ‘I’ and their exact quotes were utilized in sharing their stories in the results (p. 868)”. The 2 researchers met and discussed themes and findings. The three additional investigators who have extensive expertise with the population contributed to the final analysis and validation. Data analysis procedures were appropriate to answer the research question, and were reflective of narrative inquiry. The reader questions whether data saturation was reached since they did not state data saturation was reached. Also, due to the complexity of spina bifida (varying degrees of severity, level of lesions, medical outcomes, and potential social outcomes), I don’t believe data saturation could have been reached with 10 participants.</p> <p>2. How was the data organized? Were tables used to organize data? Were tables presented clearly, and contain relevant, and organized information?</p> <p>Data organization was not included in the article. The writer questions whether coding was used, which is an appropriate way of organizing the data for qualitative analysis and narrative inquiry (Riley &amp; Hawe, 2004).</p> <p>3. What statistical methods (if applicable) were used. Are they appropriate?</p> <p>No statistical methods were used, as it was a qualitative study.</p> <p>4. Was rigour achieved in the study?</p> <p>“Strategies to achieve rigour in this study included collection of field notes relevant of each participant and verbatim transcription, confirmability and dependability were addressed by review or results with three additional experts and researchers (p. 868).” Rigour could have been enhanced by confirming results with study</p>
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	participants. “Transferability may be limited to adolescents and young adults living with spina bifida who are accessing care for their condition and live with their families (p. 868)”	
5. Findings	<p>1. Are the findings summarized appropriately, and organized? The findings are summarized and organized appropriately into themes with supporting quotes.</p> <p>2. Do the findings reflect the data collection and data analysis? The findings appear to reflect the data collection and analysis although transcription notes are not provided due to page limitations.</p> <p>3. Do the findings answer the research question? The findings answer the research purpose, as it describes the experiences of the participants in the study.</p> <p>4. Are limitations discussed sufficiently? Limitations are described sufficiently. These include using a semi-structured interview may have limited the data, possible varying interpretations among the participants of what building inner strength means, limited sample diversity, and using only one geographical setting.</p>	4/4
Total Score		16/23
Quality Score	- 1 point for low quality - 2 points for high quality	1.5/2

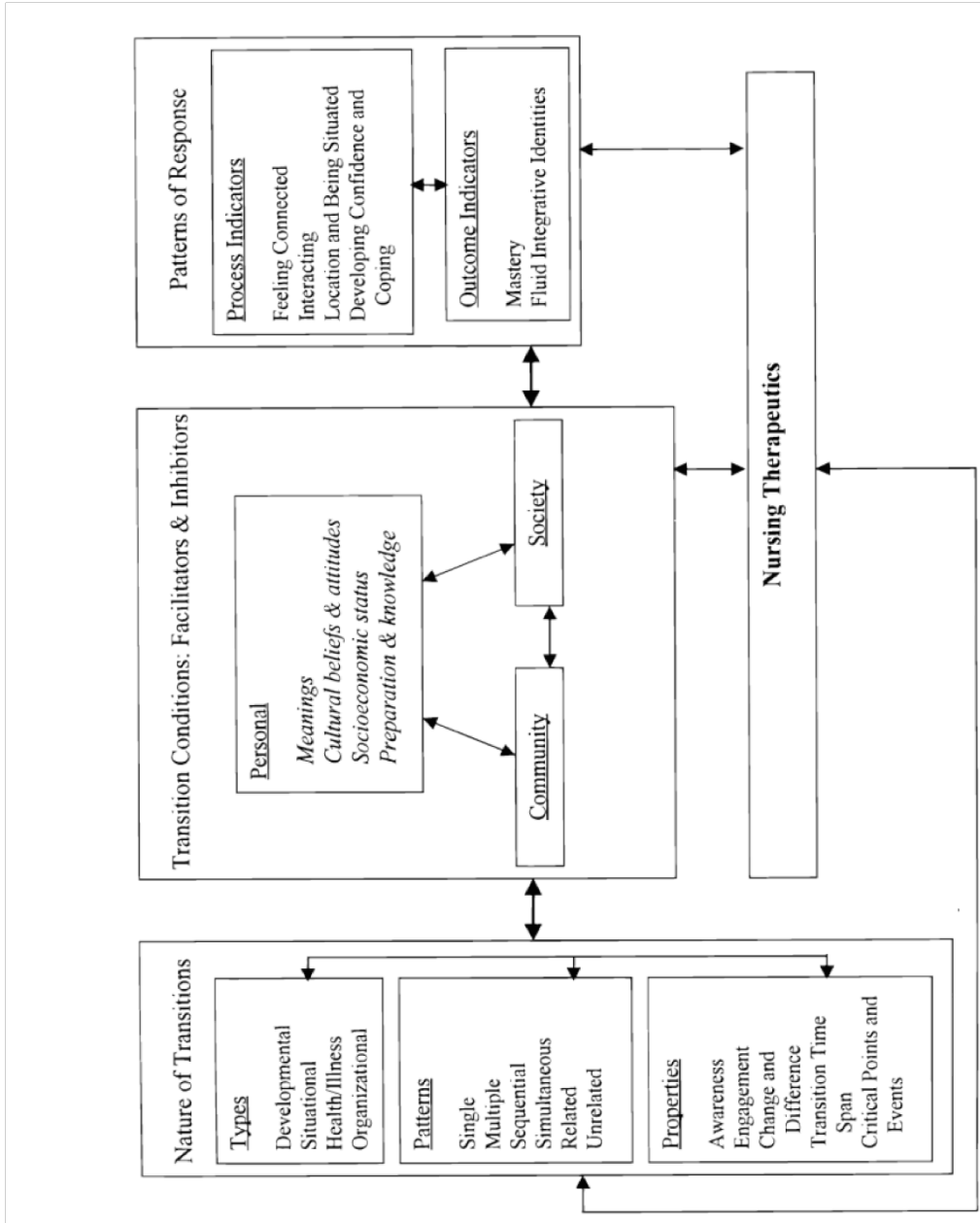
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## References

- Bleakley, A. (2005). Stories as data, data as stories: making sense of narrative inquiry in clinical education. *Medical Education*, 39(5), 534-40. DOI: 10.1111/j.1365-2929.2005.02126.x
- Riley, T., & Hawe, P. (2004). Researching practice: the methodological case for narrative inquiry. *Health Education and Research*, 20(2), 226-236. DOI: 10.1093/her/cyg122

**Appendix B: Meleis' Middle Range Transition Theory**

Figure 2: Meleis' Middle Range Transition Theory



From: Meleis, A.I., Sawyer, L.M., Im, E.O., Hilfinger Messias, D.K., Schumaker, K. (2000). Experiencing transitions: An emerging middle-range theory. *Advances in Nursing Science*, 23(1), 12-28

## **Appendix C: Draft Transition Program Outline**

### ***Self-Management.***

- Start preparing for self-management early and involve the health care team, patient and family.
- Use a step-wise approach for self-management, and increase responsibilities gradually. I would develop a large chart that includes all the self-management activities youth need to master prior to becoming an adult (i.e. bowel management, bladder management, medications, medical follow-up, etc.), and the incremental steps towards achieving them.
  - Example for self-catheterization: Based on developmental ability, start with small responsibilities for self-catheterization, and increase incrementally when appropriate. Responsibilities could include (start with step 1, and add the additional steps incrementally) 1. Wash hands and gather supplies. 2. Recite steps of self-catheterization while parents or caregiver perform procedure. 3. Help set up self-catheterization supplies, and measure output. 4. Record output on flow sheet. 5. at 3 years old, help wash hands and gather supplies. At 5 years old recite steps of self-catheterization while parents or caregiver perform the procedure. 4. Perform self-catheterizations with parental guidance and perform output. 5. Be able to identify symptoms and issues that require medical review (i.e. symptoms of a UTI) with parental discussion. 6. Be able to perform self-catheterizations independently. 6. Be able to recognize symptoms and issues that require medical review independently, and make and attend appointments.

### ***Peer support group.***

- Develop a peer support group (for both youth and parents) that both youth and parents could use to seek out information, advice and role models.
- If needed, establish a time and location for regular peer support group meetings.

### ***Community resources.***

- Identify relevant community resources and establish connections with them. Some examples of community resources that would be useful for youth with spina bifida include resources devoted to independent living, employment, social activities, mental health, etc. I would create a database of community resources that I could refer youth with spina bifida to as needed.

### ***Establishing adult services.***

- I would network with adult health care providers and provide education when needed about pediatric-specific aspects of spina bifida management (i.e. the malone to manage bowel continence).

- I would work to identify adult health care providers who are accepting young adults with spina bifida to refer youth for the transfer from pediatric to adult care.
- I would develop a clear discharge summary and communicate about each patient as they transfer from pediatric to adult care.

***Closing the gap between pediatric and adult services.***

- I would work towards developing a joint pediatric/adult clinic where youth would have a visit with both the pediatric and adult care providers prior to transitioning to adult care to facilitate communication, and minimize gaps and interruptions in care during the transfer.
- Collaboration with primary health care providers: I would collaborate with primary health care providers to enhance my knowledge of the services they can provide to youth and young adults with spina bifida, provide education to primary health care providers, and assist youth with spina bifida find a primary health care provider if they do not have one.

***Research.***

- I would use research and quality improvement methods to evaluate the outcomes of my transition program, and to continuously improve the program to enhance patient outcomes.
- I recognized a lack of research in the topic of the transition from pediatric to adult care for youth with spina bifida. I would plan to contribute to evidence-based care on the topic through evaluating the transition program.