# Urinary Continence across the Life Course

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**KEYWORDS**

• Spina bifida • Continence • Urologic care • Quality of life

Spina bifida is the most common defect of the central nervous system, affecting approximately 1000 newborns each year in the United States.[1,2] The Centers for Disease Control and Prevention (CDC) estimates that as many as 166,000 individuals with spina bifida live in the United States.[3] Spina bifida is a congenital malformation of the spine with abnormal neural tube closure occurring between the third and fourth weeks of gestation, and most frequently affecting the lumbar and sacral regions.[4] Liptak and El Samra[2] characterize it as the most complex birth defect compatible with survival. Most children with spina bifida have a normal urinary tract at birth,[5] although renal damage and renal failure are among the most severe complications of spina bifida,[6,7] resulting from lack of appropriate innervation of the bladder, and the effects of the neurogenic bladder on the kidneys.[5] Thirty to forty percent of individuals with spina bifida exhibit varying degrees of renal dysfunction throughout life,[8] and renal failure is the most common cause of death.[9] Before ventricular shunting, survival rates for children with spina bifida were low, and therefore "urologic intervention was rarely necessary."[4(p 72)] With improving technologies and clinical care, most patients can be expected to live into adulthood,[10] thus prevention of urologic complications, in particular renal failure, and promotion of continence have become critical.

This article reviews the literature regarding urinary continence, and discusses issues across the lifespan and implications for clinical practice. The pediatrician's role in the urologic care of children with spina bifida focuses on serving as the medical home for the child, assisting the child and family to become independent in care, promoting urinary continence, and monitoring for the development of urologic complications

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that threaten the health of the kidneys, in collaboration with the spina bifida special care center and other specialists. In addition, the medical home coordinates care with providers and services in the community, and works with the child and family as they transition to adult care.

## GOALS OF UROLOGIC CARE

More than 90% of children with spina bifida have normal upper tracts at birth,[5,7] although, if unattended, 50% will experience deterioration.[7] There are 4 goals of urologic care for the individual with spina bifida: (1) prevention of urinary tract infection, (2) preservation of renal function to avoid chronic renal failure and end-stage renal disease, (3) prevention of decubitus ulcers through promotion of continence, and (4) facilitation of urinary continence and independence in bladder care. Achievement of these goals is assumed to enable meaningful participation in activities (including adult sexual experiences, and typical vocations and avocations), promote positive self-esteem, and improve quality of life.[5,6,11] Successful therapeutic interventions require a working knowledge of the pathophysiology, effective treatments, normal developmental processes, and effective means of empowering parents and children to master urinary continence as a means to promote health and greatly improve activity and participation in typical societal roles as adults.

Urinary continence is a significant factor in estimating the quality of life for children with spina bifida and their families. Percentages of children who are continent range from 78% to 90%.[4,7,12] Children with spina bifida are at risk for symptoms of depression and anxiety, as well as lower levels of self-concept compared with their nonaffected peers.[13,14] This may be because of teasing, feeling self-conscious about their bodies and physical appearance, and social isolation. Daily bladder management can become burdensome for parents and children, and, as children struggle with negative feelings, parents may experience frustration with their child's bladder and bowel management programs, or adherence to these programs, resulting in tension between parents, children, and team members. Previous research conducted with other chronic conditions suggests that family cohesion is related to better treatment adherence,[15] whereas family conflict has been associated with poorer treatment adherence.[16] Siblings may also experience frustration with their brother's or sister's bladder or bowel management programs, especially if they attend the same school or share mutual friends. We have heard siblings complain about being embarrassed about catheters being left in the bathroom, where friends may discover them. However, the research on the adjustment of siblings of spina bifida patients has been mixed, and not focused on the effect of incontinence on siblings' emotional functioning.[17] Nevertheless, because spina bifida care affects the entire family, it is important to overall family functioning and quality of life to identify the factors that promote successful bladder and bowel continence programs for children who have spina bifida.

## MANAGEMENT OF THE NEUROGENIC BLADDER

In addition to causing incontinence that may affect social functioning, a neurogenic bladder can cause damage to the entire urinary tract, including the kidneys. Thirty percent of the deaths in adult patients with spina bifida can be attributed to the urinary tract.[18,19] Attainment of urinary and bowel continence is a critical component of the overall management strategy for neurogenic bladder, especially now that most children with spina bifida can expect to live into adulthood. Furthermore, because abnormal bladder function has been shown to be the principal cause of renal

damage,[20] the protection of upper urinary tract and management of continence issues often go hand in hand.

Studies for evaluation and monitoring of the urinary tract include regular renal and bladder ultrasonography, voiding cystourethrography, and urodynamics testing to provide baseline information, help detect early changes, identify children at high risk for kidney damage or poor bladder function, and assisting to identify a management plan.[6,20–24] The voiding cystourethrogram can rule out vesicoureteral reflux and assess the bladder outlet.[24] The urodynamics study is a functional evaluation of the bladder and the urethra and provides information related to bladder capacity, compliance, leak pressure, overactive bladder contractions, bladder areflexia, and bladder sphincter synergy and dyssynergy. Typically, patients are followed conservatively when studies are normal, being yearly at least through ages 3 to 4 years[5] and continuing through adulthood, because renal function may deteriorate.[7]

### *Medical Management*

General treatment strategies for urologic care for the child with spina bifida include pharmacotherapy and regular bladder emptying through clean, intermittent catheterization (CIC). During the newborn period, renal and bladder ultrasound is typically performed within 48 hours of birth to assess the urinary tract and postvoid residual, and allow for the provision of prophylactic antibiotics if hydronephrosis is present. If the infant retains a significant amount of urine, or is unable to void spontaneously, scheduled CIC is performed, adjusted based on the volume of residual urine. A wet diaper does not imply normal voiding, because it may represent overflow incontinence, and a low-pressure bladder must be maintained from birth to prevent kidney damage.[6] Further baseline studies including a voiding cystourethrogram and urodynamic evaluation are performed several months after closure of the spinal defect to determine whether the bladder is functioning properly.[5,6,24]

Two general approaches exist for the management of the urinary tract in the newborn period: an early preventive/anticipatory intervention (proactive) management approach and a wait and see (reactive) approach.[24] In the proactive approach, the infant at risk for upper urinary tract deterioration is identified and treatment is initiated before problems are evident. In the retrospective or reactive approach, the infant is followed closely and treatment is initiated at the first sign of problems. Good results exist with both approaches but large, multisite studies are needed to determine the most effective approach. About 25% of newborns leave the hospital having CIC performed by the parents.[5] In infants who do not respond to CIC and medications, vesicostomy is a safe and effective alternative.[5]

Medical therapy includes CIC and anticholinergic therapy to adequately empty the bladder and protect the upper tract.[25] Asymptomatic bacteremia is common and does not require treatment in most cases.[5] Symptomatic infection occurs less than 30% of the time, with asymptomatic bacteremia present in more than 70% of cases.[26,27] Indications for treatment of urinary tract infection include pain with catheterization, gross hematuria, worsening incontinence, and abdominal discomfort. Because fever is a less-specific indicator in children, it should not be used alone. Odor and cloudy urine without other signs of possible infection should be treated with increased hydration.[24] Prevention of the development of resistant infection is important, and thus antibiotic treatment should only be used when clearly indicated.

The use of CIC with or without anticholinergic medications such as oxybutinin permits low-pressure storage and complete bladder emptying, factors that are considered essential for maintenance of upper and lower urinary tract health. Since the introduction of CIC by Lapides and colleagues[28] in 1972, significant advances

have been made in the management of children with neurogenic bladder, but CIC remains the most popular option to achieve continence and prevent upper urinary tract deterioration.[7]

### *Surgical Management*

Some children may require urinary tract reconstruction to prevent deterioration of the urinary tract such as bladder augmentation, urethral continence surgery, and continent urinary diversion.[25,29–32] About 50% of children with spina bifida may eventually require some form of urologic surgery.[33] Indications for surgery include failure of medical management to produce a safe, low-pressure bladder, and deterioration of the upper urinary tract.[34] Surgery focuses on improving bladder capacity, lowering bladder pressure, and protecting upper tracts from damage,[7] and is generally reserved for persistent incontinence,[5] to aid in catheterization via catheterizable channels, and to prevent further damage to the kidneys. With difficulties catheterizing the urethra because of excess weight, or difficulty reaching or seeing the area, continent catheterizable channels can aid in achievement of continence. However, risks include stomal stenosis and leakage, and it requires a lifelong commitment to catheterization.[5] For those adults who have had bladder augmentation, long-term follow-up for development of malignancies is needed and typically consists of cystoscopy beginning 10 years after the initial procedure.[35]

Surgeries to increase resistance of the bladder outlet, including injection of bulking agents, bladder neck reconstruction, and placement of bladder slings and artificial urinary sphincters can be performed, although they are not all successful. Bladder neck closure with creation of a continent catheterizable conduit may be needed if all else fails, and bladder augmentation is often performed at the same time. Bladder neck closure is effective for achieving continence but success depends on compliance with CIC. However, according to Nguyen and Baskin,[36] 85% of patients ultimately achieved urinary continence 2 years after surgery. There is an increased risk for stomal stenosis and bladder stones, incontinence, and infection.[5,6,25,36,37] Complications from bladder augmentation can include metabolic imbalance, stone formation, chronic urinary tract infection, bladder rupture, and tumors.[5]

During childhood, toilet training and continence become primary goals.[5,24] Surveillance of the urinary tract for bladder hostility or deterioration of the upper tract continues.[25] Children can begin to learn self-catheterization during the early school years.[25] Before this time, parents can narrate the catheterization procedure while they are performing it, and have children help with activities such as opening packages, or putting away supplies, to begin to engage them in the process. Optimally, the child should move toward independence in bladder care during the school years whenever possible.

For adolescents, facilitation of urinary continence and preservation of renal function continue to be primary goals. Clayton reports that continence can be achieved in as many as 90% of patients.[25] Adolescence is an important time to solidify self-care skills and ensure a complete understanding of the condition to prepare for independent living, postsecondary education, romantic relationships, and gainful employment.[5] The risk of renal damage and hypertension increases with age, so close monitoring with follow-up into and through adulthood is needed.[7,24]

Any deterioration in urinary function must be examined, because one of the most common causes is tethered cord,[4,5] which occurs in 15% to 25% of patients, commonly presenting between 2 and 8 years of age. It is caused by adhesions between the spinal cord and the repaired dura mater, with resultant ischemic changes

from tension on the cord. There is the potential for improvement after cord release,[11] so early attention to symptoms is important.

Despite advances in care, urinary incontinence, urinary tract infections, and threats to renal health remain significant problems for children and adults with spina bifida. Few prospective studies have evaluated the efficacy and safety of therapies that are currently used, and significant variation in care exists from region to region, and practitioner to practitioner. A urologic standard of care for children with spina bifida is yet to be established because few data are available to adequately evaluate currently available therapies.

### *Outcomes of Treatment*

The effectiveness of existing therapies should be evaluated not only on their medical outcomes but also on their effects on the quality of life of the patients and their families. In our recent work, the relationship between quality of life and continence regimens has been inconsistent, possibly because measuring quality of life in a child with spina bifida is difficult. One reason why quality of life in children with spina bifida has been hard to measure is because there are few tools to assess it. Although there has been debate about whether general health-related quality of life (HRQoL) should be assessed, or whether it is preferable to obtain disease-specific measures of quality of life, for assessing changes related to treatment, disease-specific measures are preferred.[38] One HRQoL instrument for spina bifida has been developed,[39] but, in a review of quality-of-life measures, some shortcomings were identified.[40] However, it is the only spina bifida–specific measure of quality of life in children published and available at the present time. In addition, no information about the quality of life for children with spina bifida has included the use of qualitative methods such as interviews or focus groups.

Another limitation of previous research in quality of life is the reliance on parents and providers to rate quality. Although it is difficult to collect this type of information for very young children, it is thought that children should rate their own quality of life whenever possible.[38] Previous studies have shown that the family's experience of their child's medical condition is not as negative as health care providers perceive it to be.[41] Thus, it is important to seek information about quality of life from the children directly and, if this is not possible, from their parents.

## CONTINENCE FROM A DEVELOPMENTAL PERSPECTIVE

### *Young Children*

Bladder incontinence in infants and toddlers may not be obvious to others because all children in this age group wear diapers, thus the focus of bladder programs for this age group is primarily on optimizing medical outcomes. During the preschool years, bladder incontinence becomes an issue that is recognized in school, in public, and by the child with spina bifida. Preschool children with spina bifida recognize the differences between themselves and their nonaffected peers[42] and begin to ask questions about why they urinate differently than their friends. It is important for parents to be prepared to answer such questions and openly discuss these matters with their children.

Some parents wonder whether they should attempt to toilet train their child with spina bifida, because most individuals with spina bifida have some degree of incontinence. Only about 15% of those with spina bifida achieve complete bladder and bowel continence without the use of medications and CIC.[43] For children with spina bifida, bowel and bladder control are typically achieved later than for their nonaffected peers

(6–8 years old), if at all. However, the expectation that the child will need to participate in their continence program and gradually manage it independently should be established early, around 2 or 3 years of age. Although children with spina bifida may not develop full continence, they should be encouraged to participate in their continence program as early as possible.[44] Children of this age are naturally curious about the bathroom and should be allowed to go into the bathroom[43] as well as participate in the continence program in developmentally appropriate ways. For example, although a 2 year old is too young to insert a catheter without assistance, they can be responsible for getting the catheter and giving it to their parent. Or, the child may wash their hands before and after catheterization. It is also important to communicate the expectation that the child will learn to perform CIC independently. A parent or caregiver may convey this intention by talking through the steps of CIC and having the child watch how it is done (instead of lying on their back passively), even before the child is ready to learn how to insert the catheter. Setting the stage for being independent in self-care during the early childhood years is essential if independence is to be achieved during the elementary school years.

### *School-age Children*

By the time a child with spina bifida is in elementary school, the parents should be considering ways of increasing their child's independence in managing the continence program. The guidelines for spina bifida care published by the Spina Bifida Association[45] indicate that children should be taught self-catheterization when they are school aged (6–11 years old). It is generally accepted that, by the beginning of middle school, children should be fully independent in self-catheterization and should ideally have achieved urinary continence.

As they mature, achieving continence becomes increasingly important to children with spina bifida. It is during the school years that increases in teasing and exclusion are typically seen, and issues with low self-esteem related to incontinence begin to emerge. Moore and colleagues[46] asked spina bifida patients 7 to 19 years old to rate their academic, social, and athletic competence, as well as their physical appearance, behavior, and self-worth. The data were analyzed by continence status, gender, and other variables. In general, the findings revealed no significant differences between patients who were continent (ie, did not use protective undergarments) and the control group. However, those who were incontinent rated themselves lower in social acceptance and global self-concept than the control group. Gender differences also emerged: girls who were continent rated themselves higher in social acceptance and self-worth than girls who were incontinent; boys who were continent rated themselves higher in scholastic competence, social acceptance, appearance, and behavior compared with their peers who were incontinent.[46] The sample contained too few patients to make additional comparisons by age.

The development of good social skills becomes especially important during the school years. People with good social skills are able to make more friends, thus increasing their support systems, and have a better sense of how appropriately to share information about their medical condition with others, how much information to share, with whom to share it, and how to deal with questions or teasing that is likely to arise. By developing good social skills, a child with spina bifida can also ensure greater participation in developmentally and age-appropriate activities, such as having play dates, going to birthday parties, and going to sleepovers. Establishing such social activities at this age increases the likelihood that participation in age-appropriate activities will continue into adolescence.

During these years, it is also important to explain the concepts of appropriate and inappropriate touches, who is allowed to touch their bodies, and what to do if someone tries to touch them inappropriately. Because many children with spina bifida have decreased sensation in their genitals, and because so many caregivers (eg, parents, physicians, nurses) examine these parts of their bodies routinely, they may not perceive the same ownership of these parts as nonaffected peers. Thus, there may have to be additional teaching about what inappropriate touches are and how to recognize them. However, because children with disabilities are at increased risk of being sexually abused,[47] and because children with spina bifida often require assistance in their bladder care from others, it is important to review this information with children in a calm, matter-of-fact, nonthreatening manner.

### *Adolescents*

Ideally, adolescents with spina bifida are independent in their continence programs. If they are not, it is hoped that they are motivated to become independent because they desire the freedom to participate in typical adolescent activities like playing sports, going out with their friends, or spending the night away from home. This is more likely if developing age-appropriate social skills is a focus of their school years.

Several studies have alerted health care practitioners to important medical and social needs of adolescents and young adults with spina bifida and their families.[48–51] One recent descriptive study[52] found that, although adolescents with spina bifida had generally positive attitudes and were independent in self-care, they were not participating in the full range of adolescent activities. This finding leads to questions about the role of bowel and bladder incontinence in this lack of social participation. Another study found that adolescents and their parents had significantly divergent perspectives about the needs of the adolescent.[53] How does this extend to issues of incontinence and what are the perceptions of practitioners to the needs of children with spina bifida? Although studies are beginning to explain the overall attitudes and beliefs of individuals with spina bifida, they have not examined the complex subjective experience of living with spina bifida while managing the problems related to incontinence.

Research has shown that the transfer of responsibility for catheterization transitions from parent to child gradually over time, beginning in middle childhood.[54] Although expecting a child to self-catheterize before they are ready may have negative consequences (as seen in children with other chronic conditions[55]), not allowing a child to assume this responsibility when they are ready and capable of doing so may also thwart the transition to independence.[54] Stepansky and colleagues[54] suggest that, because parents of children with spina bifida tend to be overprotective[56], adolescents with spina bifida may be more dependent on their parents than is necessary. Their longitudinal research suggests that, as children get older, conflicts related to medical issues are related to decreased medical adherence.[54] Therefore, more information about how to assess readiness for this transition, as well as how to assist parents in transferring the responsibilities to their children, needs to be researched.

Adolescence is a difficult time in general, but being an adolescent with spina bifida is especially challenging. In addition to the typical issues of adolescence, a teenager with spina bifida must contend with managing their continence program while out with friends or in the context of dating (and possibly sexual) relationships. For these reasons, the Spina Bifida Association guidelines for spina bifida care suggest that teaching about intimacy, sexuality, and sexual functioning are key urological interventions for this age group.[45]

Adolescents with spina bifida may also rebel in ways that could ultimately cause themselves harm. Not only could refusing to do CIC affect the adolescent's physical

health, it could affect them socially if bladder or bowel accidents occur as a result, or if odors become obvious. Although such rebellion is considered typical and developmentally appropriate, it nevertheless must be addressed to prevent long-term health and psychological consequences.

### *Adulthood*

Medical advancements, such as the development of the shunt and urological surgeries, have greatly improved the survival rate of infants born with spina bifida. The literature suggests that children born with spina bifida who receive proper medical care and support for incorporating wellness interventions into their lifestyles can have a normal life expectancy. However, there are few reports describing outcomes into later adulthood, making it difficult to determine life expectancy.[57] Continuing challenges facing adults with spina bifida and their health care providers are urinary incontinence and potential kidney damage. Renal failure is the most frequently reported cause of death in adults with spina bifida,[7,19] and kidney infection is a frequent cause for hospital admissions.[58] In a study of urinary and fecal incontinence among young adults in the Netherlands,[59] researchers found that, of the 179 patients studied, 63% used diapers. Diapers were used more often for urinary incontinence (90.7% of those who used diapers). Moreover, adults who wear diapers are susceptible to pressure ulcers as an additional serious medical complication.

Incontinence has repercussions for social participation. Incontinence at any age can be the source of embarrassment and humiliation. However, quantitative studies of adult quality of life have not shown a relationship between standard measures of quality of life and continence. Lemelle and colleagues[60] conducted a cross-sectional study of 460 patients, of whom 300 were adults, across 6 spina bifida centers in France. Using the Short Form (SF)-36 Health Survey to measure HRQoL, they found no relationship between HRQoL and continence. Surgical management and 2 domains of the SF-31 (without diversion and role physical; with continent diversion and general health) were significantly related. The investigators speculated that surgical management may result in more physical independence and thus positively affect this area of HRQoL. Standard quality of life measures may not adequately evaluate the effect of incontinence. In a study of young adults with spina bifida, Verhoef and colleagues[59] asked research participants whether they perceived incontinence (defined as an accident once a month or more) as a problem. They found that 69.7% (76) of patients who were incontinent (109) perceived it as a problem. Simply asking a question about the effect of incontinence on day-to-day life may result in more useful information about adult experiences and concerns.

Neville-Jan,[61] a woman with spina bifida, used a qualitative research methodology called autoethnography to describe her experiences growing up with spina bifida. Her account provides support for the positive effect of surgical urological intervention and the stigmatizing nature of incontinence. She states:

> *Bladder incontinence became the most stigmatizing impairment for me. In 1970, I had a surgical procedure called an ileal conduit, which diverted urine from my bladder to an outside appliance on my abdomen. After the surgery I finally achieved independence. The following year, I left home, bound for New York City to study occupational therapy (61; p. 530).*

Mobility impairments and incontinence intersect in different ways across adulthood. As ambulatory young adults age, they may be more susceptible to falls. Falls sometimes occur when rushing to go to the bathroom to avoid an accident.[62] Older

adults who are wheelchair users may face similar challenges when bathrooms are not accessible and timing is a factor.

Urinary incontinence directly affects social participation. Sexuality and partnering are important areas of life in which adults with spina bifida who are incontinent may face restrictions. Several studies have identified that young adults who are incontinent tend to have limited sexual activity. Cardenas and colleagues[63] studied 121 adolescents and young adults between 15 and 35 years of age and found that those incontinent of urine were not likely to engage in sexual activity. Gatti and colleagues[64] studied the predictors of having a relationship and sexual activity in 290 patients with spina bifida. Patients ranged in age from 18 to 32 years, with a mean of age of 23.4 years. Urinary continence was a significant predictor of sexual partnering. Cullers and colleagues[65] conducted a prospective study of 143 adults with spina bifida to assess the effect of incontinence on sexual activity. They found that only 39% of the adults were active sexually. Most of these adults had lesions at lower levels, had a partner, and were working. Dicianno and colleagues[57] conducted a comprehensive review of the literature on spina bifida during the past 20 years. They reported that male and female adults with spina bifida who were incontinent were not likely to be sexually active. Medical providers should be alert to these issues and refer patients to the appropriate resources for help with both sexuality and incontinence.

We did not locate any studies that directly examined other areas of social participation, particularly employment, as it relates to incontinence in adults with spina bifida. However, the literature does suggest that individuals with spina bifida are limited in social participation. Buffart and colleagues[66] studied lifestyle factors in 51 adolescents and young adults with spina bifida (mean age of 21 years). More than half of the participants had problems related to social role functioning, particularly recreation and employment. Hunt and Oakeshott[67] followed a cohort of 54 individuals with spina bifida who survived to an average age of 35 years, and conducted a phone survey to access community living. Of the 54 survivors, 11 were continent, 13 were employed, and 11 drove cars at the time of the survey. The investigators did not report whether those who were incontinent had the most difficulty in social role performance but this is likely given the stigma associated with incontinence.

Longitudinal studies need to be conducted to assess the urological needs of young adults as they age and the influence of incontinence on community participation. Also, more needs to be understood about older adults with spina bifida. Clinically, multidisciplinary clinics need to be established for adults to manage issues related not just to urological impairments but to social role functioning, such as sexuality, partnering, and employment.

## CLINICAL IMPLICATIONS

Given the great variability in needs and outcomes of children and youths with spina bifida,[68] individualization of treatment approaches is necessary within the context of recognized standards of care. Active engagement of family members and, when appropriate, the child in decision making is important to establish a long-term partnership in care. In addition, information sharing and collaboration between the community-based medical home, special care centers, and specialists enhances care delivery and improves outcomes.

Spina bifida is a condition in which family members, adolescents, and adult patients are responsible for performing most of the care. Thus, a comprehensive educational program that provides an overview of the condition, as well as short- and long-term care, helps to achieve the best possible outcomes for the child. Ideally, this

educational program should be introduced in the neonatal intensive care unit and then continued during the first and subsequent visits to the spina bifida clinic. It may be helpful to provide families with literature or resources available on the Internet for them to explore. If possible, parents can be given a resource binder that includes information about spina bifida as well as a system for tracking medical appointments and relevant health information that can then be shared among providers to enhance coordination of care.

Providers need to be aware that such education is not a static event, but a dynamic process. The information provided to the family may not be well retained, especially when it is given during stressful times, and it may therefore need to be repeated. Written material used in collaboration with oral explanations is especially valuable, allowing parents to review the information at a later time, in a less stressful environment. Although initially education will be focused on the parents, it should transition to include the child as early as the child seems to be interested and capable of understanding. As the child becomes older, explanations may need to be revisited and updated to correspond with the child's increasing level of maturity. Likewise, important concepts need to be repeated frequently to assure that understanding is complete.

Providers should monitor continence outcomes as well as the effect of the continence programs on the child's and family's quality of life. As issues arise, referring back to the educational information previously provided and reminding the family of the expectations of the child's participation in the continence program will be necessary. In addition, close monitoring and frequent conversation allows the bladder management plan to be revised as needed to better meet the child's and family's needs and goals. The expectation that the child with spina bifida will be managing their own continence regimen by the end of elementary school needs to be established early and could be appropriately introduced during toddlerhood, when questions about potty training are likely to occur. If CIC is appropriate it can be introduced at this time. The literature identifies that children as young as 2 years old[69] and with an IQ as low as 60[70] have been able to self-catheterize. If not completely independent, it is expected that children with spina bifida should be allowed and encouraged to participate in 1 or more components of their continence routines so that they may gradually take over their self-care needs.

The occupational therapist can assess the fine motor skills needed for self-catheterization and, in collaboration with the nurse, begin a teaching program that may involve videos and dolls for simulation. Although this task may seem straightforward, the topic of independence in self-care needs to be addressed in a culturally sensitive and relevant manner, because not all cultural groups value or expect independence, especially for a child with a chronic health condition. Because children spend much of their time in school, it is also important to establish collaboration with health care providers in the child's school environment. The school nurse can greatly assist by reinforcing catheterization techniques, helping the child to monitor the status of the skin, and assist in maintaining a schedule to work toward the goals of maintaining normal renal function, achieving continence, and promoting independence.[71] Working collaboratively with the school nurse can encourage and maintain optimal continence outcomes in a child with spina bifida.

Medical management of incontinence is most frequently directed by the urologist, but the primary care provider serves important roles in reinforcing and monitoring the plan of care, assessing for complications such as urinary tract infections and skin breakdown, and promoting independence in self-care. Within the context of typical developmental expectations, the community and family environment, and

the health care needs of the child, the medical home provider is well positioned to coordinate the health care and serve as a primary resource to the family. Although mentioned earlier, asymptomatic bacteremia is considered the norm and does not need to be aggressively treated with antibiotics. Odor, cloudy urine, or other vague symptoms should be treated with increased hydration. Antibiotics are indicated only with symptomatic infection to reduce the possibility of resistant microorganisms.

For those children who need urological surgery, it is important that the parents and, when appropriate, the child have an understanding of the surgical undertaking and the care that will be required after surgery.[25] This is especially important for children less than 11 years old, because research has shown that children this young have difficulty understanding aspects of youth assent, such as the procedure or protocol.[72] In these cases, drawings and diagrams may help children and families understand complex procedures and provide rationale for surgeries. A psychologist may help the family to cope with the stress of the hospitalization, or repeated hospitalizations, and pain management following the surgery.

As discussed earlier, more and more individuals born with spina bifida are surviving into adulthood, but spina bifida care for adults is not as well defined as it is for the pediatric population. Ideally, a multidisciplinary team that functions as a one-stop clinic should follow adults to assess the complex challenges that occur throughout adulthood,[7] but only a few such centers exist. Practitioners who see adult patients with spina bifida should not simply assume that pediatric protocols can continue to be followed. Changes in mobility status or the onset of other health conditions may affect urological management strategies and it is essential that kidney function continues to be monitored. For these reasons, it is important that pediatric practitioners prepare children and their families for the transition to adult care providers early, during late childhood or early adolescence. It is imperative that practitioners begin addressing their questions to the teen and young adult with spina bifida, not just the parents, and begin establishing the expectation that the young person will need to take over monitoring their health and the need for appointments or follow-up care. Again, transition to adult care is not an event but an ongoing process that takes years to complete successfully.

Although there have been tremendous advances in care for individuals with spina bifida, incontinence and damage to the upper urinary tract continue to be significant areas of concern for patients, family members, and their physicians. Collaborations and shared goals between patients, families, and providers can help children with spina bifida become healthy and productive adults.

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