Transitioning Pediatric Urology Patients (and Their Families) to Adult Urology Care

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Introduction

For many years, children with urological issues were cared throughout their life spans by pediatric urologists as their life spans averaged in the mid-20s at the latest; the "official" definition for the age of pediatric patient care is 0–21 years. Modern medicine has extended the life span of this population of children with complex urologic conditions, and now children who were pediatric urology patients are living well into adulthood. Dr. Rosalia Misseri (2013) of Riley Hospital for Children estimates that excluding hypospadias, there are 100,000 adult individuals in the USA living with genitourinary tract diseases that began before the age of 21 years.

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This has necessitated the transition of their care to adult urology providers. The universal goals of pediatric urologists are to preserve kidney function, preserve upper tract and lower tract function, provide for safe urine storage and drainage, and attain and maintain continence, fertility, sexual function, and genital cosmesis. The last three are usually not necessarily on the minds of the parents and patients until adolescence, but need to be a factor in all pediatric surgical and medical decisions made throughout the life span of the child. The actual transition of care is complex and unique to each child, family, diagnosis, pediatric care given, and pediatric urology provider team.

Ideally this transition from pediatric to adult care should be a process that aligns with the adolescent developmental process, specifically identity versus role conflict. But there can be many practical obstacles to this actually happening. Developmental delay of the patient, difficulties with the patient taking responsibility, difficulty with the parents relinquishing responsibility, a lack of adult providers knowledgeable and/or desiring to care for these kids as adults, and the reluctance of pediatric urology providers to relinquish their patient's care to adult urology providers can all be factors. Another obstacle is the coordination of other needed medical specialties such as nephrology, PT/OT, orthopedics, neurology, neurosurgery, or endocrinology. In the pediatric hospital model, all these specialties are housed in one system, and electronic medical records facilitate seamless care transitions between specialties. Many institutions promote multidisciplinary clinics where the providers come to the patients, providing not only convenience for the patient and families, but more opportunities for provider to provider communication and continuity of care. This includes access to ancillary team members such as social work, therapeutic play specialists, and pediatric psychologists.

Currently, this issue of transition of complex pediatric patients to adult care is being addressed at many levels. Kelleher et al. (2015) describe the issues with transitions of complex pediatric patients to adult care, citing the challenges of spina bifida patients in particular, who require management from urology, neurosurgery, orthopedics, and general medical services well into adulthood. There is guidance for this transition: "Federal Policy Supporting Improvement in Transitioning from Pediatric to Adult Surgical Services" (Kelleher et al. 2015; Box 1.1). Furthermore, the American Academy of Pediatrics (2011) states that "optimal health care is achieved when each person, at every age, receives medically and developmentally appropriate care." The process includes multiple entities, including the patient, family and/or other caregivers, the pediatric and adult providers and support staff, as well as adult and pediatric hospitals and insurance companies and the health-care system as a whole. With the passage of The Patient Protection and Affordable Care Act of 2010 (PPACA), children are able to remain on their parents' insurance until age 26, providing time to identify resources for coverage due to their disability.

Due to reconstruction of the GU tract, facilities need to have pediatric-sized instruments (such as cystoscopes) available at the adult hospital, introducing the need for planning and potential financial impact. Finally, radiologists who are familiar and comfortable with the appearance of genitourinary systems that have been reconstructed are essential.

Box 1.1 The Patient Protection and Affordable Care Act of 2010 Provisions That Benefit Adolescents with Chronic GU Conditions Transitioning to Adult Care

1. Adolescents and young adults are able to remain on their parents' coverage until age 26. This means that youths with chronic medical and surgical conditions will remain insured on commercial plans.
2. Health insurance plans are prohibited from discrimination based on preexisting conditions or health status. Youths that age out of their parents' insurance or purchasing individual insurance will not have any chronic health conditions held against them through denials, higher premium rates, or complete refusal to insure.
3. Annual/lifetime limits on dollars or benefits are excluded in the PPACA.
4. The PPACA sets the minimum Medicaid eligibility for young adults at 133 % of the federal poverty level (for those states expanding Medicaid).
5. The PPACA establishes rules and requirements for the availability of insurance exchanges for the purchase of insurance by individuals in each state. These exchanges provide for new coverage of preventive benefits and provide subsidies prorated based on income.

The most pediatric urology issues and diagnoses present very early in life or even prenatally, but they can also arise throughout adolescence. The conditions can be mild to life-threatening and also have a very variable effect on the child's psychosocial well-being depending on the specific disease process and how the family has coped with the disease and its effects. Their success in management depends on the support system in place to help them and the skill of knowledgeable providers.

Transitioning

Transition to adult care obviously happens frequently in pediatrics, but one component making the urology transition different is that the conditions are uniquely pediatric and until recently have been cared for solely by pediatric providers. Both cardiology and pulmonology disciplines have led the way in pediatric to adult care transitioning with specialized fellowships. The European model as described at the European Association of Urology (EAU) 25th Annual Congress: Abstract 811 (Presented April 19, 2010) has specialized providers in pediatric to adult care, including in urology. The newness of these transitions in urology can create stress, ambivalence, and resistance among members of the team, with the patient/family feeling fear about a new system that does not know them personally. They may feel they are being abandoned by the people "who saved their child's life," while the pediatric urology team may fear that all they have "fixed" will be undone.

Depending on the child's cognitive level, issues also begin to arise regarding confidentiality, informed consent, and patient/physician decision making versus patient/ physician/family decision making. These issues are vital in the process of

ongoing care and benefit from being addressed at the same time as any physical issues are being addressed. The majority of parents/caregivers who have children with chronic disabilities that involve multiple systems have been fierce advocates for their children. While this is good, for them the process of letting go and having their children become as responsible as possible needs to start early and be directed by the care team. It can become very difficult for these families, and they can feel that they are losing control of their child's health care, which has consumed a large part of their own adult lives.

Subspecialty certification in Pediatric Urology began in 2008 for those urologists whose practice is a minimum of 75 % pediatric urology. Applicants approved by the Board to enter the process of subspecialty certification must be engaged in the active practice of pediatric urology and must hold a current unrestricted general certificate in urology issued by the American Board of Urology (http://www.abu.org/subspecialtyCert_PSCOverview.aspx). With the pediatric certificate of added qualification, pediatric urologists must not have non-pediatric patients comprising more than 25 % of their work in order for them to keep their specialty qualification. It is essential to note that if adult patients stay in a pediatric practice, there is reduced time to see pediatric patients, meaning that patients must be "aged out" of the pediatric urology practice.

Nurse practitioners (NPs) are uniquely qualified and positioned to help families with this preparation and transition process owing to their unique knowledge of child development, family systems, and disease processes. This process happens with families primarily through education within the context of the clinic visits, the strength of nurse practitioners. After training as either pediatric or family NPs, the transition to caring for patients within a specialty practice offers the opportunity for NPs to focus their training on the specific needs of pediatric GU patients.

Looking at the generalized process, it is important to start and keep a concise summary of all diagnoses, interventions, and surgical procedures. The actual surgical notes are important as there are different techniques, and which one was used originally and what any revisions were is important to future adult surgical decisions. There should be a notebook for each patient with all of this information for each child that the family/caregiver keeps and is added to with every visit and procedure so that it is complete with all surgical, procedural, and interventional information at transition. This avoids a time-consuming task to review years of care as a family presents for their last visit. A second vital issue is encouraging pediatric GU patients to enroll with a primary care provider; it is more likely for children to have a pediatrician than for adults to be able to identify a primary care provider. This is important, as pediatric providers are not trained or equipped to manage "adult" issues such as smoking prevention and cessation, obesity, type II diabetes, sexuality, birth control, or hypertension as they pertain to the adult patient.

There is a distinct need to develop transition plans for pediatric urology patients to move to adult urology providers. Some facilities have created formal plans that can be adapted to other environments. Riley Hospital for Children has a well-established program for urology transitioning, and Children's Hospital of Wisconsin website has a comprehensive section on general transitioning of pediatric to adult

care including an e-book titled *Transition Health Care Checklist: Preparing for Life as an Adult* (http://www.chw.org/medical-care/transition-to-adult-care/). Toronto's Hospital for Sick Kids *Good 2 Go* is another successful program that is available on their website and has materials for transition of care for clinicians, patients, and families. This program is based on a shared management model between family, providers, and the young adult.

Several diagnoses necessitate the transition from pediatric to adult urology care: neurogenic bladder (caused by a variety of diagnoses, one being spina bifida), bladder exstrophy, hypospadias, epispadias, disorders of sex development, posterior urethral valves, cloaca, vesicoureteral reflux, ureteropelvic obstruction, nephrolithiasis, pediatric genitourinary tract cancers, undescended testes, varicoceles, and upper tract anomalies. The remainder of the chapter is a disease-by-disease review of the items for adult care providers to remember, assess, and measure for the most common pediatric genitourinary diseases that will require lifelong care.

Discussion of Specific Pediatric Genitourinary Conditions

Neurologic Conditions

Neurologic conditions include myelomeningocele, tethered spinal cord, cerebral palsy, sacral agenesis and spinal dysraphisms, and Hinman's syndrome (non-neurogenic, neurogenic bladder). Spina bifida is the most common birth defect in the USA (www.spinabifidaassociation.org), but all of these conditions have the potential to be part of a syndrome as well. Males and females with spina bifida are the largest population of persons with urogenital anomalies in the USA. There are many treatment options for them as adults, with clean intermittent catheterization (CIC) being responsible for the marked increase in life expectancy over the last 20 years. Other treatment interventions can include augmentation cystoplasties, botulinum toxin, catheterizable channel creation (Mitrofanoff), anticholinergics and other meds to increase bladder capacity, antegrade continence enema creations (ACE or MACE), and other older types of urinary diversions. The main issue for these patients is the inability to store and release urine safely and in a controlled manner.

The primary goal for the medical team is always protection of the upper tracts, but for patients and families, their goal is likely to be socially acceptable continence. These two goals can be directly opposed to each other at any time during the patient's life span. Due to the reconstructions that they undergo, both to protect upper tracts and to achieve the continence, these patients are at a lifelong risk for true infection that can cause urosepsis (not from colonization due to CIC), nephrolithiasis, stricture of their cathing channel (urethra or surgically created channel; stenosis of a surgically created channel is an expected occurrence), upper tract damage, and bladder cancer. To effectively monitor for the upper tract damage, the most important sequelae to avoid, they need serial urodynamics (with baseline communicated to the adult urology team), renal and bladder ultrasounds, and reassessment of continence, and any change in status also necessitates a spinal cord evaluation for

new tethering. Awareness of the presence of a VP shunt and avoidance of infecting this are also essential.

For any child who underwent an augmentation cystoplasty, he/she needs lab work to assess for metabolic acidosis (specifically hyperchloremic acidosis), renal function, and vitamin B12 deficiency (if terminal ileum was used). The other things that the patient (and possibly caregivers) needs to be taught are signs and symptoms of bladder rupture, as well as that not catheterizing increases this risk, bowel obstruction due to adhesions, and bladder stones due to mucous from the bowel mucous settling in the bladder (46 % of patients have recurrent bladder stones (Wood 2015). Bladder malignancy is also increased in the population which has had an augmentation. The risk of bladder cancer in patients with bladder augmentations is higher than the general population, but it is unclear if this is related to the augment itself or the underlying disease process (Higuchi et al. 2010). The vast majority of these patients will be on anticholinergics or antimuscarinics, and monitoring for side effects of these medications is essential.

The final considerations for patients with neurologic issues are sexuality and fertility, and these may be best and most appropriately addressed in a transitional setting. It is also important to review birth control, STD prevention (remember, the risk for latex allergies is increased in pediatric urological patients due to frequent instrumentation; this has been decreasing recently due to early elimination of latex exposure), and sexual abuse prevention, especially considering the cognitive level of the patient.

Many young adult and teen spina bifida patients are sexually active, and healthcare professionals at all levels of care may be faced with issues regarding relationships and sexuality among young adults with spina bifida. Ideally these should be addressed with patients by adult specialists in these areas before sexual activity is initiated. Nevertheless, it is important to establish the information patients already have, even in the pediatric environment; some patients report they have never discussed sexuality issues with a provider and some report they would have discussed these issues if the provider had initiated the topic (Sawyer and Roberts 1999). Males with neurologic GU conditions will have possible issues with erections and retrograde ejaculation, while females will be able to conceive, but body habitus may be an issue and factor into potential delivery concerns as they become pregnant. Female spina bifida patients are less likely to use hormonal contraception and to be using no method of birth control (Cardenas et al. 2010). There is a higher incidence of precocious puberty and premature activation of hypothalamic-pituitary-gonadal axis in spina bifida girls than is seen with their healthy counterparts, and the timing of puberty may be earlier, at 10.9–11.4 years (Trollmann et al. 1998), making this a consideration in their ongoing care.

Obstructive Uropathy

Obstructive uropathy includes some degree of neurogenic bladder; these children are all born with renal disease. Posterior urethral valves are the most common diagnosis in this group and occur exclusively in males. These patients

demonstrate some degree of chronic kidney disease, from either primary renal dysplasia or due to the presence of obstruction to urine flow or both of these factors. The initial damage occurs prenatally, and the timing of this directly relates to the severity of the renal involvement and damage, resulting in significant kidney disease present in 13–28 % of patients with posterior urethral valves (Holmdahl and Sullen 2005). It is unclear whether timing of valve ablation (ideally done as soon as the valves are known, in the newborn period) changes the degree of renal damage. These patients are at continued risk of incomplete bladder emptying, which may be related to recurrence of or incomplete ablation of these valves, secondary bladder neck obstruction, or side effects of anticholinergic medications.

All of these patients will need routine urodynamic studies and repeat ones for any reported changes. Again, the baseline at transition of care is essential, and patients and their parents may need reminding that preservation of upper tracts is the most essential goal of care. The most common time to see renal deterioration is at and during puberty; the reason and pathophysiology for this is unclear (Ardissino et al. 2012). Blood pressure monitoring, serum creatinine, and urinalyses need to be routinely performed throughout the life span as it is not known if the natural history of end-stage renal disease lasts throughout the life span (Glassberg et al. 2013).

Infertility and retrograde ejaculation in male patient can be an issue, but erectile dysfunction usually is not an issue. Any potential infertility issues should be referred for additional evaluation.

Nephrolithiasis is an increasing pediatric urology issue with the incidence increasing by 6–10 % per year and affecting 50 per 100,000 adolescents (Tasian and Copelovitch 2014). Many of these children have a syndrome or lab finding that makes them at high risk, and with adult stone specialists, this may be one of the easiest pediatric urology diseases to transition to adult providers. It becomes more complicated when stones are present in children with complex urological states (such as bladder exstrophy or myelomeningocele) or with metabolic diseases (such as growth delay due to renal issues or decreasing bone density due to reabsorption of urine through a bladder augmentation) with which adult providers may not be familiar (Lambert 2015).

Bladder Exstrophy

Bladder exstrophy and associated epispadias are very complex anomalies and are more and more often diagnosed prenatally, but if not, immediately at birth. These children undergo complex reconstructions that are usually staged; many of these patients require bladder augmentation and the creation of a catheterizable continent channel. Incontinence is a huge quality of life issue as is sexual function and cosmesis. This is due to the widened pubic symphysis creating shortened penile length and ejaculation issues and for women, sexual function, and pelvic organ prolapse. Pregnancy is possible with a higher incidence of preterm birth and a planned C-section at 37 weeks is recommended (Creighton and Wood 2013). Most of these

patients are able to live a normal life span, but will continue to have the issues associated with complications of their childhood bladder surgeries such as bladder stones, UTIs, catheterization issues, and continence issues.

Disorders of Sexual Development

Disorders of sexual development and anorectal malformations are another complex group of congenital urogenital disorders. No matter what the specific disease process, these kids require endocrine, psychosocial, and urologic care throughout the life span, and a full discussion is beyond the scope of this book. Congenital adrenal hypoplasia is one of the most common genetic diseases in humans and 21-hydroxylase deficiency is the most common of these (Lambert 2011). Patients with this require long-term steroid and hormone replacement, initially to achieve adult height and pubertal development, but with changing goals in adulthood. Children with congenital adrenal hypoplasia are at risk for infertility and adrenal tumors and so routine renal ultrasounds are indicated. Gonadectomy may be indicated in late adolescence or early adulthood as the incidence of gonadal malignancy in adulthood is 14 % (Deans et al. 2012).

Dr. Rick Rink (2013) from Riley Hospital for Children provides the following list of concerns for transitions for patients with disorders of sexual development: sexual function, sexual identity, emotional well-being, concerns regarding intimacy, counseling patient on disclosure of their condition to others, informing the patient of their condition, gender dysphoria, vaginal stenosis, fertility, hormonal deficiencies, steroidal deficiencies, gonadal tumors, endocrine management, gynecological care, mucous-producing neovagina, tumors in neovagina, worsening virilization due to poor adherence to medical therapy, poor cosmesis, and bladder dysfunction.

Pediatric Urologic Cancer Survivors

Children who are genitourinary cancer survivors will have lifelong urologic needs. Adult survivors of genitourinary pediatric cancer (including Wilm's tumor, germ cell tumors, and rhabdomyosarcoma) are at risk for long-term complications and require serial follow-up and surveillance. Children are at risk for complications from chemotherapy and radiotherapy as well as complications and side effects from extirpative and reconstructive operations (Lambert 2015). These will depend on the tumor type and stage, treatment, and reconstructive procedures performed, but will affect multiple organ systems. With an 80 % cancer survival rate, the number of childhood cancer survivors is increasing, and National Cancer Institute Surveillance Epidemiology and End Results estimates 1 in every 250 young adults will be childhood cancer survivors (Howlader et al. 2011). Of non-progression, nonrecurrent causes of mortality, second malignancies are the leading cause of death among long-term childhood cancer survivors (Rink 2013).

Fertility is also a likely issue for these patients and something that pediatric providers need to address in any age-appropriate child (meaning at or approaching adolescence), as egg and sperm collection and storage are widely available, but these services are dependent on the developmental age of the child. Patients and their family must be offered information regarding these services and can be directed to organizations such as the American Society for Reproductive Medicine or Resolve in addition to information regarding facility or local services.

Congenital Kidney and Urinary Tract Anomalies

Vesicoureteral reflux, ureteropelvic junction obstruction, multicystic dysplastic kidney disease, ureterovesical junction obstruction, ectopic ureteral insertion, renal ectopia, duplicated collecting systems, ureteroceles, or a solitary kidney make up a broad diagnosis group of congenital kidney and urinary tract anomalies. These can vary greatly in severity and thus have wide-ranging impacts on adult life and consideration upon transition from pediatric to adult care. Children with chronic kidney disease require lifetime follow-up to prevent progression of the disease and monitor for early signs of renal deterioration (Mertens et al. 2008). The long-term effects of these varied congenital anomalies range in severity from none to end-stage renal disease. Many patients with these diagnoses need comanagement by urology and nephrology.

Hypospadias is a common complaint and surgical case in pediatric urology practices. The incidence is approximately 1 in 200 to 300 live male births (Lambert 2015). This condition encompasses a wide range of severity with the most mild being a mega meatus and the most severe with a perineal urethral meatus and/or penoscrotal transposition. The goals of correction are a normal urinary stream from an orthotopic urethral meatal position, prevention/correction of chordee, satisfactory cosmesis, and preservation of future ability to have intercourse. Unfortunately, at times, even a simple appearing repair can need grafting and multiple surgeries resulting in scarring, poor function, and poor cosmesis. All of these issues can be magnified during puberty with penile and scrotal growth. Some of the complications that can occur at any time are urethral stricture, chordee, persistent hypospadias, urethral diverticulum, cosmesis issues, voiding dysfunction, and sexual function issues (Rink 2013).

Varicoceles and cryptorchidism are two other pediatric urologic issues that require long-term education and adult follow-up; both can be repaired surgically and both have a potential for infertility in adulthood. Varicoceles in adolescent boys are repaired for indications including pain, testicular asymmetry, or abnormal semen parameters (which can be a challenge to obtain in pediatric patients).

The undescended testicle should be repaired and brought into the scrotum as soon as is reasonably safe; this is determined by discussion with pediatric anesthesia. This correction of an undescended testicle can take one or more surgeries, depending on the position of the testicle, so that the patient can more effectively perform testicular self-examination, to facilitate identification of a potential

neoplasm. The incidence among men with an undescended testicle is approximately one in 1000 to one in 2500 (Misseri 2013). Although significantly higher than the risk among the general population (1:100,000), it does not warrant removal of all undescended testicles, and there are times when the neoplasm is actually on the contralateral side to the undescended testicle. As adults, these men must be reminded of their need for follow-up periodically with ultrasounds.

Summary

The goals of attaining preservation of kidneys and upper tracts, safe and effective urine storage and elimination, continence, sexual function, fertility, and genital cosmesis can only happen throughout the life span with planned and coordinated transitions from pediatric to adult urologic care. This takes time and is not simply saying "here are your records; your next appointment should be with an adult urologist." This approach is destined to fail pediatric patients for whom all on the pediatric urology team have worked diligently, usually throughout the patient's entire life to date, to achieve the abovementioned goals.

The obstacles that have been outlined include the need to shift patient/caregiver paradigms, locating and encouraging adult urologists with interest in these complex and challenging patients to take them into their practices, providing adult urologists' and other adult urology team providers' appropriate support from the pediatric team, coordinating care with other necessary specialists, and navigating the adult health-care world. These issues must be negotiated and overcome to provide exemplary care for complex pediatric urology patients as they transition to become complex adult urology patients.

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