

W43: Transitional Care – Paediatrics to Adulthood. Part 1: The Transitional Urology Clinic and Management of Spina Bifida

Workshop Chair: Sandra Elmer, Australia

Start	End	Торіс	Speakers
		History of Adolescent Care in Urology	Sandra Elmer
		Establishing a Transitional Urology Clinic:	Hadley Wood
		The perfect 'age' to transition.	
		Barriers to Transition.	
		Building the MDT.	
		Quality and Safety.	
		Benefits of a mixed paediatric and adult practice	Danielle Delaney
		Spina bifida: Optimising bladder function	Ashani Couchman
		Spina Bifida: Augmentation, diversion and catheterisable	Hadley Wood
		stomas	
		Spina bifida: When follow-up goes wrong	Ashani Couchman
		Spina bifida: Case discussions	Sandra Elmer

Aims of Workshop

Attendees will learn how to establish an effective Transitional Urology Service and manage patients with spina bifida.

Learning Objectives

Establish an effective Transitional Urology Clinic

Target Audience

Urology, Conservative Management

Advanced/Basic

Advanced

Suggested Learning before Workshop Attendance

Kovell RC, Skokan AJ, Wood DN. Transitional Urology. Urol Clin North Am. 2018 Nov;45(4):601-610. doi: 10.1016/j.ucl.2018.06.007. Epub 2018 Sep 7. PMID: 30316314.

Speaker abstracts

History of Adolescent Care in Urology (Dr Sandra Elmer)

For many children with congenital conditions of the genitourinary tract, lifelong care is essential. Transition Urology describes the care of these individuals from adolescence onward. The importance of a well set-up Transition Clinic is becoming increasingly important as more of these children live into adulthood. In the past, these patients were almost exclusively managed by paediatric providers. However, with better understanding of the management of many congenital conditions, their life-expectancy has dramatically improved, and these children are becoming adult patients with chronic and complex needs. The ultimate aim of the transition clinic is to ensure optimal care from adolescence onward, in order to set them up with excellent health outcomes throughout the rest of their lifetime. The transition of these individuals from paediatric to adult care is a highly individualised process and can require an extensive multidisciplinary team.

The primary role of the urologist is to closely survey bladder function in order to prevent upper tract damage. Other important goals are to minimise urinary tract infections, achieve continence, improve sexual function, and maximise fertility potential. Optimising the overall quality of life of these often complex patients can be challenging, and achieving these goals often requires significant resources, expertise and ancillary support. In the past, this role has traditionally fallen into the lap of over-stretched paediatric urologists, or sometimes ill-prepared adult urologists with inadequate interest, knowledge or training.

We know there are many barriers to the transition process, including physician, patient, institutional and systemic factors and any of these factors can result in failure to transition. Failure of transition can have negative effects on the individuals' health outcomes, and many studies have shown that inappropriate follow-up and care of these complex adolescents can increase the rate of future hospital admissions and is associated with non-adherence to treatment recommendations.

It cannot be underestimated the importance of successful transition. We have an incredible opportunity to positively impact the lives of the adolescents and their families that we care for. We can make major quality of life gains by preserving renal function and optimising continence, and we know this has a positive impact on school and workforce participation and their mental health. And the health economics are potentially huge, by preventing the worst cost of renal failure, and decreasing future hospital admissions.

Establishing a transitional urology clinic (Dr Hadley Wood)

Transition from pediatric to adult care is challenging, and the needs of the patients will vary depending on the individual patient, system of care, and support system around the patient. The goal of the transition process should be to provide developmentally appropriate, uninterrupted care for patients as they pass from pediatric care to adult care. While this seems simple, in fact no one has yet "mastered" a model of transition, particularly since no model will be a "one size fits all" approach. This lecture will focus on when it is most appropriate to begin and complete the transition process for patients with congenital urological conditions and provide some simple tools to aide in the process. Moreover, we discuss various barriers to successful transition and provide some simple solutions to help reduce those barriers. We also discuss how one should think about building a multidisciplinary team to care for patients with multi-system disease in an adult care model. Finally, we emphasize the importance of collecting data and defining success in transition.

Augmentations, Diversions and Catheterizeable channels (Dr Hadley Wood)

Bladder reconstructions can be done across the lifespan, but the majority are done in adult life in the setting of bladder cancer. Patients with congenital and acquired bladder conditions may require augmentation cystoplasty or diversions early in life and often have long-term survival following those reconstructions. Risks associated with pediatric bladder reconstructions in adulthood are poorly characterized and urologists unfamiliar with complex pelvic surgery may feel intimidated to treat these complications. This lecture addresses evaluation and treatment for the rare but serious complications like augmentation ruptures and secondary bladder cancers as well as commonly encountered problems associated with long-term survival, such as metabolic challenges, stones, secondary incontinence, and strictures and perforations of channels.

The Benefits of a mixed paediatric and adult practice (Dr Danielle Delaney)

Traditionally many Urologists had a mixed adult and paediatric practice. Transition services arose as paediatric hospitals became larger stand-alone institutions from previously co-located larger adult-based hospitals and there was greater need and provision of specific paediatric services. The traditional adult crossover model continues to occur in some specialties as such Dermatology, Ophthalmology and also surgical subspecialties including Orthopaedics, ENT, Neurosurgery, Plastics depending on need and local service availability.

"Cradle to grave" Urology services are currently provided by several Urologists throughout Australia and New Zealand, based on individual training, specialist interest and location of practice. There is no formal paediatric urology training program in Australia and New Zealand, and training can come via Paediatric surgery or Urology training programs with subspecialty training once general training is completed. Many regional adult Urologists will provide some level of paediatric urology services especially in the common conditions such as nocturnal enuresis, urinary tract infections and circumcision.

A combined paediatric and adult practice can be a very successful and satisfying clinical model for all involved and hence negates the requirement for transition. There are significant benefits of cradle to grave urology for both the patient, family and clinician. It is important to have patient centric care from an early age rather than simply parent focused care and engage children with their care although the primary decision makers are the parents. The continuity of care can help with patients who will go through a series of significant transitions as adolescents. As a professional you have very intimate window in the patient and their family and understand the dynamics of the parent-child relationship.

There is significant clinician satisfaction watching young person to develop into adult with a chronic medical clinician. Professional skills are enhanced both clinically and surgically providing an all-ages urological service. For example, PUV resection the surgical technique is similar to any transurethral resection technique which is learnt more commonly in adult urology with TURP and TURBT. Also, exposure to new therapies (eg medications such as beta3 agonists) and surgical techniques which is more common in the adult sphere.

There are few disadvantages of combined adult and paediatric practice including moving on some challenging patients or families, occasionally a lack of collaborative practice from colleagues in either world and financial disparity.

Optimising bladder function in Spina Bifida patients (Dr Ashani Couchman)

Spina bifida is a condition that has a spectrum of presentation and as such requires an individualized approach to evaluation and management.

Literature supports a 90% reporting rate of active urological issues in this population with nearly all of these requiring further evaluation and intervention. Incontinence and UTI are the most reported issues in combination with urinary tract calculi and difficulties in catheterization. There are very little data about sexual or reproductive issues.

Optimizing bladder function requires a different lens depending on age and stage of development. Preservation of renal function remains an underlying tenant throughout life with focus on continence, support of independence, sexual function, and fertility considerations in time. Socio-economic and geographic factors will also overlay decision making.

Following appropriate assessment in the form of a clear history, examination, bladder diary, exclusion of red flags (MSU, imaging) and urodynamics dictate the immediate management approach with the end goal of maintaining renal function, attaining continence and prevention of UTI.

In the appropriate patient medication in the form of an antimuscarinic, beta adrenergic agonist or indeed an alpha blocker could be considered. If third line therapies are considered both the bladder and the outlet should be considered and the management must involve both entities. The use of Botulinum Toxin has revolutionized ongoing need for further reconstruction. It may also be used as an adjunct in refractory overactivity with an augmentation cystoplasty. Sacral Neuromodulation is an emerging therapy in this patient population with reports of successful trials in the ambulant population. Augmentation cystoplasty in combination with a bladder neck reconstruction, fascial sling, artificial urinary sphincter or mitrofanoff formation are procedures that are important to be familiar with in managing the patient with spina bifida. Bladder neck closure and urinary diversion have historically been used with regularity, however, in the appropriate patient at the correct time these could have utility. Finally, it cannot be stressed enough that we must assess these patients on an individualized basis. Their needs like any other will change over time and there must be a clear approach to assessing and managing the bladder to ensure that we support social engagement and maintaining an excellent quality of life.

When follow-up goes wrong (Dr Ashani Couchman)

This is a case presentation involving a 37-year-old non ambulant spina bifida patient with a native bladder which she manages with clean intermittent self-catheterization (CISC). She presented with a complaint of secondary nocturnal enuresis and intercatheter leak. She describes one episode of pyelonephritis requiring hospitalization in 2016 and a recent diagnosis of breast cancer.

She has been imaged annually from 2010 2018 when she presented for urological evaluation. At that point note was made of progressive bilateral hydroureteronephrosis with no intervention. Fluoroscopic urodynamics demonstrate neurogenic detrusor overactivity wet with a 260mL capacity and a DLPP 52cmH2O. GFR was estimated at 66mL/min.

Following treatment with intradetrusor Botulinum Toxin, repeat assessment a year on was undertaken. Note was made of an increase in the hydroureteronephrosis. Functional imaging indicated bilateral ureteric obstruction and a reduction in the GFR to 43mL/min. Fluoroscopic urodynamics demonstrated no reflux, no leak and pDet max of 20cmH2O.

Management discussions encompassed the improvement in pressures and the progression of upper tract dilatation and objective deterioration in renal function. The loss of functional capacity remained an issue with recurrent UTI and high patient anxiety levels. Operative options ranged between a pure endoscopic approach with the limited comparative morbidity but persisting UTI risk versus an augmentation cystoplasty and ureteric reimplantation.

This case is an example of the complexity of managing these patients. The initial lack of regular follow up may not change the current presentation - which is the ongoing deterioration in all of the important factors in managing the urological tract – maintaining renal function, continence and protection from UTI.

Ultimately, assessment and management of patients should be individualized. Health belief, stage of life, socio-economic and geographic factors play an important part along with overall health state. We have a responsibility to consider these factors in planning follow up as part of the ongoing management plan. Without these supports the patient will fall between the cracks and lose confidence in their care. A crucial window for intervention maybe lost. Wide ranging education and support is important, along with an interdisciplinary model of care. Working with the patient in a collaborative fashion, acknowledging and attempting to remediate barriers to care is the best way forward to support good health and maintain quality of life.