

Further thoughts on transition of care for spina bifida patients: Experiences in BC

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In the October 2016 issue of *CUAJ*, we featured an article by Koyle et al, entitled "A proposed solution to a urological tightrope walk: The challenge of transition of spina bifida patients from pediatric to adult care in Ontario," with accompanying commentaries on the transition of care in the U.S. and Atlantic Canada. Below is a reflection on the BC experience.

Pediatric-to-adult healthcare transition is an anxiety-provoking concept for adolescents with spina bifida and even more so for their parents. Care in the pediatric system is typically administered using a one-stop shop multidisciplinary specialty clinic overseen by a medical director and nurse coordinator. In British Columbia, these patients are transitioned from a multidisciplinary clinic on an ad-hoc basis with not much more than a list of adult healthcare providers to hopefully assume care. It's no surprise these families and their pediatric healthcare providers worry about how patients will fair when they transition to a system without anyone to coordinate their specialty care.

These patients represent some of the most medically complex patients in pediatrics and have varying degrees of neuromuscular, urological, and bowel dysfunction. From the urological standpoint, these patients often have undergone extensive lower urinary tract reconstruction to correct refractory incontinence, protect the upper tracts, and facilitate easier clean intermittent catheterization (CIC). These complexities are then superimposed on the social aspects of transition as they move on to the challenges of adulthood, such as societal integration, post-secondary education, and onwards.

Managing a spina bifida patient is like walking a thin line. Life-threatening complications, such as ventriculoperitoneal (VP) shunt failure, may present with little more than a headache, and a urinary tract infection in the context of

neurogenic bladder can easily progress to urosepsis. At BC Children's Hospital (BCCH), we follow approximately 250 such patients and have graduated over 450 since the inception of the clinic. However, the stories of "transition-gone-wrong" are too many. Perforated Mitrofanoffs, advanced urolithiasis, delayed detection of augmentation ruptures, upper tract deterioration to the point of transplantation, and zany intraoperative consults to the labour and delivery suite are some of the outcomes we have experienced.

What happens to reverse the hard work of patients, parents, and healthcare providers in the pediatric system? Our thoughts in BC's microenvironment are that these patients' social circumstances, aging parents, and challenges of navigating a different health authority all contribute to them falling through the cracks. Spina bifida tends to affect socially marginalized families who live in rural areas, where healthcare is less readily accessible. It is not uncommon for our patients to have to fly into Vancouver from the very northern edges of BC for care. In the pediatric system, there is financial support for travel, and our patients make the trip with their parents and the reassurance that they will receive all of their followup in one visit to BCCH. Following transition, there is no support, no coordination of appointments and tests, and the onus of seeking followup care is placed on the individual. It is difficult enough for patients in larger cities to arrange transportation, let alone patients who are hours away from a tertiary care centre. In addition, these patients tend to move from one group home to another, often in different cities. Over time, they lose contact with the adult specialists who were assigned at transition. Without a central care coordinator advocating for patients in concert with progressive caregiver burnout, these patients lose the driving factors for seeking the followup they require and only episodically re-appear to emergency rooms when they develop a complication.

In a recent online survey of our graduates the most common health concerns were urinary incontinence (71%) and urinary tract infections (UTI, 65%). However, only 47% of respondents saw a urologist at least annually and 30% of

those with a self-reported urological issue (incontinence, UTIs, or stones) were not followed by a urologist. Moreover, 32% of patients felt that not seeing a specialist has led to the development of complications, in particular, urological ones. Over half of participants (62%) were dissatisfied with the transition process, whereas only one urologist felt SB patients were not adequately prepared, suggesting a disconnect between patient and physician impressions of transition. SB patients listed transportation (44%) and difficulty finding qualified specialists (22%) as the greatest challenges to transition, while urologists cited a lack of understanding of the adult healthcare system (57%), transportation (50%), and poor patient understanding of the complications of SB (36%). A substantial number of survey respondents also noted that it was difficult to get certain specialists to see them on a followup basis when there were no new active issues.¹

Solutions to improving transition essentially revolve around either establishing adult multidisciplinary clinics, appointing a central nurse coordinator, allowing transitioned patients to be followed by their pediatric specialists, improving transition preparedness, or some combination thereof.

Most pediatric specialists will agree that a multidisciplinary adult spina bifida clinic makes sense. This strategy has the potential to provide the highest quality of care while being cost-effective by limiting complications of neglected spina bifida. We have explored the possibility of implementing a multidisciplinary spina bifida clinic here in BC, unfortunately to no avail. Support for transitioning patients is limited in the adult world for two key reasons: (1) despite a publically funded system, money does not follow complex patients, which means that any new model of care in the adult system will be an added cost to a fixed budget; and (2) lack of interest among adult providers in caring for transitioned patients who are typically complex, requiring time-consuming services that are relatively poorly remunerated in a fee-for-service model.

Appointing a central nurse coordinator to monitor and followup on these patients by phone/email is a less costly alternative to establishing a multidisciplinary clinic; however, we have not been successful in obtaining provincial funding for this initiative either. "Too much money for too few patients," was the assessment of a recent proposal.

Because adult and pediatric hospitals are administratively, financially, and geographically separate silos, it is impractical for pediatric specialists to provide care in adult centres or for graduates to continue to be followed in pediatric hospitals.

Presently, we are left only with ways to improve pre-transition planning and post-transition guidance for patients and their adult physicians. As part of this initiative, we are working on establishing a network of adult specialists who have expressed interest in looking after spina bifida graduates in their region and sharing this with recent and former graduates. In particular, we are connecting graduates with psychiatrists to coordinate and oversee their overall care. Psychiatrists are well-suited for this role, given their experience with spinal cord injury patients and their access to resources at rehabilitation centres. Lastly, we are working with several specialists to establish transition care pathways for the longitudinal care of these patients, specifically focusing on certain surgical modifications that may be foreign to the adult provider, such as a Mitrofanoff channel, bladder augment, VP shunt, and cecostomy.

Ultimately, a robust transition program will involve addressing the unique social circumstances of these patients, climbing the administrative obstacle course, and improving lines of communication between adult and pediatric care providers. Thirty years ago, most of these patients did not live to the point of transition. Today, medical advances have allowed most to live well into adulthood and lead productive lives. Even though the incidence of spina bifida has gone down drastically with improved prenatal care, the total number of individuals living with the condition continues to rise to over 500 patients in BC. These patients represent some of the most medically and surgically complex in the pediatric system and are indeed much more complex than many other conditions for which a transition network already exists (e.g., diabetes, chronic renal failure, cystic fibrosis). The current status of spina bifida transition care in BC is episodic, urgent, and suboptimal without any coherent infrastructure. These patients and their families deserve better.

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Reference

1. Chehroudi C, Duffy D, Irwin B, et al. Aging out: Experiences with transition to adult healthcare for spina bifida patients in British Columbia. *Can Urol Assoc J* 2016;10(suppl1):S84.

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