ORIGINAL PAPER

TRAUMA AND RECONSTRUCTIVE UROLOGY

The need for specialized training for adults with congenital urologic conditions: differences in opinion among specialties

Joshua Roth[1,2], Sean Elliott[2], Konrad Szymanski[1], Mark Cain[1], Rosalia Misseri[1]

[1]*Department of Urology, Riley Hospital for Children at Indiana University Health, Indianapolis, Indiana, United States*
[2]*Division of Pediatric Urology, Riley Hospital for Children, Indiana University School of Medicine, Indianapolis, Indiana, United States*

Citation: Roth J, Elliott S, Szymanski K, Cain M, Misseri R. The need for specialized training for adults with congenital urologic conditions: differences in opinion among specialties. Cent European J Urol. 2020; 73: 62-67.

Article history
Submitted: Sept. 18, 2019
Accepted: Jan. 13, 2020
Published online: March 23, 2020

Corresponding author
Joshua Roth
Riley Hospital for Children at Indiana University Health
Department of Urology
705 Riley Hospital Drive
Suite 4230
Indianapolis, Indiana
46202-5225, USA
phone: +1 317 944 7446
joshuarothmd@gmail.com

Introduction The aim of this study was to survey pediatric urology fellowship directors (PFD) and adult reconstruction fellowship directors (AFD) to assess who they believe has sufficient training to care for adults with congenital urologic conditions (ACUC).

Material and methods An online survey was created to assess attitudes towards specific training to care for ACUC. The survey was administered to 27 PFD and 26 AFD [16 from genitourinary reconstructive surgery (GURS) and 10 from female pelvic medicine and reconstructive surgery (FPMRS)]. Both groups were asked if specific training is warranted, and if general urologists, pediatric urologists or adult reconstructive urologists were sufficiently trained to care for ACUC.

Results A total of 26 (96%) PFD and 10 (39%) AFD completed the survey. All PFD were fellowship trained in pediatrics. Of the AFD, 5 were GURS trained, 4 were FPMRS trained and 1 was not fellowship trained. The majority (65% PFD, 90% AFD) believed specific training is warranted. Few believed general urologists have sufficient training (8% PFD, 20% AFD). Most PFD believed pediatric urologists have sufficient training (85%), but a minority believed those with adult reconstructive training do (40%). Conversely, a minority of AFD believed that pediatric urologists have sufficient training (40%), while those with adult reconstructive training do (FPMRS: 67%, GURS: 60%).

Conclusions Both pediatric and adult reconstructive urologists believe specific training to care for adults with congenital urologic conditions is warranted. Neither group considers the other to be ideally suited to care for this complex patient group. This suggests both groups may have something to learn from each other.

Key Words: urologic congenitalism ‹› transitional care ‹› fellowship ‹› training

INTRODUCTION

Major congenital genitourinary disorders historically had poor survival due to associated spinal cord defects and a complex constellation of diseases due to various birth syndromes. However, advances in medical and surgical therapy have allowed for improved management of children, which has resulted in more adults living with congenital urologic conditions (ACUC) [1]. This includes adults living with conditions such as posterior urethral valves, exstrophy-epispadias, prune belly syndrome, myelomeningocele, cloacal malformation, disorders of sexual development, and even conditions like hypospadias, vesicoureteral reflux and undescended testes. Long term care of any chronic childhood disorder has significant financial implications due to costly resource utilization, expertise and ancillary support [2, 3]. Patients are often ill-prepared to manage their transition due to a variety of factors [4, 5, 6]. Additionally, adolescents and young adults with major urologic congenital anomalies in North America are often managed by overextended pediatric urologists and adult urologists, who may be ill-prepared to manage

doi: 10.5173/ceju.2020.0038

these conditions [4, 7]. In North America, all urologists initially complete a urology residency in which they are exposed to both adult and pediatric urology and then pediatric urologists complete an additional two year fellowship specifically in pediatric urology, which adult reconstructive urologists can complete an optional one year fellowship in genitourinary reconstruction surgery (GURS) or two year fellowship in female pelvic medicine and reconstructive surgery (FPMRS). Specialists currently interested in caring for ACUC in North America are rare [7].

A significant number of ACUC are lost to urologic follow-up and are more likely to present to emergency departments for acute and sometimes preventable healthcare issues [8]. Such disorganized, reactive care is not an ideal approach to managing and preventing acute exacerbations of chronic problems. General consensus on who and how to best follow this population is lacking, particularly due to the heterogeneous needs of ACUC [9]. Several transition models have been proposed for long-term urological care in adulthood, including transferring care to a transitional urology clinic staffed by both a pediatric urologist and an adult urologist, a pediatric urologist with an interest in ACUC or an adult urology provider [9]. Currently, each center in North America handles transition differently, and transition can sometimes be forced by institutional policy or limitations of the health care provider's license [10]. In one survey, pediatric urologists reported that patients with prior complex surgical reconstruction should be followed by a urologist with specific interest, training, and experience in the area of transitional urology. However, this survey found this area to be an unmet need in the field of urology and concluded that specific training may be warranted to care for ACUC [11]. The present study sought to elucidate opinions of leaders in urology training and education regarding the most appropriate training needed to care for ACUC by surveying pediatric urology fellowship directors (PFD) and adult reconstruction fellowship directors (AFD).

MATERIAL AND METHODS

A 6-question non-validated online survey was drafted to assess attitudes towards optimal urology training specifically for the care of ACUC. The survey was administered via SurveyMonkey.com to fellowship directors in the United States and Canada: 27 PFD and 26 AFD (16 GURS and 10 FPMRS) in 2016.

Information was collected on previous fellowship training, if specific training is warranted to care for ACUC, and if general urologists, pediatric urologists, or adult urologists who had additional fellowship training in reconstruction had sufficient training to care for ACUC.

The survey consisted of multiple-choice questions with free text options. In addition to the above questions, several proposed fellowship options were proposed to determine if these training scenarios would provide satisfactory training to care for ACUC, keeping in mind that the typical pediatric urology fellowship includes one year of clinical training and one to two years of research, the typical GURS fellowship is one clinical year with no dedicated research experience, and the typical FPMRS fellowship is one year of clinical training and one year of research. We proposed two and three year options for an ACUC fellowship with varying levels of pediatric, adult reconstructive and research experience. PFD were additionally asked to indicate if completing each combined fellowship should allow the applicant to be eligible for added qualification in pediatric urology by the American Board of Urology.

RESULTS

Twenty-six of the 27 (96.3%) PFD and 10 of the 26 AFD (38.5%) completed the survey, giving an overall 63.2% response rate. All PFD were fellowship trained in pediatric urology. Of the AFD, 5 were GURS trained, 4 were FPMRS trained and 1 was not fellowship trained.

The majority (65.4% pediatric, 90.0% adult) believed specific training was warranted to care for ACUC. Very few from either group believed general urologists were sufficiently trained to care for ACUC (8.0% pediatric, 20.0% adult). Most PFD believed pediatric urologists have sufficient training to care for ACUC (84.6%), while a minority of PFD believed those with adult reconstructive training do (40.0%). Conversely, a majority of AFD believed that those with adult reconstructive training have sufficient training to care for ACUC (FPMRS: 66.7%, GURS: 60.0%), but a minority felt that pediatric urologists do (40.0%) (Table 1).

In summarizing the various proposed fellowship models for a fellowship to care for ACUC, PFD believed that ideal training should include one full clinical year of pediatric urology training. AFD believed that such fellows should require one full clinical year of adult reconstructive urology training (Table 2).

Some specific comments from PFD included:

- "I think that the [pediatric providers] could care for the adult patients but suspect most don't want to. That is the crux. If there were folks interested in adult care that had a pediatric background that would be ideal."
- "I'm not sure how many would sign up for this after 2 years of fellowship, although we could all

Table 1. *Responses to the administered survey regarding who has sufficient training to care for adults with congenital urologic conditions (ACUC) from pediatric urology fellowship directors (PFD) and adult reconstructive fellowship directors (AFD)*

Survey question	PFD (N = 26)			AFD (N = 10)			p-value
	Yes	No	No response	Yes	No	No response	
Is specific training warranted?	17 (65%)	9 (35%)	–	9 (90%)	1 (10%)	–	0.22
Do general urologists have sufficient training to care for ACUC?	2 (8%)	23 (88%)	1 (4%)	2 (20%)	8 (80%)	–	0.56
Do pediatric urologists have sufficient training to care for ACUC?	22 (85%)	4 (15%)	–	4 (40%)	6 (60%)	–	0.01
Do adult reconstructive urologists have sufficient training to care for ACUC?	10 (38%)	15 (58%)	1 (4%)	6 (60%)	4* (40%)	–	0.45

*The survey administered to AFD had this question broken into two separate questions, asking if those trained in female pelvic medicine and reconstructive surgery (FPMRS) and genitourinary reconstructive surgery (GURS) had sufficient training to care for ACUC. Responses were the same, except for one person who answered 'no' for GURS fellowships providing sufficient training did not answer whether FPMRS fellowships provide sufficient training.

Table 2. *Responses from pediatric urology fellowship directors (PFD) and adult reconstructive fellowship directors (AFD) on the acceptability of different scenarios of how a combined fellowship in transitional care could be constructed*

Survey question	PFD (N = 26)			AFD (N = 10)			p-value
	Yes	No	No response	Yes	No	No response	
2 years peds + 1 year recon	13 (50%)	4 (15%)	9 (35%)	2 (20%)	6 (60%)	2 (20%)	0.03
*peds eligible	14 (54%)	3 (12%)	9 (35%)				
1 year peds + 1 year recon	13 (50%)	4 (15%)	9 (35%)	8 (80%)	2 (20%)		1.0
*peds eligible	12 (46%)	5 (19%)	9 (35%)				
1 year peds + 6 months recon + 6 months research	14 (54%)	2 (8%)	10 (38%)	1 (10%)	6 (60%)	3 (30%)	0.001
*peds eligible	13 (50%)	3 (12%)	10 (38%)				
6 months peds + 1 year recon + 6 months research	6 (23%)	9 (35%)	11 (42%)	4 (40%)	3 (30%)	3 (30%)	0.56
*peds eligible	3 (12%)	11 (42%)	14 (54%)				
6 months peds + 6 months recon + academic year	2 (8%)	13 (50%)	11 (42%)	2 (20%)	5 (50%)	3 (30%)	0.65
*peds eligible	1 (4%)	13 (50%)	14 (54%)				

peds – pediatric urology fellowship; recon – adult reconstruction fellowship; *peds eligible refers to if the PFD believe completing that fellowship would make one eligible to become pediatric subspeciality certified

use someone with this training since the adult urologists in general are never going to want to see these transitional patients, so we are stuck taking care of them by default."

- "Options with only six months of pediatric urology are not enough for a transition specialist to really understand pediatric reconstruction. You can't really get that in a year."

Some specific comments from AFD included:

- "Even the programs in adult reconstruction that have an emphasis on congenitalism (do not perform a sufficient amount of cases on ACUC). It would be hard to spend less than a year on the adult side. There are so many things other than congenitalism that these programs spend time on. Although I am not a pediatric urologist, I think the pediatric community would have a hard time supporting added qualification in pediatric urology for people who have done only 6 months of pediatric urology training. So, I think it needs to be 1 year of clinical for each. Unfortunately, this leaves no academic time if we try to keep the programs to two years. We don't want to make this three years because that will just scare people away. Something else to consider is once you get the added qualification in pediatric urology, how do you keep it when a significant portion of your cases are adult? The pediatric board may need to consider exceptions for congenitalism cases."
- "I suspect that there would be a low demand for such fellowship if more than two years. Even if (a combined fellowship was completed in) two years, (the fellow) cannot get boarded in either pediatric urology or FPMRS under current ACGME rules."
- "Two years [of fellowship training] is enough, and I don't think 1 full academic year is needed."

DISCUSSION

A critical part of successfully transitioning pediatric patients with complex genitourinary disease is establishing appropriate long-term urologic care. This current study shows that there is a difference in opinion among fellowship directors that care for these patients about who is ideally suited to fulfill this role. Ideal training should consist of exposure with both specialties.

Patients with complex congenital genitourinary conditions require life-long urologic follow-up due to management of renal function, lower urinary tract function, urologic malignancy risk, sexual/reproductive function, or managing complications of prior urologic reconstructions [9, 12]. Unfortunately, only 8% of PFD and 20% of AFD believe general urologists have suitable training to care for these patients, which corroborates a prior survey of pediatric urologists, who believed that general urologists are not the most appropriate specialists to undertake the responsibility of following adults with a history of prior complex genitourinary reconstruction [11.The majority of both groups (65.4% PFD, 90.0% AFD) believe that specific training is warranted to take care of ACUC.

Less than half of AFD (40.0%) believe that pediatric urologists have sufficient training to care for ACUC, while those with additional training in adult reconstruction do (60.0–66.7%). While we did not ask why AFD felt this way, possible reasons include the potential paternalistic approach of the provider, limited contact with adult primary providers and unfamiliarity with adult community resources [3]. In addition to these concerns, indefinitely caring for chronic congenital conditions in a pediatric setting is unsustainable [13, 14]. In the United States, approximately 500,000 children with special healthcare needs turn 18 every year [15]. Additionally, an estimated 4.5 million (18.4%) Americans aged 12–18 have special health care needs [16]. The number of patients over the age of 18 with childhood conditions admitted to children's hospitals has increased over the last decade, and these adults have longer hospital stays and higher charges, resulting in disproportionally higher resource utilization compared to their pediatric counterparts [17].

Most PFD believe pediatric urologists have sufficient training to care for ACUC (84.6%), while those with adult reconstructive training do not (40.0%). Furthermore, comments from PFD indicate that many pediatric urologists "could care for the adult patients but suspect most don't want to." This reinforces findings from Szymanski et al., who found that 70% of pediatric urologists would refer their patient to a urologist specializing in transitional care, but less than half had such a colleague in their practice [11]. Sub-specialization in post-graduate medical training is effectively separating pediatric from adult urology practices. A position statement from the International Children's Continence Society concluded that unless a sub-specialty for those caring for ACUC is developed, it is too difficult for adult providers to assume care of complex pediatric problems of which they have little knowledge [3].

The good relationships that patients and families have with their pediatric providers often foster reluctance by all parties to let go [18, 19, 20]. Adult providers, who may have little to no relationship with a newly referred patient, may often assume care when patients have particularly difficult problems, resulting in medical decisions being made before trust has been established [21]. Healthcare barriers to adult providers offering a seamless transition include the adult provider's large non-ACUC patient load, time required to care for ACUC, lack of knowledge of previous clinical information, lack of training in adolescent healthcare, poor tolerance for immaturity, inability to recognize a young person's unmet psychosocial needs that influence self-management, and potentially being disincentivized by a low reimbursement for transitional services due to many being unemployed and thus on Medicare and Medicaid, or uninsured [3].

The present study has several limitations. The results may not represent the views of the entire pediatric urology or adult reconstructive urology community. However, responses from those who train future urologists in these fields may have a clearer understanding of the skills necessary to care for this complex population. The response rate was modest but comparable to other clinical surveys, and those who responded to this survey may be particularly motivated and interested in the field of transitional care. Additionally, the survey was not validated and the response rate limits our ability to make any statistically significant conclusion. Although this study did not offer a formal mechanism for improving the transition process, it offers valuable information on opinions regarding transitional care. Lastly, the opinions presented were only from North American providers, and may not be representative of opinions in other healthcare systems around the world.

In a time when preventive care is being prioritized to reduce healthcare cost [22], transitional care for ACUC should be more of a focus in urology. A congenital urologist offers the potential for marked cost reduction through routine follow-up appointments and small interventions that will hopefully prevent extensive and costly admissions or surger-

ies after extended periods of loss of follow-up [23]. While PFD and AFD both believe specialized training should exist to train congenital urologists, meeting the increasing needs of this growing population will likely require workforce changes. In order to maintain subspecialty certification in pediatric urology, the American Board of Urology requires that a pediatric urologist's practice log must contain at least 75% pediatric patients. Since this survey has been administered, this certification has changed to allow congenitalism cases to count as pediatric cases, recognizing the importance of allowing pediatric urologists to care for this population. Allowing congenital urologists to maintain pediatric subspecialization allows these providers the opportunity to provide expert care to transitioning patients across hospital systems with complex urological conditions, which may encourage patient adherence and improve long-term outcomes. At a minimum, urology residency and fellowship training should place more of an emphasis on transitional care of the complex congenital patient.

CONCLUSIONS

Program directors of pediatric and adult reconstructive urology fellowship programs believe specific training in transitional urology is warranted. Neither group considers the other to be ideally suited to care for this complex patient group. More attention is needed in developing specific training in the field of transitional urology to create more specialists ideally trained to care for these complex patients.

CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

References

1. Wood D. Adolescent urology: developing lifelong care for congenital anomalies. Nat Rev Urol. 2014; 11: 289-296.
2. Bethell CD, Kogan MD, Strickland BB, Schor EL, Robertson J, Newacheck PW. A national and state profile of leading health problems and health care quality for US children: key insurance disparities and across-state variations. Acad Pediatr. 2011; 11 (3 Suppl): S22-33.
3. Bower WF, Christie D, DeGennaro M, et al. The transition of young adults with lifelong urological needs from pediatric to adult services: An international children's continence society position statement. Neurourol Urodyn. 2017; 36: 811-819.
4. Hsieh MH, Wood HM, Dicianno BE, et al. Research Needs for Effective Transition in Lifelong Care of Congenital Genitourinary Conditions: A Workshop Sponsored by the National Institute of Diabetes and Digestive and Kidney Diseases. Urology. 2017; 103: 261-271.
5. Hettel D, Tran C, Szymanski K, Misseri R, Wood H. Lost in transition: Patient-identified barriers to adult urological spina bifida care. J Pediatr Urol. 2018; 14: 535.e1-535.e4.
6. Roth JD, Szymanski KM, Ferguson EJ, Cain MP, Misseri R. Transitioning young adults with neurogenic bladder-Are providers asking too much? J Pediatr Urol. 2019; 15: 384.e1-384.e6.
7. Woodhouse CRJ, Neild GH, Yu RN, Bauer S. Adult care of children from pediatric urology. J Urol. 2012; 187: 1164-1171.
8. Szymanski KM, Cain MP, Hardacker TJ, Misseri R. How successful is the transition to adult urology care in spina bifida? A single center 7-year experience. J Pediatr Urol. 2017; 13: 40.e1-40.e6.
9. Summers SJ, Elliott S, McAdams S, et al. Urologic problems in spina bifida patients transitioning to adult care. Urology. 2014; 84: 440-444.
10. Misseri R. When Patients with Congenital Urological Problems Become Adults. J Urol. 2018; 199: 904-905.
11. Szymanski KM, Misseri R, Whittam B, Large T, Cain MP. Current opinions regarding care of the mature pediatric urology patient. J Pediatr Urol. 2015; 11:251.e1-4.
12. Roth JD, Casey JT, Whittam BM, et al. Complications and Outcomes of Pregnancy and Cesarean Delivery in Women With Neuropathic Bladder and Lower Urinary Tract Reconstruction. Urology. 2018; 114: 236-243.
13. Kaufmann Rauen K, Sawin KJ, Bartelt T, Waring WP, Orr M, Corey O'Connor R. Transitioning adolescents and young adults with a chronic health condition to adult healthcare- an exemplar program. Rehabil Nurs. 2013; 38: 63-72.
14. West C, Brodie L, Dicker J, Steinbeck K. Development of health support services for adults with spina bifida. Disabil Rehabil. 2011; 33: 2381-2388.
15. Hagood JS, Lenker CV, Thrasher S. A course on the transition to adult care of patients with childhood-onset chronic illnesses. Acad Med. 2005; 80: 352-355.
16. McManus MA, Pollack LR, Cooley WC, et al. Current status of transition preparation among youth with special needs in the United States. Pediatrics. 2013; 131: 1090-1097.
17. Goodman DM, Hall M, Levin A, et al. Adults with chronic health conditions originating in childhood: inpatient experience in children's hospitals. Pediatrics. 2011; 128: 5-13.
18. Wong LH, Chan FW, Wong KF, et al. Transition care for adolescents and families with chronic illnesses. J Adolesc Health. 2010; 47: 540-546.
19. Rutishauser C, Akré C, Surìs J-C. Transition from pediatric to adult health care: expectations of adolescents with chronic disorders and their parents. Eur J Pediatr. 2011; 170: 865-871.
20. van der Toorn M, Cobussen-Boekhorst H, Kwak K, et al. Needs of children with a chronic bladder in preparation for transfer to adult care. J Pediatr Urol. 2013; 9: 509-515.

21. Tong A, Wong G, Hodson E, Walker RG, Tjaden L, Craig JC. Adolescent views on transition in diabetes and nephrology. Eur J Pediatr. 2013; 172: 293-304.
22. Smith C, McCoskey K, Clasing J, Kluchinsky TA. Using the Army Medical Cost Avoidance Model to prioritize preventive medicine initiatives. US Army Med Dep J. 2014; Jul-Sept: 72-77.
23. Misseri R. Dialogues in pediatric urology transition to adulthood: concerns and considerations for the pediatric urologist. Dialogues Pediatr Urol. 2014; 34: 1-20. ■