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Demographics and baseline care among newly transitioning adult congenital urology patients

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Summary

Introduction

In 2017, UCSF established a formal Transitional Urology (TU) clinic co-run by pediatric and adult urology aimed at providing comprehensive urologic care for people progressing into adulthood with complex urologic histories.

Objective

We aim to describe baseline demographic and disease characteristics of this population, understand gaps in care, and gauge follow-through.

Study design

We performed a retrospective chart review of all new patients in the TU clinic at UCSF from February 2017 through January 2019. After approval from an institutional review board, demographic and clinical data were collected from medical records.

Results

39 new patients were seen in UCSF's TU clinic during a 23-month period. Our cohort included 20 patients with spina bifida and neurogenic bladder, 5 with bladder exstrophy, 3 with disorders of sexual development (DSD), 5 with obstructive uropathy, 2 with cloacal anomalies, and 1 patient each with calcinuria, reflux nephropathy, prune belly syndrome, and urachal cyst. Mean age of patients was 26 years, 63% were male, 88% spoke English, and 70% had public insurance. Patients lived an average of 94 miles from the clinic and had a mean zipcode-based household income of $70,110. There was an average of 19 months between the initial TU visit and the most recent prior urology visit. The median time since last creatinine as well as last renal ultrasound was 9 months. 19 (54%) patients warranted a total of 28 referrals to other providers at their initial visit, and 42% of these were obtained within 6 months.

Discussion

According to our demographic data, TU patients are likely to have public insurance, live far from the TU clinic, and come from low SES backgrounds. At initial presentation over half of patients warranted updated tests like creatinine and renal ultrasound. Furthermore, nearly two-thirds of patients required at least one referral to a different provider, suggesting a majority of these patients had unmet medical needs at the time of presentation to the TU clinic.

Conclusion

Our data indicate that new patients to the TU clinic often warrant additional workup, updated testing, and referrals to sub-specialty care as these needs are often unmet at the time of presentation. The etiology of this is unclear and it may be due to insurance difficulties, inability to identify an appropriate adult subspecialty provider or access to care issues. Further investigation into barriers to implementation of transitional care is needed to provide comprehensive management to this challenging patient population.

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Summary Table New transitional urology clinic patients for whom studies or labs were warranted at time of presentation, and whether or not these were completed within 6 months of being ordered

Patient follow through: labs and imaging studies

Lab/Imaging	Number of studies warranted at initial TU clinic visit		Patients who completed study within 6 months	
	N	%	n	%
Creatinine	25	86	22	88
Renal ultrasound	19	65	11	58
Urodynamic profile	18	62	11	61
Urine culture	3	10	9	81
KUB	11	38	3	100
CT abdomen/pelvis	2	7	2	100
Cystoscopy	5	17	4	80
Other	12	41	8	67

**excluding DSD patients.*
Other studies include MRI, Lasix renogram, scrotal ultrasound, and antegade nephrostogram.

Introduction

Transitional urology is a developing subspecialty within the field of urology driven by new demands for age-appropriate care for adolescents progressing into adulthood with complex congenital urologic histories [1]. Transition has been defined by the Society for Adolescent Medicine as "a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centered to adult-oriented healthcare systems." [2,3] Data across disciplines and diseases including diabetes, arthritis, and chronic kidney disease suggest that adolescent patients in a transitional clinic have improved clinic attendance, better medication adherence, higher health-related quality of life, and benefits in parent satisfaction [4—8]. Conversely, poorly planned transition to medical care in adulthood can be associated with increased risk of nonadherence to treatment and lack of follow-up, with subsequent adverse consequences in mortality as well as social and educational outcomes [7]. Specifically, the transitioning population in urology is at risk for bladder dysfunction, stone formation, metabolic and neoplastic changes, and renal damage [9].

In 2017 the University of California, San Francisco (UCSF) Department of Urology established a formal transitional urology (TU) clinic co-run by pediatric and adult urology aimed at providing comprehensive urologic care to adults with urologic congenitalism. Little is known about the transitioning genitourinary population, and thus as we build our TU clinic, our goal is to better understand the needs and barriers to access for this population so that we can best serve them during their transition. The aims of this study are to characterize the sociodemographic and disease characteristics of these transitioning urology patients, identify gaps in care, such as which studies were needed at the initial TU visit, and to characterize patient follow-through. Ultimately, we hope that by better defining the needs and barriers of newly transitioning urologic congenitalism patients, we can increase access to comprehensive medical care, improve patient quality of life and quality of care, clarify patients' understanding of their illness and improve clinical outcomes over time.

Materials and methods

A total of 39 patients were seen as new patients in the UCSF TU clinic between the clinic's inception in February 2017 through January 2019. At each new visit to the UCSF TU clinic, the patient's case is first discussed in our TU conference. Each new patient is seen jointly by a dedicated pediatric urologist (HLC) and adult reconstructive urologist (LAH) who work as a team to facilitate the transition and develop a comprehensive management plan. The clinic is focused on the urological aspects of these complex patients's care; a social worker is available as needed for patients who require assistance and the urology care team has developed relationships with other subspecialty transitional providers so that patients are referred to these providers when necessary.

Retrospective electronic medical record review was utilized to obtain data for this study. Sociodemographic variables of interest included age, sex, primary language, distance from home to clinic, median household income, and insurance status. Median household income was extrapolated using the patients' home address zipcode (https://www.incomebyzipcode.com).

We recorded primary diagnosis and intake creatinine associated with first TU clinic appointment. Additionally, imaging and subspecialty referrals were tracked, including whether or not they were completed within a six-month period. We utilized annual creatinine and renal ultrasound as a proxy to understand patients' previous adherence to care upon transition in addition to their adherence to other studies ordered at their first presentation to the TU clinic.

Descriptive analysis was performed using Microsoft Excel. Mean was calculated for numeric variables and percentage was calculated for categorical variables. In our analysis of adherence to care, we excluded patients whose underlying disease process did not require yearly creatinine [10] and renal ultrasound, such as patients diagnosed with disorders of sexual development (DSD). Institutional Review Board committee approval was obtained through UCSF for this study (IRB#18-26217).

Results

39 new patients were seen in UCSF's TU clinic during a 23-month period. Our cohort included 20 patients with spina bifida and neurogenic bladder, 5 with bladder exstrophy, 3 with disorders of sexual development (DSD), 5 with obstructive uropathy including one with posterior urethral valves, 2 with cloacal anomalies, and 1 patient each with calcinuria, reflux nephropathy, prune belly syndrome, and urachal cyst. Mean age of patients was 26 ± 6.7 years, 63% were male, 88% spoke English, and 70% had public insurance. Patients lived an average of 94 ± 84 miles from the clinic and had a mean zip code-based income of $70,110 ±$31,912 (Table 1).

64% of patients seen in the TU clinic had a urology appointment within the last 12 months. There was a median of 5.7 months between the initial TU visit and the most recent prior urology visit (range 11 days—17 years). Excluding patients with a diagnosis of DSD or a urachal cyst, just over half of the patients had a creatinine and a renal bladder ultrasound at their initial TU visit (53% and 55% respectively). Specifically, the mean time since last creatinine was 15 ± 16 months (median 8.8 months), and last renal ultrasound was 16 ± 22 months (median 9.4 months) (Summary Table). Of the 25 patients for whom a creatinine was ordered at the time of the initial TU appointment, 22 (88%) completed the lab draw within 6 months. In contrast, only 58% of the 19 (non-DSD) patients who were due for renal bladder ultrasound and had them ordered at their TU clinic visit completed their imaging within six months. The follow-up rate, defined as number of patients seen in follow-up after an initial TU clinic visit, even if outside the recommended timeframe, was 64%. Patients with spina bifida and neurogenic bladder had an average of 5 years (±5 years, range 34 days to 12 years), between their prior urodynamic profile (UDP) and their presentation to transitional clinic. Additional studies that were ordered for some patients included MRI, Lasix renogram, scrotal ultrasound, and antegrade nephrostogram, and labs including vitamin B12 and CBC (Table 2).

19 (54%) patients warranted a total of 28 referrals to other providers at their initial visit, and 42% of these were obtained within 6 months. Fig. 1 illustrates the number of referrals to each subspecialty, and the number of completed appointments within 6 months of the referral.

Table 1 Patient demographics. N = 39.

Patient Characteristic		N = 39
Age, mean (SD)		26 (6.7)
Sex, n (%)	Male	22 (56)
	Female	17 (44)
Language, n (%)	English	31 (79)
	Other	8 (21)
BMI, mean (SD)		28 (6.3)
Insurance, n (%)	MediCal	27 (69)
	Private	13 (31)
Distance from clinic (in miles), mean (SD)		94 (84)
Zipcode-based income, mean (SD)		$70,110 (31,912)
Diagnosis, n (%)	Spina bifida	20 (51.2)
	Bladder exstrophy	5 (12.8)
	DSD (CAH, CAIS, PAIS)	3 (7.6)
	Obstructive uropathy (PUV, bilateral hydronephrosis)	5 (12.8)
	Cloacal anomaly	2 (5.1)
	Other congenital GU anomaly[a]	4 (10.2)

[a] Diagnoses include: calcinuria, reflux nephropathy, prune belly syndrome and urachal cyst.

Discussion

Our data show that our TU clinic patients are likely to have public insurance, live long distances from the TU clinic, and come from low SES backgrounds. This represents a vulnerable and often minority population who are already known to have worse health outcomes within the general population. The presence of congenital urogenital and chronic diseases, often in the context of intellectual or developmental disability, only adds to the risk of this patient group. Furthermore, the care that this population requires is often complex, diverse and specialized. Transitional urology spans the breadth of the field of urology and, as we noted in our own population, spills into other disciplines including nephrology, neurosurgery, physical medicine and rehabilitation, infectious diseases, urinary continence, sexual function, fertility, mental health and sexual identity [11]. Not only did we find that patients often require the expertise of other specialties, but many required referrals to multiple specialties, suggesting that these patients could face significant burden in terms of the number of clinical encounters they require for follow-up and maintenance care. In our cohort, the maximum number of recommended referrals per patient was three, which was the case for three patients in our cohort. Comprehensive care requires coordination between several subspecialists, social support resources and a clear understanding of patients' home-lives, goals, and expectations. It is notable that many of our transitional patients do not have a primary care physician, therefore one of the principle goals our transitional team has when we establish care within the transitional clinic is ensuring patients get plugged in with a primary care physician. Our TU clinic has a social worker available as needed to assist in managing social challenges and coordination of subspecialty care, however we do not have dedicated psychiatric support and refer to these specialists only when needed. In our current medical system, unfortunately, there are no standard procedures in place for this type of cross-discplinary care, particularly among adults.

At our institution, the pediatric urologist begins a discussion about the transition to TU clinic with their patients at age 14, and provides them with an educational handout

Table 2 New transitional urology clinic patients for whom studies or labs were warranted at time of presentation, and whether or not these were completed within 6 months of being ordered.

Patient follow through: labs and imaging studies

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Other	12	41	8	67

**excluding DSD patients.*
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with information about the transition and TU clinic. We aim to transition all pediatric urology patients to the TU clinic by age 21 when appropriate. There is currently no coordinator that helps with this process, though our institution is working to bring someone onto the team to facilitate this process.

In response to the difficulty of transition, the National Institute of Diabetes and Digestive and Kidney Diseases convened a working group to analyze and improve transitional urology care, and this group identified the following barriers to successful transition: 1) systemic (incompatible insurance coverage), 2) physical (lack of transportation, ill-equipped facilities) 3) psychoemotional and 4) lack of education on the part of the patient, or training on the part of the urologist [11]. Our TU clinic population reflects the same vulnerabilities including having to transition from pediatric to adult insurance plans, and living a significant distance from our clinic with over 40% of our patients residing greater than 100 miles away [12,13]. Our patients are at risk for overwhelming barriers to care resulting in deficient follow-up, social isolation and poor outcomes. Over half of our patients had a urology appointment within the last 12 months, however those with larger gaps in their care (up to 17 years) were a combination of patients previously managed by outside clinics and previous UCSF patients who were lost to follow up and when they reached out to be seen, were then referred to the transitional clinic because of their age.

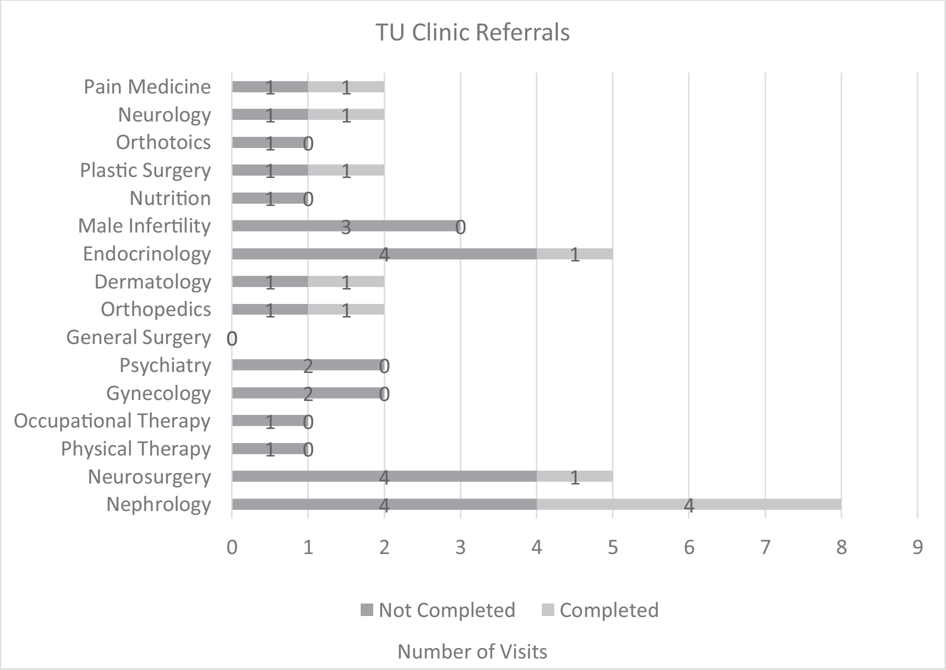

Fig. 1 Number of referrals ordered at initial TU appointment, and whether they were completed within 6 months of the referral order. Subspecialists in the "other" category include urology, nutrition, plastic surgery, orthotics, neurology and pain medicine.

Our observed no-show rate in our TU clinic was 34% for follow-up patients; it is disappointing, though not surprising to anyone who cares for these patients, that one-third of patients who come for initial evaluation do not follow-up as instructed. Moreover, the no-show rate for initial appointments is likely much higher given patients who come for their first appointment may be more likely to follow up thereafter. Our data does not capture the percentage of TU patients who never made it to their first appointment. In an ENT clinic, no-show rates were shown to have been significantly higher among patients with Medicaid and Medicare [14], which describes over half of the TU patients in our clinic. Furthermore, younger patients, age 18-40 were at highest risk of no-showing to their appointments [14], which is a factor for most TU patients. Moreover, patients with complex congenital abnormalities require simultaneous and ongoing care from multiple subspecialties in large medical centers which entails multiple appointments and long commutes. The TU population is not only at risk of missing their urology appointments, but also their follow-up imaging, labs, procedures and other subspecialty clinic appointments. At our institution there is no transitional coordinator; our TU patients are responsible for following up and getting their requested labs and imaging studies. We therefore maintain a list of all patients who have missed their follow-up appointments, and periodically the transitional urology physician will go through each patient to determine who has been lost to follow-up and who is missing necessary studies. The primary care provider can also play a key role in ensuring TU patients obtain appropriate studies and follow-up.

We observed long gaps between studies such as UDP, however it may be noted that these are not necessarily warranted annually, or even within two to three years. However, 3 of the 20 patients with spina bifida and neurogenic bladder had not had UDP in over 12 years. While nearly 90% of patients completed their recommended creatinine within 6 months of their initial TU visit, only 58% completed their renal bladder ultrasound within that timeframe. There is significant room for improvement and further investigation is warranted to better understand why this is the case. Nonetheless, results from a 7-year observational study of transitioning spina bifida patients from a multidisciplinary spina bifida clinic demonstrated a trend toward more services outside the SB clinic and more radiographic studies if they did not establish care with either a TU clinic or pediatric or adult urologist within 24 months of their previous visit. Furthermore, transitioned patients were significantly less likely to visit the emergency department than their non-transitioned counterparts [15]. While these outcomes are intuitive, the evidence of streamlined care and decreased use of emergency services have long-term implications for improved outcomes.

Our study evaluates access and barriers among newly transitioning urologic congenitalism patients. This study is limited in its small sample size and short follow-up given the newly instated TU clinic. Another limitation is our assessment of socioeconomic status. The mean income is a calculated value based on zip-code and does not reflect each individual's true income, nor does it account for whether the patient lives independently or with parents/partner. We do not currently have the data to more accurately reflect our patient population's true income, though we have created a prospective registry which will allow us to capture more data on this patient population as we continue to see patients in our clinic. Its major strength is that it captures all transitioning urology patients at a critical point in time: during their transition. This vantage point gives us a unique insight into identifying barriers in this population and, ultimately, we hope to use these as predictors for lack of follow up. Next steps include investigating the most successful tools to address these barriers, not least powerful of which is patient activation and engagement in their own care [16].

Conclusions

While most patients who present to TU clinic are likely to complete studies such as creatinine and urine culture within the recommended time-frame, these patients are less likely to complete studies that are more time intensive, like renal bladder ultrasound and urodynamic profile. Our study indicates that TU patients possess many characteristics that function as potential barriers for access to their ongoing care both within the TU clinic and across subspecialty providers. The better we understand the key drivers for the lack of follow-up, the more effectively care teams can target their efforts in this complex cohort.

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Conflicts of interest

None.

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