Congenital Genitourinary Profile and Management of Syrian Children: Single-Center Experience

Suriyeli Çocukların Konjenital Genitoüriner Profili ve Yönetim Şekli: Tek Merkez Deneyimi

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ABSTRACT

Objective: Aim of the study is to evaluate congenital genitourinary tract anomaly prevalence in Syrian refugee children population and detect difficulties in management of this population.

Material and Methods: Syrian refugee patients who applied to Adana City Training and Research Hospital Pediatric Urology and Pediatric Nephrology outpatient clinics between February 2020 and June 2022 were retrospectively analyzed. Patients aged between 1 month and 18 years with the diagnosis of congenital genitourinary disease were included in the study. Age, gender, application dates, follow-up periods, surgical needs, and hospitalization needs of the patients were recorded from the electronic patient files.

Results: A total of 288 Syrian refugee children (183 male/105 female) with the diagnosis of congenital genitourinary disease were included in the study. Among 288 Syrian refugee children, congenital anomalies of the kidney and urinary tract (CAKUT) was the leading congenital urogenital disease with 175 patients (60.8%). This was followed by nonspecific hydronephrosis in 61 patients (21.2%), urogenital anomaly in 47 patients (16.3%), and cystic kidney disease in 5 patients (1.7%).

Conclusion: As a conclusion, we think that close cooperation between health personnel, social workers, and interpreters will not only protect patients from long-term complications and provide a better quality of life, but also protect the health system from additional financial burden. Interdisciplinary training on cultural sensitivity and special problems of refugees should be established in treatment centers. We believe that special education programs for patients and their families can improve understanding of the disease and its treatment.

Key Words: CAKUT, Children, Syrian refugee

ÖZ

Amaç: Çalışmanın amacı, Suriyeli mülteci çocuk popülasyonunda konjenital genitoüriner sistem anomali prevalansını değerlendirmek ve bu popülasyonun yönetimindeki zorlukları tespit etmektir.

Gereç ve Yöntemler: Şubat 2020-Haziran 2022 tarihleri arasında Adana Şehir Eğitim ve Araştırma Hastanesi Çocuk Ürolojisi ve Çocuk Nefrolojisi polikliniklerine başvuran Suriyeli mülteci hastalar retrospektif olarak değerlendirildi. Çalışmaya 1 ay ile 18 yaş arasında konjenital genitoüriner hastalık tanısı alan hastalar dahil edildi. Hastaların yaş, cinsiyet, başvuru tarihleri, takip süreleri, cerrahi ihtiyaçları ve yatış ihtiyaçları elektronik hasta dosyalarından kaydedildi.

Bulgular: Konjenital genitoüriner hastalık tanısı almış toplam 288 Suriyeli mülteci çocuk (183 erkek/105 kız) çalışmaya dahil edildi. İki yüz seksen sekiz Suriyeli mülteci çocuk arasında konjenital böbrek ve üriner sistem anomalileri (CAKUT)

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Contribution of the Authors / Yazarların katkısı*: *EKBERLİ G: Taking responsibility in necessary literature review for the study, Taking responsibility in the writing of the whole or important parts of the study, Reviewing the article before submission scientifically besides spelling and grammar. ***TANER S:*** Constructing the hypothesis or idea of research and/or article, Planning methodology to reach the Conclusions, Organizing, supervising the course of progress and taking the responsibility of the research/study, Taking responsibility in patient follow-up, collection of relevant biological materials, data management and reporting, execution of the experiments, Taking responsibility in logical interpretation and conclusion of the results.

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175 hasta (%60.8) ile önde gelen konjenital ürogenital hastalıktı. Bunu 61 hasta ile (%21.2) nonspesifik hidronefroz, 47 hasta ile(%16.3) ürogenital anomali ve 5 hasta ile (%1.7) kistik böbrek hastalığı izledi.

Sonuç: Sonuç olarak sağlık personeli, sosyal hizmet uzmanları ve tercümanlar arasındaki yakın işbirliği, hastaları uzun vadeli komplikasyonlardan koruyarak daha iyi bir yaşam kalitesi sağlamanın yanı sıra sağlık sistemini ek mali yükten de koruyacağını düşünüyoruz. Tedavi merkezlerinde kültürel duyarlılık ve mültecilerin özel sorunlarına yönelik disiplinler arası eğitimler oluşturulmalıdır. Hastalar ve aileleri için özel eğitim programlarının, hastalığın ve tedavisinin, hasta ve yakınları tarafından anlaşılmasını kolaylaştırabileceği kanısındayız.

Anahtar Sözcükler: CAKUT, Çocuk, Suriyeli mülteciler

INTRODUCTION

Turkey is one of the countries facing the enormous amount of refugee population after the beginning of the civil war in Syria on March 11, 2011. Syrian people thought to be under ''temporary protection", but nowadays in 2022 this population became permanent especially in cities bordering Syria. The most important problem brought by human migration is the burden added to the existing health system. Missing medical records of patients, communication problems, logistic problems, lack of literature information about relevant society are factors which make the physician's diagnosis and treatment process challenging. To determine the congenital disease profile of refugee population may be meaningful for the host country in preventive and curative health care.

Because of the preventable nature of especially congenital renal problems proper follow up is mandatory. Expected obstacles after irregular migration of Syrian children may result in end-stage renal disease. In this study we aimed to evaluate congenital genitourinary disease profile, follow-up compliance and difficulties in management of refugee population.

MATERIAL and METHODS

Syrian refugee patients who applied to Adana City Training and Research Hospital Pediatric Urology and Pediatric Nephrology outpatient clinics between February 2020 and June 2022 were retrospectively analyzed. Patients aged between 1 month and 18 years with the diagnosis of congenital genitourinary disease were included in the study. Age, gender, application dates, follow-up periods, surgical needs, and hospitalization needs of the patients were recorded from the electronic patient files.

Chronic Kidney Disease (CKD) was defined as on the 'The Kidney Disease: Improving Global Outcomes (KDIGO)' clinical practice guidelines.

This study was approved by Adana City Training and Research Hospital Ethic Committee on 21 April, 2022 (Ethics committee approval number 1911).

Statistical Analyses

All statistical analyses analyzed by SPSS version 21 software package. Data collection and definitions are described below. Normal distribution of numeric variables was tested with Kolmogorov-Smirnov test. Continuous data were defined by means of mean± SD under the parametric conditions and median (interquartile range-IQR) under the nonparametric conditions. P values less than 0.050 were statistically significant.

RESULTS

Patients

A total of 288 Syrian refugee children (183 male/105 female) with the diagnosis of congenital genitourinary disease were included in the study. Median age of the patients was 48.3 months (IQR 90 months) and the median follow-up time was 8 months (IQR 10 months). Of them, 54.5% (157 patients) did not come to their regular follow-ups or scheduled surgical interventions. Surgical intervention was performed in 23.6% (68 patients) of the admitted patients. Among 288 Syrian refugee children, congenital anomalies of the kidney and urinary tract (CAKUT) was the leading congenital urogenital disease with 175 patients (60.8%). This was followed by nonspecific hydronephrosis in 61 patients (21.2%), urogenital anomaly in 47 patients (16.3%), and cystic kidney disease in 5 patients (1.7%).

Congenital Anomalies of The Kidney and Urinary Tract

In 175 CAKUT patients, the three most common etiologies were vesicoureteral reflux (VUR) in 47 patients (26.9%), neurogenic bladder (NB) in 40 patients (22.9%), and obstructive pathologies

Table I: The etiological distribution of the patients with Congenital Anomalies of The Kidney and Urinary Tract

CAKUT (n=175)	Number of the patients, (%)
Vesicoureteral reflux	47 (26.9)
Neurogenic bladder	40 (22.9)
Obstructive pathologies	36 (20.6)
Ureteropelvic junction obstruction	23 (13.1)
Posterior urethral valve	7 (4.0)
Ureterovesical junction obstruction	6 (3.4)
Hypodysplasia/ atrophy	13 (7.4)
Agenesis	12 (6.9)
Ectopic kidney	10 (5.7)
Multicystic dysplastic kidney	8 (4.6)
Others	9 (5.1)
Megaureter	4 (2.3)
Duplex collecting system	3 (1.7)
Bladder diverticulum	1 (0.6)
Horseshoe kidney	1 (0.6)

Table II: Detailed information of end-stage renal disease (ESRD) patients

	Age (months)	Sex	Etiology	Surgery	Surgery country
1	186	F	NB+ ARM	Uretero-cutaneous ostomy	Turkey
2	211	F	NB+ Wolfram Syndrome	-	-
3	186	F	NB+ AA	-	-
4	95	M	PUV	PUV ablation /Nephrostomy	Syria/Turkey
5	194	M	NB+ AA	-	-
6	184	M	NB	-	-
7	174	F	VUR nephropathy	-	-
8	32	M	VUR nephropathy	-	-
9	56	M	PUV	PUV ablation	Tukey
10	125	M	PUV	PUV ablation	Syria
11	124	M	Hypoplasia	-	-

***F:** Female, **M:** Male, **NB:** neurogenic bladder, **ARM:** Anorectal malformation, **PUV:** posterior urethral valve, **AA:** aplastic anemia, **VUR:** vesicoureteral reflux*

Table III: Urogenital Anomaly profile of Syrian Refugee Children

Urogenital Anomaly (n=47)	Number of the patients, (%)
Hypospadias	27 (57.4)
Distal Hypospadias	15 (31.8)
Penoscrotal Hypospadias	6 (12.8)
Penile Hypospadias	6 (12.8)
Cryptorchidism	5 (10.6)
Inguinal hernia	4 (8.5)
Chordee	4 (8.5)
Hydrocele	2 (4.3)
Exstrophy vesica	2 (4.3)
Others	3 (6.3)
Epispadias	1 (2.1)
Meatal stenosis	1 (2.1)
Megameatus intact prepuce	1 (2.1)

in 36 patients (20.6%). The etiological distribution of CAKUT patients was shown in Table I. Chronic kidney disease (CKD) was found with a frequency of 54.3% in CAKUT patients. The frequencies of CKD patients were, Stage 1 CKD 58.9%, Stage 2 CKD 21.1%, Stage 3 CKD 7.4%, Stage 4 CKD 1.1% and Stage 5 CKD (end-stage renal disease) 11.6%, respectively. Detailed information of end-stage renal disease (ESRD) patients is shown in Table II.

Among 47 patients with VUR, 31 (66%) had high-grade reflux, and 23 (48.9%) had bilateral reflux. Median age at diagnosis of the patients was 49 months (IQR 106 months. When the kidney functions of patients with VUR were evaluated, 83% had CKD and only 5% of them were ESRD patients. Of the 26 patients who underwent surgical intervention, ten underwent subureteric injection, six had ureteroneocystostomy (UNC), three had subureteric injection and UNC, one had vesicostomy and one had cystoscopy.

The leading cause of NB was neuro-spinal dysraphism with 33 (80%) patients; of these 32 was myelomeningocele, one was anorectal malformation. Other causes were transverse myelitis, Guillain-Barre syndrome, Wolfram syndrome and post-traumatic injury (firearm injury, traffic accident and spinal operation), respectively. The frequency of CKD in patients with NB is 47.5% and 12.5% of them are ESRD. The frequency of patients not complying with clean intermittent catheterization treatment was 65%. Surgical intervention was performed in 4 patients: vesicostomy in two, ureterocutaneous ostomy in one, and cystolithotripsy in one.

In patients with obstructive pathologies, 75% were male. The frequency of CKD was 58.3% and 8.3% of them are ESRD. Surgical intervention was performed in 80.6% of the patients (59% in our center/ 41% external or Syria), and the remaining patients did not come to the scheduled surgery appointment or did not give consent for the surgery. Ureteropelvic junction obstruction (UPJO) constituting 65.7%, was the most frequent reason of the obstructive pathologies. Of these, 65.2% were left UPJO, 30.4% were right, and 4.3% were bilateral. Of the 6 ureterovesical junction obstruction, four were left-sided, one was right-sided, and one was bilateral.

Urogenital Anomaly

Among the urogenital anomalies, hypospadias was the most common with 57.4%, and distal hypospadias constituted more than half of the patients (55.6%) with a diagnosis of hypospadias. Other urogenital anomalies are shown in Table III. The median age of patients diagnosed with hypospadias was 30 months (IQR 47 months). Surgical intervention was performed in 15 (55.6%), 9 patients (33.3%) did not come to the scheduled surgery day. Of the remaining 3 patients (11.1%), 2 were waiting for the operation day, and 1 was waiting for the decision of the sex determination commission.

DISCUSSION

Defects in embryonic kidney development can lead to congenital anomalies of kidney and urinary tract (CAKUT). In developed countries CAKUT represents %20-30 of all antenatally detected pathologies and prevalence reported to rang between three and six per 1000 births (2). With the development of technology, the expected significant increase in the rate of prenatal diagnosis and treatment makes CAKUT diagnosis more common than in the past. Even positive predictive value of ultrasound in detection of urogenital anomaly such as hypospadias has been reported as 72% (3). The available data on CAKUT from Arabic population are very scanty and extracted. There are only few studies evaluating CAKUT or other kidney related diseases. (4,5). But lately, studies have been reported from Turkish centers in Syria neighborhood regarding refugee population (6-9).

National and regional registries in Europe reported CAKUT to be the leading cause of end-stage renal disease (41.3%) (10). CAKUT (especially obstructive anomalies and renal dysplasia) is reported to be most frequent etiological factor of Chronic Kidney Disease (CKD) in neonatal period and may require prompt surgical intervention (11). A retrospective study from Saudi Arabia evaluated etiological factors of CKD in full term neonates. Obstructive uropathies are reported to be the most common underlying etiology of CKD (5). But very small percentage of these patients required renal replacement therapy (RRT). Most of the patients reported to had ongoing urine production and managed without dialysis after respiratory complications. Bongdaji et al. reported another study from Saudi Arabia regarding congenital genitourinary anomalies. As a conclusion they claimed that, genitourinary anomalies diagnosed in the antenatal period constituting 38.6% of all anomalies diagnosed in that center (5). Among 288 Syrian refugee children, congenital anomalies of the kidney and urinary tract (CAKUT) was the leading congenital urogenital disease with 175 patients (60.8%). Obstructive urinary pathologies (ureteropelvic junction obstruction, ureterovesical junction obstruction and posterior urethral valve) constitute 20.6% of all study population. Raboei et al. (12) in their study conducted with 23.000 babies reported urinary tract malformation incidence to be 7:1,000. This incidence is higher than the studies reported from Sweden or England (13,14). An explanation for this significant difference is high degree of consanguinity in Arabic population (4,12). Resent studies reported no decrease in consanguinity marriage (15). Bongdaji reported 57 (40.4%) of affected fetuses to be products of consanguineous marriages. Although, we do not have data about consanguinity marriage in our study group because of communication problems with study population. Considering the factor that consanguineous marriages are not uncommon in our region awareness rising programs can be helpful for populations with overmentioned traditions.

Chronic kidney disease (CKD) was found with a frequency of 54.3% in CAKUT patients. Frequency of CAKUT related ESRD in presented study is 11.6%. The three most common etiologies were vesicoureteral reflux (VUR) in 47 patients (26.9%), neurogenic bladder (NB) in 40 patients (22.9%), and obstructive pathologies in 36 patients (20.6%). Among patients with obstructive pathologies the frequency of CKD was 58.3% and 8.3% of them are ESRD. All of the identified etiological factors can be prevented with early and proper management.

In presented study of 288 patients with congenital genitourinary anomaly 157 (54.5%) detected to be incompatible with treatment, follow-up and scheduled surgical interventions.

The reasons for bad compliance for follow-up and treatment can be explained by multiple factors such as: socioeconomical factors, cultural reasons, religious issues, communication problems, logistic problems. Lemke et al. (16) in their educational review discussed different challenges which health care professionals may encounter during pediatric refugee patient with renal replacement. Language challenges, perception challenges, social/cultural challenges, medical history, mental health, dietary/medication issues, administrative problems are determined as the factors which hinder access to adequate health services (16). All Syrian people can receive health care in government hospitals for free in Turkey. So, it can be claimed that access to health services by the patient or caregiver in not sufficient for proper management. This group of patients should be managed with holistic perspective and awareness should be raised in caregivers regarding vulnerabilities of children with genitourinary pathology requiring close follow-up or surgical intervention.

Hypospadias is one of the most commonly detected genitourinary pathologies in our study population (57.4). None of the patients had antenatal diagnosis. In concordance with literature majority of patients had distal hypospadias. Most of the reported studies prefer intervention of hypospadias to be before the rise of genital awareness (17). The median age of patients diagnosed with hypospadias was 30 months (IQR 47 months). In patients with proximal hypospadias staged repair prolongs period of surgery. Surgery and hospitalization in advanced ages have many negative aspects, especially post-operative complications.

Hypospadias repair was performed in 15 (55.6%), 9 patients (33.3%) did not come to the scheduled surgery day. We do not have data to explain the reason for not coming to the planned surgery. Education programs for this population about the problems that hypospadias surgery may cause in the older age group may be a solution.

While evaluation of study population's compliance during pre and postsurgical period, it can be said that despite all the advantages provided by the health system, the reason why some patients do not continue their follow-up and treatment and do not neglect their planned surgical interventions is closely related to the socio-cultural structure and education level of the patient population.

CONCLUSION

Our findings support the need for robust and multidisciplinary screening that addresses congenital genitourinary anomalies, taking into account their forced migration experiences, socio-cultural backgrounds and belief systems, in order to facilitate and contribute to the lives of refugee children.

Close cooperation between health personnel, social workers, and interpreters will not only protect patients from long-term complications and provide a better quality of life, but also protect the health system from additional financial burden. Interdisciplinary training on cultural sensitivity and special problems of refugees should be established in treatment centers. Special education programs for patients and their families can improve understanding of the disease and its treatment.

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