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EDITORIAL OPEN ACCESS

Principles of transition of children with chronic kidney diseases

Matjaž Kopač

The purpose of a planned health care transition is to optimize well-being and lifelong functioning for all youth, including those who have special health care needs. This process must enable access to high-quality and developmentally appropriate health care services during transition period, from adolescence to adulthood, occurring between the ages of 18 and 21 years but being specific to each person. Coordination of patient, family, and provider responsibilities helps young patients to optimize their capacity to assume adult roles and activities [1]. In addition, every patient should have an individualized transition plan no matter what specific health care needs are. Providers need support to achieve this goal. The transition should begin at 12 years of age, according to American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians. There are four specific activities in transition: discussing the medical home transition policy, initiating a transition plan, reviewing the transition plan, and implementing an adult care model. Primary care providers and medical subspecialists are encouraged to make this process specific for their own and their patients [1].

The transfer of pediatric patients to adult health care facilities takes place after a completed transition process with cooperation of medical staff from pediatric and adult units. It should be adapted to a single young patient, with emphasis on developing independence and ability to take advantage of support provided by appropriate personnel. Young people are in the transition process from 14 to 24 years of age and, therefore, good communication between pediatric and adult services (especially at the point of transfer) is of utmost importance [2]. There has been increasing number of young patients transferring from pediatric to adult renal care due to improved therapeutic options with a consequent improved survival. Non-adherence at the time of transfer from pediatric to adult care and among the cohort of young adult patients (under 25 years of age) is a well-known phenomenon. In general, patients with chronic kidney disease (CKD) stage 3–4 should be transferred to adult services and those with CKD stage 1–2 could usually be followed by a primary care physician. However, instructions must be provided in order to refer to nephrologists if signs of progressive kidney damage occur, such as hypertension and/or proteinuria. Growth and development are especially important aspects for children. For those with CKD, caretaking by a comprehensive multi-disciplinary team of clinicians, nurses, psychologists, dietitians, social workers, play therapists, and educators is the most effective way of minimizing disabilities and maximizing the capabilities of each child. Providing support for children and families from such a multi-disciplinary team is one of the major differences between pediatric and adult care. The most frequent causes of CKD stage 5 in adolescents are glomerular diseases, whereas congenital abnormalities of kidney and urinary tract (CAKUT), such as renal dysplasia, reflux nephropathy, and many others, represent the most frequent cause of advanced CKD in younger children. Nephrologists dealing with adult population are usually less familiar with these conditions. Adolescent patients with chronic illness, combined with other physical, psychological, and sexual changes of their development can thus represent a major challenge in the management and transition process for medical staff as well as for members of patient's families [2]. According to the Society for Adolescent Medicine, the phrase “transition” is a process that involves purposeful, planned efforts to prepare the pediatric patient to move from caregiver-directed care to disease self-management in the adult unit [3].

It is often difficult for pediatric patients who had received long-term management at pediatric units to be transferred to adult health care facilities. Even in cases of completed transfer, some of them do not adapt well to the adult services and return to pediatric units, and some of them even drop out, which causes deterioration of the underlying disease. In pediatric units patients are

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closely connected to their families and parents are often overprotective, which may impair children's ability to develop independent living skills. However, adult health care facilities emphasize patients' autonomy and issues related to occupation and family planning whereas issues related to growth, development and relations with patients' families receive much less attention [4]. A survey conducted in Japan demonstrated that only 31% of patients at 20 years of age and above, with childhood-onset chronic kidney diseases who had been managed at pediatric units, were transferred to adult renal units over a period of 5 years. The reasons for failure of transfer were refusal of patients or their families to transfer (in 43%) and inability to decide on transfer (in 33%), which may be due to families' dependence on pediatricians or pediatricians themselves. In addition, a survey revealed that about 20% of patients at 20 years of age and more were unemployed and thus had financial difficulties. Therefore, it is necessary to provide them with education that suits their abilities in order to become employed and financially independent [5].

Main points of a recent Japanese consensus statement on health care transition of patients with childhood-onset chronic kidney diseases are:

- avoiding disruption in advanced, high-quality medical care in the transfer from pediatric to adult care,
- transferring patients after they have achieved relevant education, sufficient psychological and social development as well as after completed preparation and assessment,
- avoiding the transfer if the patient's symptoms or psychological status is unstable.

Regarding the transition programs, they should:

- be started as early as possible,
- physicians who are familiar with transition programs and should be available for pediatric and adult care,
- multi-disciplinary team should be organized,
- patients, their families, and health care providers should always consider the patient's future independence, avoiding overprotection, and that the patient should be at the center of the program and capable of participating in decision making,
- health care providers should take time to discuss with patients the changes that are expected in the future and should give patients at least basic information about health insurance and medical costs,
- pediatricians should prepare a medical summary for each patient in order to facilitate self-management and to utilize it at the time of transfer to adult medical care services,
- adult care physicians should try to understand the special characteristics of pediatric CKD patients in order to provide adequate medical care.

Regarding necessary support by medical societies/associations, it is suggested to identify financial problems, to request the administrative personnel, to provide adequate support, to conduct surveys on patients in transition process, to discuss problems, and to carry out education about transition for health care providers [4].

Congenital anomalies of the kidney and urinary tract (CAKUT) are the most common cause of end stage renal disease (ESRD) in children. Bilateral renal hypoplasia and dysplasia with or without associated renal anomalies are present in over 50% of children and adolescents that start renal replacement therapy (RRT). In adult population, on the other hand, CAKUT cause ESRD much less commonly (in less than 5%) [6, 7]. Therefore, CAKUT represent a big pool of patients that ultimately need a structured transition to adult health care services but face with a lack of knowledge and experience of adult care physicians about these rare kidney diseases, since they are mostly occupied with diabetic and hypertensive nephropathies and other glomerular diseases of adult age. Chronic kidney disease progresses more slowly in patients with CAKUT than in those with glomerulonephritis, with an average glomerular filtration rate (GFR) decline of 2.4 mL/min per year. Despite improved survival of children with ESRD, their survival is about 30 times smaller compared to healthy peers. These children die due to cardiovascular diseases and infections much more commonly than due to renal failure [8, 9].

The natural course of CAKUT in children is very heterogeneous [6, 10, 11]. Renal function usually improves after infancy in these children and reaches a peak at the age of about three years. A period of stable renal function lasts until the puberty, followed by faster CKD progression to ESRD. Children with more pronounced proteinuria, hypertension, several febrile urinary tract infections and with a baseline GFR less than 40 mL/min/1.73 m^2 experience faster deterioration of renal function [10]. Approximately 25% of children with bilateral CAKUT and renal dysfunction need RRT in the first two decades of life. However, data about long-term prognosis of patients with CAKUT in adult age are scarce [6, 10, 11].

The median age of patients with CAKUT at RRT initiation is 31 years, compared to 61 years in the entire population of renal disease patients, according to results of big European International Study with ERA-EDTA (European Renal Association – European Dialysis and Transplant Association) registry as data source. Renal replacement therapy incidence of patients with CAKUT reaches maximum in the age group of 15–19 years, followed by a gradual decline throughout entire adult age. On the other hand, the number of patients with other primary renal diseases that need RRT gradually increases with advancing age. There has been a trend toward a later initiation of RRT in the last three decades while the number of young patients starting RRT has not changed much in this period [6]. It is worth to mention that male patients with CAKUT, especially those with obstructive and reflux nephropathy, are significantly younger (5.2

years on average) than female patients at RRT initiation, depending on the type of CAKUT. But female patients with renal impairment due to neurogenic bladder, on the other hand, start RRT sooner compared to male patients with this disorder. However, sex does not have influence on age of RRT initiation in patients with renal hypoplasia and dysplasia [6].

The renal transplantation rate in patients with CAKUT depends on age of dialysis initiation, the highest (90.2%) being if it has been initiated before the age of 18 years. However, the survival of patients as well as of renal grafts is better in patients with CAKUT than in patients with other renal disease. The 10-year survival of patients with CAKUT depends on the age of RRT initiation, the highest (92%) being if it has been initiated before the age of 18 years. Survival in these patients depends on the type of CAKUT and is lowest in patients with renal impairment due to neurogenic bladder and highest in those with renal hypoplasia [6].

More than two-thirds of patients with CAKUT experience ESRD in adult age and about half of those do not need RRT until the fourth decade of life. The number of these patients is likely bigger in practice because ESRD occurs without prior history of renal disease in childhood in some adults, especially those with unspecified nephropathy. CAKUT represent a leading group of diseases in children, leading to CKD and ESRD, yet they represent only a minor fraction of adult patients with CKD in need of RRT. These diseases, therefore, cannot be in domain of pediatric nephrologists and urologists only and demand a well prepared transition strategy from pediatric to adult-oriented nephrology services [6].

A trial on development of a new transition protocol in a pediatric nephrology tertiary care center included adolescents over 15 years of age and young adults living with a RRT, either kidney transplant or dialysis. Individual transition-related perceptions and concerns were assessed with specially designed questionnaires and by conducting semi-structured interviews during group sessions. The gathered information was then used to amend existing transition models, which lead to the formation of a most suitable country-specific protocol, considering local health care capacities and individual patient needs. In addition, the patients' psychological coping strategies and potential behavioral and emotional problems related to CKD and transition were surveyed by applying established psychological tools incorporated in the used set of questionnaires. The median age at transfer was 18.5 years (range: 18–22 years). The study showed that emotional and behavioral problems remained either unchanged or were less expressed after transfer. Despite good preparation, the first unaccompanied adult outpatient clinic visit was still perceived as stressful, especially by adolescent girls. All patients were highly satisfied with the experienced transfer process. Results suggest that the applied transition protocol has appropriately addressed transfer-related anxieties and concerns, although compliance and graft outcomes were not subject of a study [12].

In conclusion, despite continuous improvement in our knowledge of pediatric-onset renal diseases, further steps are needed in order to make progress in therapy and self-management. In this respect, better understanding of the underlying genetic and maternal environmental factors, contributing to development of CKD, and an awareness of differences between the pediatric and an adult kidney are especially important. Furthermore, this vulnerable population would benefit from strategies to improve treatment adherence and training of the medical staff about transition skills [13].

Keywords: Children, Renal diseases, Transition

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REFERENCES

1. American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians; Transitions Clinical Report Authoring Group, Cooley WC, Sagerman PJ. Supporting the health care transition from adolescence to adulthood in the medical home. Pediatrics 2011;128(1):182–200.
2. Watson AR, Harden PN, Ferris ME, et al. Transition from pediatric to adult renal services: A consensus statement by the International Society of Nephrology (ISN) and the International Pediatric Nephrology Association (IPNA). Kidney Int 2011;80(7):704–7.
3. Blum RW, Garell D, Hodgman CH, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. J Adolesc Health 1993;14(7):570–6.
4. Kubota W, Honda M, Okada H, et al. A consensus statement on health-care transition of patients with childhood-onset chronic kidney diseases: Providing adequate medical care in adolescence and young adulthood. Clin Exp Nephrol 2018;22(4):743–51.
5. Hattori M, Iwano M, Sako M, et al. Transition of adolescent and young adult patients with childhood-onset chronic kidney disease from pediatric to adult renal services: A nationwide survey in Japan. Clin Exp Nephrol 2016;20(6):918–25.
6. Wühl E, van Stralen KJ, Verrina E, et al. Timing and outcome of renal replacement therapy in patients with

congenital malformations of the kidney and urinary tract. Clin J Am Soc Nephrol 2013;8(1):67–74.
7. Mong Hiep TT, Ismaili K, Collart F, et al. Clinical characteristics and outcomes of children with stage 3–5 chronic kidney disease. Pediatr Nephrol 2010;25(5):935–40.
8. Harambat J, van Stralen KJ, Kim JJ, Tizard EJ. Epidemiology of chronic kidney disease in children. Pediatr Nephrol 2012;27(3):363–73.
9. Neild GH. What do we know about chronic renal failure in young adults? II. Adult outcome of pediatric renal disease. Pediatr Nephrol 2009;24(10):1921–8.
10. González Celedón C, Bitsori M, Tullus K. Progression of chronic renal failure in children with dysplastic kidneys. Pediatr Nephrol 2007;22(7):1014–20.
11. Sanna-Cherchi S, Ravani P, Corbani V, et al. Renal outcome in patients with congenital anomalies of the kidney and urinary tract. Kidney Int 2009;76(5):528–33.
12. Kocjančič D, Battelino N, Oblak M, Novljan G. Slovenian approach to the transition of adolescents with kidney transplant. In Proceedings of the 7th Slovenian Congress of Nephrology: 11–14 March 2021; Ljubljana. Edited by Škoberne A: Slovenian Society of Nephrology - Slovenian Medical Association; 2021. p. 87–94.
13. Bates CM, Charlton JR, Ferris ME, et al. Pediatric kidney disease: Tracking onset and improving clinical outcomes. Clin J Am Soc Nephrol 2014;9(6):1141–3.

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Author Contributions

Matjaž Kopač – Conception of the work, Design of the work, Acquisition of data, Analysis of data, Interpretation of data, Drafting the work, Revising the work critically for important intellectual content, Final approval of the version to be published, Agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved

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Data Availability

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