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# Survey on Management of Transition and Transfer From Pediatric- to Adult-based Care in Pediatric Kidney Transplant Recipients in Europe

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**Background.** Transition from pediatric- to adult-based healthcare is a challenging period and bears a high risk of medication nonadherence and transplant loss in adolescents and young adults after kidney transplantation. Yet, it remains unclear how the 2011 International Society of Nephrology (ISN)/International Pediatric Nephrology Association (IPNA) guidelines on transition are implemented in practice and which healthcare transition modalities are currently used in Europe. **Methods.** We performed an online survey inviting all members of the European Society of Paediatric Nephrology mailing list to participate. Adherence to ISN/IPNA guidelines was scored with a maximum of 15 points. **Results.** Thirty-nine centers from 24 countries accounting for approximately 2500 children after kidney transplantation participated in the survey. At 3 centers, patients remained under pediatric care for their whole life, and 5 centers did not use any transition procedure. From the remaining 31 centers, 82% confirmed the existence of at least 1 unwritten transition procedure. None of these centers used IT or social media for patient training in transition. Specialized transition clinics are held at 15 of 31 centers for the patients. Most patients were transferred at 16 to 21 years of age. Transfer age was subject to regulation at 20 of 36 centers. Median score of guidelines adherence was 10 (range, 0-14). The adherence score was significantly correlated with gross national income ( $r^2 = 0.631$ , P < 0.0001). **Conclusions.** The 2011 ISN/IPNA guidelines on transition are implemented insufficiently in European pediatric nephrology centers. Therefore, further development is needed, and the use of information technology and social media should be promoted.

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ransition of adolescents and young adults with chronic kidney disease from pediatric- to adult-based healthcare has received increasing attention in the past decade.<sup>1</sup> The

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concept of healthcare transition began to develop in the 1990s. Transition was described as a process involving purposeful, planned efforts to prepare the pediatric patient to move from caregiver-directed care to disease self-management in the adult unit.<sup>2</sup> Transfer, therefore, is an event that desirably takes place at the end of a successful transition period.<sup>1</sup> Transition can be considered successful if it promotes the patients' health competence, supports their psychosocial rehabilitation, and improves their self-determination efficacy, including their ability to make decisions and communicate about their care.<sup>3</sup> The overarching goal of transition is to enable patients to be as independent as possible and have the best possible quality of life.<sup>3</sup>

Adolescents and young adults aged 14 to 25 years need specialized medical attention due to ongoing brain development in puberty and the phase of emerging adulthood (18-25 years).<sup>1,4,5</sup> This period is characterized by increased risk taking, impulsive behavior, and nonadherence issues, which makes it equally challenging for patients and their healthcare professionals.<sup>4-8</sup> In nephrology in particular, the transition constitutes an important intersection in patient care.<sup>9</sup> Medication nonadherence in adolescents and young adults with a kidney transplantation (KTx) increases the risk for rejection and graft loss.<sup>5-7</sup> Relative to age, highest rates of allograft loss occur in patients aged 16 to 21 years.<sup>5,10</sup> Such

graft failure requires a return to dialysis, which reduces quality of life, increases morbidity, shortens life expectancy, and leads to considerable additional healthcare expenses.

In 2011, the International Society of Nephrology (ISN) and the International Pediatric Nephrology Association (IPNA) published a consensus statement on essential and desirable components of transition and transfer from pediatric to adult renal service.<sup>1</sup> In addition, several studies highlight the effect of different transition procedures and specialized care (eg, young adult clinics).<sup>11-16</sup> However, clinical implementation of guidance provided by consensus statements can be difficult and may in addition be hampered by economic and human resource shortages.<sup>17</sup> A survey at 15 European pediatric dialysis sites in 2013 concluded that awareness of the 2011 ISN/IPNA consensus was suboptimal.17 Nationwide analysis of transition procedures and structures in pediatric nephrology are scarce and only available for Japan<sup>18</sup> and Germany/Austria.<sup>3</sup> To date, there is no published literature on transition procedures and structure or clinical implementation of the consensus guidelines for children with KTx in Europe. Thus, we conducted a survey on transition on behalf of the European Society for Paediatric Nephrology (ESPN) working group "Transplantation." The main aim of the survey was to assess the current clinical implementation of and adherence to the 2011 ISN/IPNA consensus statement on transition from pediatric- to adult-based healthcare<sup>1</sup> in Europe. Hence, areas needing improvement could be identified.

#### **MATERIALS AND METHODS**

The survey was developed as part of the TRANSNephro project.<sup>3,9,19</sup> The initial study protocol<sup>9</sup> was modified, and the amendment was approved by Hannover Medical School Ethics Committee. The study was then approved by the council of the ESPN.

An online-based cross-sectional survey was conducted on behalf of the ESPN working group "Transplantation." All ESPN e-mail contacts were invited to fill in the survey between January 17, 2017, and May 23, 2017. Six weeks after this first contact, a reminder message was sent. The complete survey is accessible in Materials and Methods, SDC, http:// links.lww.com/TXD/A122. The questionnaire opened with items assessing center characteristics, such as size. Institution and city were asked to identify double participation. In case of double participation, results were pooled for the center. The survey was designed to assess data on 3 main questions: (1) Is there a transition process and how is it clinically implemented? (2) How is the transfer from pediatric- to adult-based care managed and at what age? (3) How is awareness of, and adherence to the 2011 ISN/IPNA consensus statement on transition from pediatric- to adult-based healthcare?<sup>1</sup>

A database including all the responses of the participants was provided by the questionnaire service for further analysis. Inclusion criteria for analysis were: European geographical location (Europe was defined geographically from Portugal in the west to the Ural Mountains in the east and from Iceland in the north to Levant in the south), pediatric nephrology center, and care for pediatric patients after KTx. A map showing countries and number of ESPN members is displayed at http:// www.espn-online.org. Survey participants from other countries (ie, Canada, United States, Japan, and South Africa) were excluded from the analysis. To assess centers' compliance with ISN/IPNA recommendations on transition we calculated a score based on the fulfillment of those 15 items which were considered essential by the authors of the consensus paper (3). Each of those items scored 1 point, and fulfillment of each item could be rated on a 5-point Likert scale from 0 (not at all) via 0.25, 0.5, 0.75 to 1 (fully met). Maximum score was 15 points, and compliance with consensus was considered very good (13-15 points), good (10-12 points), acceptable (7-9 points), and low (<7 points).

We used data of the World Bank (http://www.worldbank.org/) on gross national income<sup>20</sup> and on gross domestic product<sup>21</sup> from the year 2015 for correlation analysis.

Statistical analysis was performed using Prism 6.0 (GraphPad Software, Inc., La Jolla, CA). Continuous variables are expressed as median and range, because no normal distribution is assumed. Discrete variables are expressed as percentages.  $\chi^2$  test was used to compare groups. Spearman coefficient was used for correlation analysis, as normal distribution was not assumed. Statistical significance was set at *P* less than 0.05.

## RESULTS

#### **Participating Centers**

Thirty-nine centers from 24 countries accounting for a total of approximately 2500 children after KTx participated in the survey, corresponding to 11% of the 362 active ESPN members: Armenia (n = 1), Austria (n = 1), Belarus (n = 1), Belgium (n = 1), Denmark (n = 1), Finland (n = 1), France (n = 5), Georgia (n = 1), Germany (n = 5), Greece (n = 1), Hungary (n = 1), Ireland (n = 1), Italy (n = 2), Netherlands (n = 2), Norway (n = 1), Poland (n = 2), Portugal (n = 2), Russia (n = 1), Slovakia (n = 1), Spain (n = 1), Sweden (n = 1), Switzerland (n = 2), Turkey (n = 2), and United Kingdom (n = 2). Most pediatric nephrology facilities were located at university hospitals (34/39). Most centers (21/39) cared for a large number (>50) of children after KTx, 11 of 39 centers provided care for 20 to 50 children after KTx. Transplantation clinics were held daily (workdays) in 12 of 39 centers, 2 to 4 times a week in 13 of 39 centers and weekly in 11 of 39 centers, respectively. Most commonly, transplantation clinics were held in the morning (36/39), but 5 centers offered additional consultation hours in the afternoon, and 3 centers offered clinics all day long.

Three centers declared that patients after pediatric KTx remained under pediatric care at all ages. Choosing this answer terminated the survey for these centers. Of the remaining 36 centers, 2 declared to never introduce the concept of transition to their patients, because transfer to adult-based care was performed without special preparation. These 2 centers skipped all questions on transition policy and procedures.

#### **Transition Policy and Procedures**

Twenty-eight (82%) of 34 centers confirmed the existence of an at least unwritten transition agreement, plan, or procedure at the center. From the remaining 6 centers, 3 respondents confirmed personal use of some kind of transition procedure; the other 3 centers skipped the survey part on transition.

Components of transition and frequency are given in Table 1. One center ticked "other" and specified:

"At the age from 18 to 25 years the patients are seen by the pediatric nephrologist at the adult clinic for transition."

# TABLE 1.

components of transition and frequency of use in st pediatric nephrology centers in Europe (multiple choices p	permitted)
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Descriptions	Used by
The concept of transition and goals in self-management to acquire are explained to the patient (and family) in early adolescence.	27/31
An unwritten plan for transition is made and communicated with the patient.	26/31
A written transition plan is made and communicated with the patient.	7/31
From a certain age the patient consults the nephrologist without a parent first-if applicable, the parent joins the consultation later on.	18/31
Individual in-house training courses of transition relevant skills.	10/31
Group training courses of transition relevant competencies at your center.	11/31
External training of transition relevant skills (including inpatient rehab programs).	10/31
Written information material about transition/transfer (eg, handout, magazine, flyer, book).	10/31
Transition medical passport.	4/31
Computer-based training/education (eg, software, online/internet/intranet, app, etc).	0/31
Progress of self-management skills is monitored by nephrologist/social worker WITHOUT special tools.	10/31
Progress of self-management skills is monitored by a score-based system.	1/31
Progress of self-management skills is monitored by questionnaire.	9/31
Readiness of transfer is determined by using an appropriate tool (eg, transition scale, questionnaire, self-rating)	6/31

One component of transition (as per ISN/INPA guidelines) was that "the concept of transition and goals in selfmanagement to acquire are explained [...] in early adolescence,"<sup>1</sup> marking the starting point of a transition program. Twenty-seven of 31 centers ticked this as part of their transition procedure (87%). In another section, the survey asked for this age in particular: Three centers introduced the concept of transition to their patients at age younger than 12 years, 9 of 31 centers at age 12 to 14 years, 10/31 centers at age 14 to 16 years, 6 of 31 centers at age 16 to 18 years, and 6 of 31 centers at age older than 18 years (Figure 1). More than 70% of centers started their transition procedure far later than recommended.<sup>1</sup>

The existence of at least 1 transition/transfer coordinator (nephrologist, social worker, nurse, etc), who is responsible for management of all transition relevant issues, was confirmed by 20 of 31 centers. All 31 centers actively included parents/guardians into the transition process; 8 of 31 included the patient's boyfriend/girlfriend, 5 of 31 siblings, 4 of 31 peers, and 2 of 28 teachers, respectively. Individualized and gradually timed transition schemes were implemented in most centers; however, monitoring of self-management skills was less common (Table 2).



**FIGURE 1.** Age of introduction of the concept of transition to adolescents and young adults after KTx at 34 centers in Europe. The age groups marked in white are recommended by the 2011 ISN/ IPNA consensus on transition.<sup>1</sup>

At 15 of 31 centers, transition clinics are held for the patients. Transition clinics were held less frequently compared with pediatric nephrology outpatient clinics (ie, 1-3 times/ month or less). Organization of transition clinics is shown in Figure 2.

#### **Transfer Age, Policy, and Procedure**

In all but 1 center, the pediatric nephrologist was actively involved in the process of transfer to adult-based care. In the majority (31/34) of centers, the adult nephrologist was actively involved, too. Other healthcare professionals involved are given in Table 3. In 22 of 34 centers, the patient was offered the opportunity of an informal visit to the nominated adult service before transfer. Five-level Likert scale medians and ranges on transfer policy statements are given in Table 4.

Patients were most commonly transferred to adult-based care at age 18 to 19 years (17/36 centers); yet, 7 centers frequently transferred patients younger than 18 years. A comparison of the actual transfer age with the age considered most appropriate by the caring professionals is given in Figure 3.

Transfer age was subject to regulation at 20 of 36 centers. Most cases transfer age were defined as not only at age of 18 years (n = 15), but also at age 16 years (n = 1), 17 years (n = 1), and 19 years (n = 2). Most commonly (n = 10), age regulations were placed by the care provider (eg, hospital), followed by insurance company (n = 7), physicians' association (n = 7), the pediatric nephrology unit itself (n = 5), and government (n = 2). Multiple selections were possible for this question. At 15 of 20 centers, it was possible to postpone

## TABLE 2.

Five-level Likert scale medians and ranges on transition policy statements of 31 pediatric nephrology centers in Europe

Policy statement	Median (range)
"At our clinic information about transition is given to the patient in a	5 (3-5)
gradual manner appropriate to developmental state."	
"The transition plan is individualized for each patient."	4 (2-5)
"Progress of self-management skills is monitored on a regular basis."	3 (1-5)



FIGURE 2. Types of transition clinics used by 15 European centers (multiple choices permitted).

transfer beyond the defined age or individual exemptions were granted to extend pediatric-based care. Exemptions were requested by these 15 centers for 50% of their patients.

Finally, we asked to what kind of adult-based healthcare provider patients were transferred to (multiple selections possible). The most common answer was university hospital (n = 35), followed by nephrologist's practice (n = 9) and community hospital (n = 8).

## Adherence to ISN/IPNA Consensus

The 2011 ISN/IPNA consensus considered 15 components of transition and transfer essential. We scored each participating center for compliance with these components with a maximum of 15 points score (1 point per component). Median compliance score for all centers was 10.0 (range, 0-14.25). A score below 7 was considered low compliance. We divided centers by location (east vs west and south vs north) and found no statistically significant north-south divide. However, Western centers more commonly scored 7 points or higher compared with eastern centers (24/27 vs 5/12, P = 0.0018) and more frequently had scores higher than the overall median of 10.0 (19/27 vs 2/12, P = 0.0019). Centers with very good compliance (score 13 or higher) came

### TABLE 3.

## Healthcare professionals actively involved within the transfer process to adult-based care at 34 European pediatric nephrology centers

Profession	Involved by
Pediatric nephrologist	33/34
Adult nephrologist	31/34
Family doctor/general practitioner	3/34
Pediatrician	4/34
Psychologist (pediatric)	22/34
Psychologist (adult)	7/34
Social worker (pediatric)	19/34
Youth worker	2/34
Social worker (adult)	6/34
Nutritionist (pediatric)	14/34
Nutritionist (adult)	3/34
Nursing staff (pediatric)	25/34
Nursing staff (adult)	12/34

#### TABLE 4.

Five-level Likert scale medians and ranges on transition policy statements of 34 European pediatric nephrology centers

Policy statement	Median (range)
"Transfer at our center is individualized for each patient after s/he has completed a transition plan; this will depend upon completion of physical growth and, where possible, educational, social and psychological attainment".	4 (1-5)
"Transfer at our center is agreed upon jointly by the patient and his/her family/careers in conjunction with the pediatric and adult renal care teams."	4 (2-5)
"Transfer at our center DOES NOT take place during a period of crises, especially if there is unstable social support."	5 (2-5)
"Transfer at our center takes place after completing school education." "We take into account treatment plans by other subspecialties (eg,	3 (1-5) 4 (2-5)
urological supervision).	

from Denmark, Finland, Germany (n = 1), Switzerland (n = 1), and United Kingdom (n = 2).

The score for compliance with recommendations was significantly correlated with gross national income ( $r^2 = 0.631$ , P < 0.0001; Figure 4) and gross domestic product ( $r^2 = 0.677$ , P < 0.0001). There was no statistically significant correlation between center size (number of patients under care) and score for compliance, nor did center size and application of a transition procedure correlate.

#### DISCUSSION

This survey sheds some light on current management of transition and transfer from pediatric- to adult-based care in pediatric KTx recipients in Europe. It further indicates the adherence of pediatric nephrologists to the 2011 ISN/IPNA consensus guideline.<sup>1</sup> Although not all European centers answered the survey, most (70-100%) of the countries large pediatric nephrology units participated. Thus, we assume the survey being representative.

At least 1 unwritten transition procedure was confirmed by 82% of participating centers. This is comparable with data we collected in Germany and Austria 3 years ago.<sup>3</sup> Unfortunately, only 7 (18%) centers used a written transition plan and communicated its content with the patient. A commendable variety of documents, for example, "healthcare transition plan," "young person self-referral letter," and checklists can be found at the Royal Children's Hospital Melbourne Transition Support Service website.<sup>22</sup>

Although an overwhelming majority of centers stated that the concept of transition was introduced in early adolescence, only 35% of them actually introduced the concept below the age of 14 years. The 2011 ISN/IPNA guidelines define early adolescence precisely at ages 12 to 14 years.<sup>1</sup> This is one of the most important findings of the survey: The majority of centers started the transition process rather late and with only little time left to successfully train the patient. This leaves much potential for optimization of care.

Only one third of centers offered training courses, for example, therapeutic recreation camps, which have been proven to help knowledge transfer and to improve selfcare skills.<sup>16,23,24</sup> Young people heavily rely on social media,





FIGURE 3. Transfer age. Comparison between the age when patients were most commonly transferred (A) and the opinion of the pediatric care provider on the most appropriate age for transfer (B) at 36 European centers.

internet, and computer-/smartphone-based information.<sup>9</sup> Therefore, it is striking and difficult to understand that not a single center used information technology (IT) based training/education. A prospective study in adult patients after lung transplantation showed a benefit on immunosuppressant adherence using tablet-computer-based education.<sup>25</sup> Unfortunately, studies on IT-based patient education after organ transplantation are scarce. Healthcare professionals caring for adolescents should keep up with the times in regard of IT and social media. Societies such as the ESPN or the International Pediatric Transplant Association or the IPNA could take the lead in developing these urgently needed IT-based educational tools which can then be adapted to national and/or local needs.

Only half of the centers used an appropriate tool to monitor progress of self-management skills over time and less than 20% determined readiness to transfer by using an appropriate tool. In this regard, adherence to the ISN/IPNA guidelines must be improved significantly in the future.

More than half of the centers got a good or very good mark regarding adherence to the ISN/IPNA guidelines on healthcare transition. This can be seen as an improvement compared to the survey performed by Forbes et al years ago<sup>17</sup> even if the centers do not completely match with those of our current survey and a between-study comparison of data may be methodologically not sound. Interestingly, we found a significant correlation between adherence to the guidelines and gross national income. Implementing guidelines into daily practice seems to depend at least partially on the availability of resources. On the other hand, these resources need to be directed to the improvement of transitional care which can only be achieved if there are national efforts for directing money to transition and to properly reimburse transition programs.

Following our results, patients were most commonly transferred to adult health services at age 16 to 21 yearswhich is the age span with the highest risk of transplant loss.<sup>5,8</sup> Poor treatment adherence is believed to be the main cause of increased graft failure in emerging adulthood.<sup>5</sup> At this point, a young adult clinic with peer support can be fa-vorable.<sup>11,12,15</sup> However, only 2 centers used this concept

as transition clinic. Another option would be the use of transition readiness scales to ensure that transferred patients are ready for adult care.<sup>26-31</sup> Obviously, changes in transition age can most often not been achieved by centers themselves. Political action is required to change national health systems in this respect. Political engagement on a European level, that is, by working on directives of the European Parliament and/or the European Commission that have to be implemented in national legislation might be a possible way to go.

Only 65% of the centers offered their patients an informal visit to the nominated adult service before transfer. Yet, it has been shown, for example, that clinic attendance rates are improved if the pediatric patient is able to meet the adult transplant unit team before transferring.<sup>32</sup> The first appointment at the adult center is a critical one, and there should be a preparatory phase to ensure that there is a gradual introduction of the young person to the adult unit and its staff.<sup>32</sup> Less than



FIGURE 4. Spearman correlation between the GNI and the guidelines adherence score in 39 European pediatric nephrology centers. GNI, gross national income.

half of the centers used transition clinics with alternate or shared consultations with adult and pediatric nephrologist.

Our study has some limitations: The results are based on an internet survey and not on personal interviews, which might make answers less reliable. Despite the fact that most European countries are covered, the survey does not include all centers for pediatric KTx in Europe, and one should keep in mind that practice of transition can vary widely in the same country as recent studies show.<sup>19,32</sup>

We conclude that the 2011 ISN/IPNA guidelines on transition are implemented insufficiently in European pediatric nephrology centers. Therefore, further development is needed, and there are crucial issues to be addressed in the future: IT and social media should be implemented in patient training and education and transition should take place at an individual time point when transition readiness is achieved.

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