

Received: 2017.07.19
Accepted: 2017.10.02
Published: 2018.01.16

Pediatric Renal Transplantation: Focus on Current Transition Care and Proposal of the “RISE to Transition” Protocol

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Source of support: Self financing

The transition from pediatric to adult medical services is an important time in the life of an adolescent or young adult with a renal transplant. Failure of proper transition can lead to medical non-adherence and subsequent loss of graft and/or return to dialysis. The aim of this study was to conduct a systematic review and survey to assess the challenges and existing practices in transition of renal transplant recipient children to adult services, and to develop a transition protocol.


We conducted a literature review and performed a survey of pediatric nephrologists across the United States to examine the current state of transition care. A structured transition protocol was developed based on these results.

Our literature review revealed that a transition program has a positive impact on decline in renal function and acute rejection episodes, and may improve long-term graft outcomes in pediatric kidney transplant patients. With a response rate of 40% (60/150) from nephrologists in 56% (49/87) of centers, our survey shows inconsistent use of validated tools despite their availability, inefficient communication between teams, and lack of use of dedicated clinics. To address these issues, we developed the “RISE to Transition” protocol, which relies on 4 competency areas: Recognition, Insight, Self-reliance, and Establishment of healthy habits.

The transition program decreases acute graft rejection episodes, and the main challenges in transition care are the communication gap between health care providers and inconsistent use of transition tools. Our RISE to transition protocol incorporates transition tools, defines personnel, and aims to improve communication between teams.

MeSH Keywords: Health Transition • Kidney Transplantation • Medication Adherence • Transition to Adult Care

Full-text PDF: <https://www.annalsoftransplantation.com/abstract/index/idArt/906279>

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Background

Pediatric renal transplant recipients face a unique challenge in their medical care when they reach adolescence. As this time, they must transition from pediatric to adult medical care providers. During this transition, adolescent patients are expected to begin self-management of their disease [1]. Adolescent patients are expected to learn how to navigate insurance, medication adherence, appointment adherence, and other responsibilities that were previously managed primarily by parents or providers [1]. It is also important for the patient to be prepared in non-medical areas, namely educational/vocational goals and skills, peer and community relations, and psychological health. In other words, they will have to shift from parent-directed and provider-directed care to self-management of their disease process.

These skills are expected to be learned during a time of increased high-risk behaviors secondary to major cognitive and psychosocial development [2]. As such, this is a very tenuous period in the patient's renal disease timeline. Failure to have a proper transition can result in poor long-term health consequences, most notably, loss of transplant or the need to initiate or return to dialysis [3]. The goal of transition care is to minimize the risk during this period and thereby decrease the adverse effects associated with this time period.

The American Academy of Pediatrics describes transition is a process "to maximize life-long functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood" [4].

The American Society of Transplantation also states the importance and need for transition: "Adolescents represent a unique and challenging population with high incidence of graft failure felt to be related to non-adherence and inadequacies related to the transition process. This group of patients requires a higher degree of programmatic and psychosocial support best provided in a transplant center equipped to understand and address their unique needs. These issues, many of which are unique to the pediatric transplant population, require special study. Increased support for both basic science and clinical research is needed to allow children to maximally benefit from organ transplantation. Pediatric patients have much to gain from a successful transplant, including the optimization of growth, neurological and psychological development, the ability to attend school, learn, and enter college, and ultimately to become productive citizens as they enter the workplace as adults" [5].

Currently, there is no standardized transition protocol in place to help guide this process [6]. As a result, the transition of

adolescents is not fully optimized from a patient or physician standpoint [7]. While the main goal of transition care is ultimately self-reliant adult medical care, it is extremely important for transitioning patients to fully understand their medical condition and treatments. Multidisciplinary transition teams and dedicated transition clinics help to address most of the transition problems. However, the major constraint for this is the financial burden and the challenges involved in bringing adult and pediatric teams along with subspecialties under one roof, especially in freestanding children's hospitals [8].

We performed a literature review to examine the existing studies on transition care methods and tools used for renal transplant children. Also, to assess the current state of transition care in renal transplant children, we administered a survey to various nephrologists across the United States. The goal of this review and survey is to develop a transition protocol that can contribute to defining evidence-based guidelines in the future that can assist in the successful transition of transplant recipients into adulthood.

Systematic review

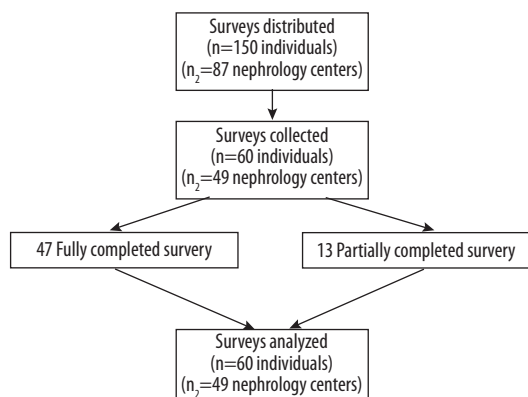
A review of the existing literature was done for studies on current transition practices and tools used in the transition of renal transplant children from pediatric to adult nephrology/transplant services. Only studies that focused on transition care practices, transition care interventions, and their effects on long-term renal graft survival and outcome were included in the review, which followed PRISMA guidelines (Supplementary Table 1). A PubMed/Medline search was performed using the search string "transition care in pediatric renal transplantation". Two independent reviewers extracted the data with regards to type of study, number of subjects in the study, interventions/tools used in the transition process, outcomes, and recommendations. Any differences in reviewer data extraction was resolved by reaching consensus or involving a third reviewer if necessary.

Survey of transition care problems

We designed a survey, which was administered to various nephrologists across the United States to assess the current state of transition care in pediatric transplant nephrology. We distributed a 17-question survey in order to gain the most information while still being simple and quick for practitioners to respond to (Table 1). The survey was distributed to 150 nephrologists in 87 centers across the country via SurveyMonkey (Figure 1). The percentages of "yes" answers for each question were calculated (Table 1). Free-text answers were counted and similar answers were grouped accordingly (Table 1, questions 14–16). The percentages were examined to determine which tools, personnel, and processes were used consistently

Table 1. Transplant transition survey questionnaire and responses.

Question	Total responses	Yes	No
1. Is there a transition clinic for transplant patients in place at your hospital?	60	14 (23%)	46
2. Is there an up-to-date health summary (Passport) composed for each patient?	60	22 (37%)	38
3. Is there a written health care transition plan for each patient and their family?	60	20 (33%)	40
4. Did you complete a checklist of critical tasks and milestones to achieve throughout childhood and adolescence prior to transfer?	59	23 (39%)	36
5. Was the patient prepared for his/her responsibilities in regard to health care, education, financial and social responsibilities as he/she matures?	59	36 (61%)	23
6. Was there collaboration between adult transplant team regarding their expectations, clinic set-up and clinic protocols?	60	33 (55%)	27
7. Was there an effective partnership with the pediatric team for bidirectional information exchange in the following areas?	56	32 (57%)	24
Practices	56	27 (48%)	29
Protocols	56	31 (55%)	25
Treatment Plans			
8. Was there a standardized assessment of readiness for care conducted?	46	14 (30%)	32
9. Do you utilize transplant transitional care questionnaires to help guide this process?	48	11 (23%)	37
10. Is there involvement of adult transplant physicians involved at least 1 year prior to transition?	60	15 (25%)	45
11. Is there a designated transplant transition coordinator?	60	15 (25%)	45
12. Was there effective communication and education on behalf of the primary care provider regarding care beyond the norm for the young adult ESRD patient?	60	18 (30%)	42
13. Do you have a reproductive specialist and urologist proficient in congenital urologic malformations?	60	48 (80%)	12
14. What personnel are utilized during the transition of care process?	49	n/a	n/a
Pediatric nephrologist	40		
Adult nephrologist	34		
Social worker	27		
Transition coordinator	10		
Nursing	16		
Transplant coordinator	4		
Dietician	5		
Psychology	6		
Nurse practitioners	3		
Teachers	1		
Pharmacy	1		
Med-peds nephrologist	1		
Young health workers	1		
Adult Transplant surgeon	1		
Child Life	1		
Primary care physician	1		
15. How many transplant patient transitions do you complete each year?	59	n/a	n/a
0-5	47		
5-10	9		
10-15	3		
>15	0		
16. At what age does the patient begin the transition process?	59	n/a	n/a
8-10 years	1		
10-12 years	4		
12-14 years	11		
14-16 years	14		
16-18 years	29		
17. Is the transition process complete at the time of transfer to adult-focused services?	59	35 (59%)	24



150 surveys were distributed in 87 nephrology centers the country. 60 responses received from 49 centers (40% response rate). All 60 responses were used for our analysis.

Figure 1. Flow diagram of survey distribution and responses received.

or inconsistently during the transition process across different practices.

Systematic review results

With the search string mentioned above, 48 articles returned and were screened for studies about transition care and transition tools/interventions in renal transplant children (Figure 2); 19 were excluded based on title screening, and of the remaining 29 articles, 19 were excluded based on abstract screening. The final 10 articles qualified for full review, and the data were extracted and are summarized in Table 2. Tools and resources used in transition care included: structured transition programs [9]; dedicated transfer/transition clinics to address the needs of at-risk adolescents [10, 11]; administering questionnaires to assess the transition needs and readiness of patients, providers, and parents [12–14]; and monitoring of immunosuppressive drug trough levels to estimate the level of adherence during transition [3]. Questionnaire-based surveys were shown to be helpful tools in assessing the needs and readiness of patients, family members, and healthcare providers [12,14]. Use of dedicated transition/transfer clinics has been shown to improve patient compliance and long-term kidney transplant outcomes [10]. Furthermore, standardized multilevel transition programs involving patients, pediatric nephrologists, nurses, parents, siblings, teachers, social workers, and dieticians have been shown to reduce the rate of decrease in kidney functions and acute rejection episodes [9]. Immunosuppressive drug trough level monitoring can be used to check patient compliance during transition; however, a study has shown that the compliance was not related to transition; rather, adolescent age is a risk factor for non-compliance [3].

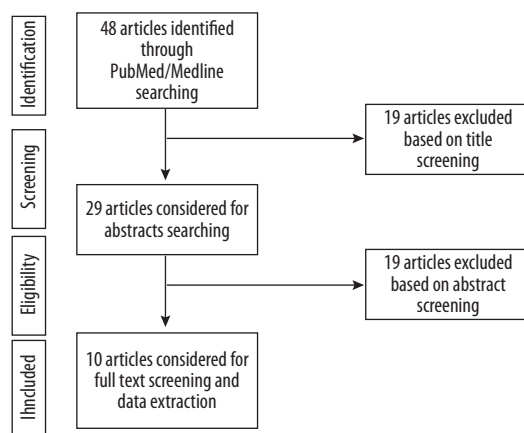


Figure 2. Screening flow chart.

Survey results

We received 60 responses from 49 centers (40% response rate) (Figure 1). The vast majority of those surveyed complete 0–5 transitions a year and report 59% of patients complete the process at the time of transfer to adult services. Approximately half begin the transition process at age 16–18 years, while the other half begins the process at age 16 and under. The personnel involved in the transition process vary widely across practices, and only 23% used a dedicated clinic. Sixteen different services were reported as being used (Table 1, question 14), with most common being pediatric nephrologists (40/94), adult nephrologists (34/49), and social workers (27/49). Very few respondents took advantage of psychology, pharmacy, and primary care services. Interestingly, 80% reported the use of a team member proficient in congenital urologic malformation.

Only 33% reported that a written transition plan was given to patients, 37% incorporated healthcare passports into their transition process, and 61% reported that the patient was prepared for future health care, education, financial, and social responsibilities. Only 30% used a standardized assessment of readiness, 23% utilized a transitional care questionnaire, and 39% completed a checklist of some sort indicating achievement of milestones.

Less than 60% of respondents said that practices, protocols, and treatment plans are effectively communicated between adult nephrology and pediatric teams. Only 30% reported extra involvement of the PCP during transition and 25% reported involvement of adult nephrology at least 1 year prior to transition. Another finding was that only 55% reported collaboration with adult teams regarding expectations and clinics.

Table 2. Studies on transition care in pediatric renal transplant patients.

Study/Year	No. of patients	Tools/ intervention used	Outcomes	Conclusion/ recommendations
Weitz et al. [8] 2015 Retrospective cohort study	59	Transition programs	Fall in eGFR was significantly low at 3 yrs after transition despite age of graft in TP group was almost twice the age of graft in control group. Also, decreased number of AR's in TP group compared to control group although it was not statistically significant	Standardized multilevel TP has a positive impact on decline in renal function and AR episodes in pediatric kidney transplant patients
McQuillan et al. [9] 2015 Retrospective cohort study	32	Kidney transplant transfer clinic	Improved adherence & renal function	May improve long-term graft outcomes in transplant recipients
Marchak et al. [11] 2015	49	Readiness for Transition Questionnaire – Provider (RTQ-Provider), RTQ-Teen & RTQ-Parent	RTQ has ability to strengthen interpersonal communication among patients, families and healthcare providers to assess and recognize factors that affect transition readiness.	Future research is required to demonstrate predictive validity of this intervention post transition to adult care
Kreuzer [12] 2015	119	Standardized questionnaire to assess present transition care practices in Germany & Austria	Transition care varies significantly between centers despite existence of highly specialized care. Significant rise in serum creatinine levels noted in 21% of patients during last visit to pediatric clinic. Majority of patients demonstrated coefficient of variation for immunosuppressive medication trough levels <20% which was indicative of good medication compliance evidenced by reduced rates of transplant rejection (coefficient of variation for tacrolimus trough levels <40% not found to be associated with increase in risk of transplant rejection)	Recommended for improvement in transition and psychosocial care including patient education. Phase 2 of the study, a prospective randomized control trial is ongoing which is aimed at providing a model of structured transition
Akchurin [3] 2014 Retrospective study	97	Tacrolimus trough levels and its variability used to assess differences in medication compliance before and after transition, and between transitioned and control groups	No statistically significant difference in medication compliance was found in the transitioned group before and after transition, and between transitioned group and young adult control group who had renal transplantation under adult care. However, medication non compliance rate was found to be higher in non-transitioned adolescent control group who had graft loss when they were still under pediatric care compared to transitioned group	Medication compliance was not related to transition from pediatric to adult care in the same center, but adolescent age was shown to be risk factor for non-compliance. However larger prospective trials required to demonstrate this relationship
Pape et al. [10] 2013 Retrospective study	66	Specialized transition clinic	Patients transferred to transition clinic showed high level of satisfaction and small number of medication regimen changes compared to the other two groups transferred to nephrologists in private practice and general transplantation clinic. However, there were no significant differences in renal function decline among three groups in short-term	Transfer to specialized clinic was not associated with short-term benefits in terms of graft function and survival

Table 2 continued. Studies on transition care in pediatric renal transplant patients.

Study/Year	No. of patients	Tools/ intervention used	Outcomes	Conclusion/ recommendations
Andreoni et al. [14] 2013 Retrospective study to determine high risk age group for renal transplant loss	168,809	NA	Patients between 14 and 16 years of age, found to have high risk of graft loss with black adolescents having worst outcome. Further, patients who had deceased donor and government insurance were found to have highest risk of death compared to those with living donor and private insurance.	Adolescents between 14 to 16 years of age are at higher risk of renal transplant failure with highest risk observed among black population and patients with government insurance
Van Den Heuvel et al. [15] 2010 Retrospective cohort study to determine the effect of transition on the renal graft survival	162	NA	Acute graft rejection episodes were significantly higher before transition. The risk of graft rejections reduced after transition to adult care and this reduction was more pronounced in native Dutch patients compared to immigrants	Acute graft rejection risk reduces after transition to adult care
Koshy et al. [16] 2009 Retrospective cohort study to examine the effect of transition on the renal graft survival	115	NA	There was no increase in risk for renal allograft failure during transition. Furthermore, hospitalizations for graft rejection or biopsy were found to be lower after 18 years of age.	Transition to adult care does not increase the risk of allograft failure
Chaturvedi et al. [13] 2009 Retrospective study	11	Transition questionnaire was used to demonstrate level of satisfaction and transition process perception in patients who were transitioned through transition clinic.	This study demonstrated that adolescents participation in transition planning and preparation before transfer to adult care were insufficient	Adolescents should be involved actively in transition planning from the beginning

Discussion

While our sample size is small, this survey still provides some insight into the current state of transition care in the United States. With a response rate of 40% from nephrologists in 49 centers (56% centers surveyed) across the country, we believe we have a representative sample of current nephrology transition practices. Several areas of concern become apparent in our survey results. First, there is considerable variation across practices in personnel involved in the process, use of dedicated clinics, and use of patient-centered tools. Second, there is inconsistent communication between the adult and pediatric

teams, as well as with the primary care provider. Third, there is inconsistent use of transition surveys and assessment of readiness, despite evidence that they improve outcomes.

From our literature review, it became apparent that various tools and resources were used during transitioning in order to enhance graft survival. There is evidence that a multidisciplinary team has a positive impact on patient outcomes [9]. Studies have shown that the use of dedicated transition clinics improves long-term patient outcomes and patient satisfaction [9,10]. In contrast, a study found that specialized transition clinics have no positive impact on short-term graft function

and survival [11]; however, the same study found that use of these specialized clinics is associated with a high level of patient satisfaction and a small number of medication regimen changes in comparison to the patients transferred to general transplantation clinics and private-practice nephrologists [11]. Questionnaire surveys aid in identifying and addressing deficiencies in transition preparedness, and improve interpersonal communication among all the personnel involved [12,14].

Multidisciplinary teams are also able to help patients in non-medical aspects. Availability of social work, financial assistance personnel, community workers, and other non-medical staff improve the health disparity seen during transition, as well as improving the effectiveness of transition [15–17]. Despite the evidence and the benefit potential, our survey shows that dedicated transition clinics are not widely used at this time. Also, the lack of communication between healthcare teams, patients, and primary care providers is an area of concern. Transplant recipients typically have a complicated care plan that must be continued throughout their lives; therefore, effective communication is a key to success. The use of a dedicated transition clinic can improve communication between teams by having all parties involved in a single clinic. Joint appointments with pediatric and adult teams would help foster bi-directional communication. This will also increase patient contact with the healthcare system by having all services delivered in a single day in one facility. Increased contact has been shown to be part of a successful transfer to adult services [18]. Use of a single clinic would also improve communication with primary care services by acting as a link between transplant teams and primary care offices. The major obstacles to this are the financial burden and the challenges faced in bringing all services under one roof, especially in freestanding children's hospitals [8].

Currently, there are validated assessments available for use in transition care [19]. There are also several tools available, such as the health care passport and medication adherence assessments, to facilitate the transition process [20]. These tools allow identification of at-risk individuals, and implementation of these assessments will help prevent premature transition and improve long-term outcomes. Our findings suggest the need for a structured transition protocol and the establishment of dedicated transition clinics to optimize care for adolescent and young adult (AYA) transplant recipients. In order to contribute to defining evidence-based guidelines in the future and to address the inconsistencies in healthcare personnel, ineffective communication, and minimal use of transition tools, we have designed the “RISE to transition” protocol for renal transplant recipients.

Transition Protocol: RISE to Transition

Here, we outline our transition protocol based on our survey findings and literature review. We have identified 4 competency areas to educate patients prior to transition.

1. **Recognition** of their disease process, reason for transplant, and the healthcare system;
2. **Insight** into the short- and long-term impact of their disease, therapy, non-adherence, and emotional needs;
3. **Self-reliance** in scheduling and attending appointments, refilling medications, and identifying urgent/emergent changes to their health on their own;
4. **Establish** healthy lifestyle choices, life-long adherence to medications and follow-up, psychosocial skills, and educational/vocational goals.

These 4 competency areas are key to an effective transition. Self-reliance and the establishment of healthy choices aim to improve patient autonomy, reduce emotional burden, and minimize disruptions in daily life [21,22]. Recognition and insight aim to educate the patient about all aspects of their disease. Education about medical, social, vocational/educational, and interpersonal effects of their disease and treatment will help to improve adherence and to alter patient perspectives on their disease [17,23]. Proficiency in all 4 areas will allow patients to establish themselves in the adult medical world.

Transplant transition clinic

The transition clinic, headed by the transition team, will be the central location for the transition process. The goal of the transition clinic is to provide a single area for patients to meet their entire medical team and improve collaboration between pediatric and adult teams. This will be achieved through the use of dedicated personnel and a structured protocol.

Key teams in transition

There are 5 groups of key players that must work together seamlessly to achieve optimal transition:

1. The patient and family;
2. Pediatric transplant team;
3. Transition team (med-peds nephrologist, social worker, transition coordinator, allied health professionals, and community resource providers);
4. Adult transplant team;
5. Primary care provider (PCP).

Transition tools

Tools to be utilized in the protocol include:

1. **Medical passport:** The medical passport helps in the areas of recognition, self-reliance, and establishment of good

Table 3. Milestone checklist.

- Understanding of and ability to describe the original cause of their organ failure, need for transplantation
 - Use passport and My precious life gift handout; repetition is necessary to ensure they understand their condition
- Awareness of the long and short-term implications of the transplant condition on their overall health and other aspects of their life (e.g. infection prevention, cancer surveillance, academic and vocational aspirations)
- Comprehension of the impact of their illness on their sexuality and reproductive health, including
 - The impact of pregnancy on their own wellbeing
 - The effect of their medications on fertility any potential teratogenicity of their medications
 - The role of genetic counseling, and genetic risk of their disease recurrence in future offspring, if pertinent to their condition
 - Their own increased susceptibility for sexually transmitted disease
- Demonstration of a sense of responsibility for their own healthcare
 - Knowledge of the names, (and shapes/colors), indications and dosages of their transplant and ancillary medications (or carry this information in wallet/purse)
 - Call for their own prescription refills and renewals
 - Prepare their own medication dose boxes, if not done by their pharmacist
 - Independently communicate their health care needs to their providers
 - Teach them when and how to seek urgent medical attention, including health emergency telephone number(s)
 - Ability to make, keep a calendar of and follow through with their own health care appointments
 - Understanding of their medical insurance coverage and eligibility requirements
- Capacity to provide most self-care independently
- An expressed readiness to move into adulthood
- Ownership of their medical information in a concise portable accessible summary
- Make them CEO of their own health problem.

healthcare habits [20,24]. The passport is designed to include medical history, diagnosis, date of transplant, medications, providers, and any other important information the patient may need in case of emergency. This will be updated each clinic visit. To assess its efficacy, a survey is conducted at 3 months and 6 months into the transition (medical passport survey).

- 2. Milestone checklist:** To track progress across the 4 competencies and through transition, milestone checklists (Table 3) will be used by adult and pediatric transplant teams. We will provide a basic checklist, which will be adjusted accordingly by the adult and pediatric team for each patient.
- 3. Kidney transplant questionnaire for baseline assessment:** Each patient will undergo a baseline assessment at the initiation of transition. This will help identify problem areas and allow the transition team to make appropriate changes.
- 4. Transition readiness assessments:** Transition readiness assessments will also be performed every 6 months. Based on these results, the patient's personalized milestones and the transition focus areas will be adjusted to fit the patient's strengths and weaknesses.

Stages of transition

We have divided the entire process of transition into 3 stages depending on the age of the patient and illustrated in Figure 3.

- 1. Pre-transition stage:** This will occur when the patients are 14–18 years of age.
- 2. Active transition stage:** Transition will occur at age 18–21.

- 3. Post-transition stage:** Transfer will be complete by age 21 and post-transition follow-up will be done up to age 26.

Pre-transition stage (age 14–18 years)

The pediatric transplant team will handle the initial preparations for transition. While the official transition process begins at age 18, family-led education should begin as young as age 14. At this time, the pediatric transplant team will initiate use of educational tools with the patient and family (Table 4). They will also encourage families to begin seeking financial, educational, and vocational support for the patient's future academic/career goals. Early interventions help to enforce healthy skills and independence and foster a sense of normalcy for the adolescents and young adults [23]. During this time, interventions will aim to improve quality of life for transplant recipients by targeting psychosocial aspects of transplant and transition [25,26].

A checklist of tasks will be provided to the pediatric transplant team outlining their responsibilities, which contains the requirements of the RISE protocol (Table 5). The team will create a transition plan in conjunction with the patient and family, which will lay the groundwork for transition by defining milestones to be achieved (Table 3). The transition plan will be given to the patient, family, adult transplant team, and transition team. The pediatric transplant team will also be responsible for providing the patient with an up-to-date medical passport. If not already established, they will also assist the family in finding an adult primary care provider and begin communications.

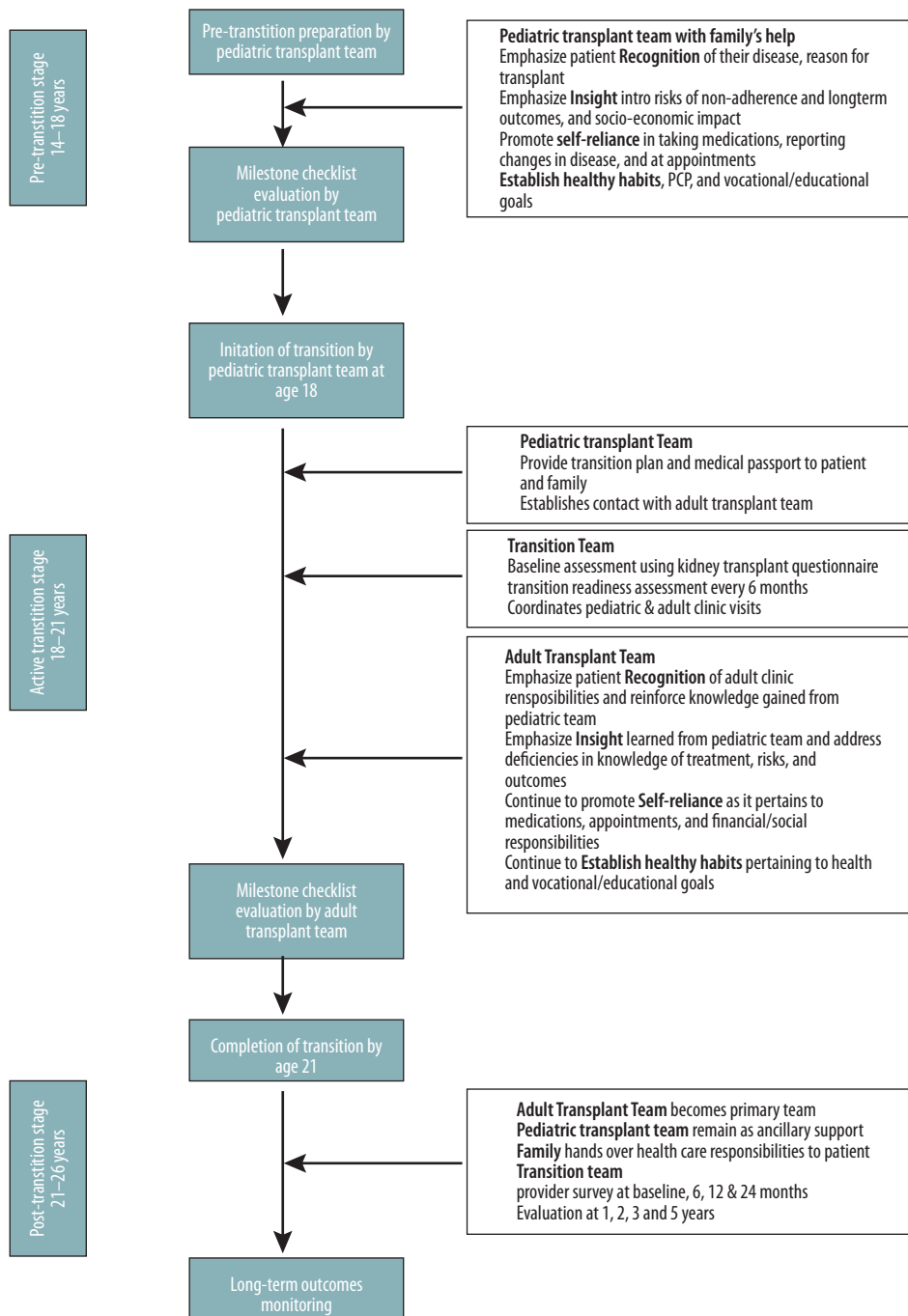


Figure 3. Transition flow diagram.

Active transition stage (age 18–21 years)

Needs Assessment: Once the patient is 18 years of age, the pediatric transplant team will initiate the transition process. A baseline level of readiness will be assessed in the patient and family at the start of transition. These assessments will not only determine the level of need, but also allow for the transition

process to be personalized for each patient. Assessments are done using:

1. Rapid Estimate of Adolescent/Adult Literacy in Medicine (REALM);
2. Appointment and Medication Adherence Report;
3. Family Relationship Index and Social Support (SSQSR – short form).

Table 4. Pre-transition stage: age 14–18.

- During this phase, the pediatric transplant team will begin laying the groundwork for transition
- Begin searching for adult PCP with help of family
- **Pediatric Transplant Team and Family**
 - i. Emphasis on **recognition** of disease and medication treatments
 1. Understand their disease
 2. Understand reason for transplant
 - ii. Emphasis on **insight** into consequences
 1. Begin understanding risk of non-adherence
 2. Begin understanding the long-term health effects
 - iii. Laying the groundwork for **self-reliance**
 1. Medication regiment becomes a routine
 2. Begin understanding urgent/emergent changes in their health
 3. More involvement at appointments
 4. Encourage the patient to ask questions on how to prepare for transition
 - iv. Begin **establishing healthy habits**
 1. Healthy choices
 2. Emphasis on adherence to treatments
 3. Emphasis on vocational and educational future
- In order to assist with the transition, a checklist of milestones will be provided to the pediatric transplant team

Table 5. Check list of tasks for pediatric transplant team.

- Demographics
- Transplant date and organ
- H&P summary
- Last clinic note and lab work
- Medication list
- Problem list
- Pharmacy and lab numbers
- PCP
- Insurance status
- Present to the Transition Committee
- Date anticipated for transfer
- Review the process with patient/family
 - Verbally
 - Letter
- Confirm the patient is able to make the transition successfully
- Present to adult transition team
 - Specific template
 - Adult and pediatric participants
 - Multidisciplinary group: surgeon/doctor, nurses (NPs), social work
 - Financial counselor
 - Discussion and recommendations
- Schedule a combined adult – pediatric clinic
- Written health care transition plan should be created together with the patient and family
- Milestones to achieve prior to transfer are described
- Standardized transition preparedness questionnaire for an assessment of transition readiness
- Communicate to adult providers at transfer and incorporate areas in need of attention, including individualized information about methods most successfully used to optimize immunosuppressive medication adherence
- Patients should be provided with a portable concise, up-to-date summary of their medical/surgical history and medications (Medical Passport)

Table 6. Active transition stage: age 18–21.

- Transition will be initiated by the Pediatric transplant team
- **Pediatric Transplant Team and Family**
 - i. Written transition plan to be provided by pediatric team
 - ii. Adult PCP should be fully established with effective bi-directional communication
 - iii. Establish contact with adult transplant team
 - iv. Provide patient with a medical passport
 - v. Continue with education of RISE competencies
- **Transition Team**
 - i. Baseline assessment of RISE competencies
 1. Based on the results, education will be tailored for weaknesses
 - ii. Use of standardized readiness assessments (STARx, TRxANSITION)
 1. After baseline assessment, these will be used to monitor progress
 2. Readiness will be reassessed every 6 months
 - iii. Facilitate combined pediatric and adult clinic visits
 - iv. Coordinate use of transition tools: Passport, milestone checklists
 1. Passport use will be examined 3 and 6 months into transition (Medical passport survey)
- **Adult Transplant Team**
 - i. **Recognition**
 1. Educate patient on expectations of adult clinic
 2. Reinforce disease and treatment knowledge
 3. Assist in knowledge acquisition of insurance and other non-clinical aspects of health care
 - ii. **Insight**
 1. Reinforce long term outcomes for their disease
 2. Reinforce long term consequences of non-adherence
 - iii. **Self-Reliance**
 1. Educate patient on skills such as making appointments, refills, and other clinic related skills
 2. Reinforce prior education on identifying urgent/emergent changes to their health
 - iv. **Establish health habits**
 1. Reinforce healthy habits established in pediatric care
 1. Continue to promote gaining healthy habits
 - v. Adult transplant team will have a milestone checklist to complete

Active Transition: The first visit will always be a combined appointment. The adult transplant team will be brought on by the pediatric and transition teams. During this visit, the pediatric team will provide a written transition plan and the adult team will define their expectations moving forward. The adult transplant team must ensure that the patient has achieved all milestones as defined by the pediatric team prior to transition. This will be accomplished by clinic visits consisting of pediatric transplant, adult transplant, and transition teams at the transition clinic (Table 6).

The adult team will also establish communication with the primary care provider. This key area has been underutilized in the past [27]. Primary care physicians should be involved during active transition in order to facilitate good communication with the patient's primary point of contact in the health-care community. Together with family and primary care, the adult team will communicate all guidelines pertaining to the patient's disease, treatment, complications, impact on daily life, and other areas of impact. The adult team will have their own checklist that must be completed prior to successful transition (Table 7). After the initial visit, the adult team will work with the patient to continue improving competencies in RISE.

The transition team will assist the patient and the pediatric transplant and adult transplant teams with the transition, which is tailored for the patient based on the results of the baseline assessment. The transition team will assess the patient's progress in the 4 key areas through the use of readiness surveys given to patient, family, and physician. The team acts as the primary conduit between pediatric and adult services and ensures milestones are made and provides a safety net for patients. During the transition period, assessments will be performed every 6 months to establish the patient's level of readiness. Standardized assessment questionnaires will be used for this aspect of transition. At each visit, patients will also be evaluated for milestone achievements. This will continue until patients have successfully exhibited competency in all 4 areas of RISE and has reached all their milestones.

When the patient is deemed ready to fully transition to adult services, the adult team must communicate with the pediatric team all residual responsibilities prior to the patient's first appointment. The adult team will also ensure they have obtained all records from the pediatric team and, if needed, have the ability to consult the pediatric team.

Table 7. Checklist of tasks for adult transplant team.

- Welcoming and orienting the new young adult into the adult practice
- Following review of the transfer package, the initial appointment should address any concerns that the young adult may have in transferring to a new adult provider and distinctions between pediatric and adult care
- To discuss confidentiality, access to information, and shared decision-making and to elicit how to best communicate with the young adult
- Over the next few visits, the provider should work with the young adult to assess and strengthen self-care skills
- Providers can use the results of this assessment to develop a plan of care with the young adults
- The adult practice must communicate with the pediatric practice about their residual responsibility for care until the first visit to the adult provider is completed (e.g. medication refills or acute care visits)
- In the case of young adults with complicated health or psychosocial needs, direct provider communication is encouraged
- Adult providers can also establish a plan for further consultation with the pediatric provider should the need arise
- Community resource information on insurance, self-care management, and culturally appropriate supports can be helpful to young adults

Post-transition stage (age 21–26 years)

Adult transplant team

When the patient is fully ready for transfer (ideally by age 21), the adult team will take over patients care. Prior to this, the adult team will have completed their transition checklist (Table 7), established effective communication with primary care, and ensured the patient is fully competent in all RISE areas.

Pediatric transplant team

When the transition is completed, the pediatric transplant team will remain with the patient until the first adult visit. They will also remain available for consultation by the adult team if the need arises.

Transition team

The transition team will continue to follow the patient into adulthood (Table 8). This is to not only create continuity for the patient and act as a safety net, but also to assess the success of transition and to identify areas for improvement. At 6 months after transition, a combined care teleconference will be conducted between all pediatric and adult services. After 3 consecutive visits to the adult nephrologist, quality outcomes will be evaluated, with further evaluation at 1, 2, 3, and 5 years. This will allow the transition team to perform continuous quality improvement in order to improve the transition experience.

Implementation of the RISE to Transition Protocol at Our Facility

The primary aim of this protocol is to help define evidence-based guidelines for transition in the future. Given the scope of the protocol, secondary goals are validation and improvement

of transition tools. We have implemented RISE to transition protocol and the study is ongoing at Akron Children's Hospital. Seventeen patients (6 females and 11 males) who received a renal transplant (mean age, 14.5 years) in the preceding 2–9 years (mean, 5.6 years, median 7 years) received transition protocols in their clinical visits. We laid down the transition plan incorporating key adult physicians and related services. The final transition will be completed after the patient turns 21 years old. So far, we have successfully transitioned 6/17 patients.

The preliminary assessment suggests that the transition clinic helped give family and/or care givers, as well as the other subspecialists, sufficient time to prepare for the young person to transition from pediatric care to adult care (satisfaction score 90%). Educating the young person and their family about the transition process, kidney condition, healthcare rights, and adult health care environment were identified as the key factors for RISE to transition (90th percentile). Adolescents and parents did not differ significantly in their general views and stated that they would appreciate the support provided by a transition program. However, the parents appreciated the support during transfer significantly more than did the adolescents. Eighty-five percent of patients and family felt generally well-informed about the RISE to transition, but 70% preferred to receive more information about their disease and overall health during their transfer period. When asked for the key person during the transfer, 62% of respondents mentioned the pediatrician, 6% said "others," and 30% stated that it was the nurses. The relevant issues during transfer were: 35% of respondents cited medication, 27% cited education and employment, 13% cited disease knowledge, and 25% cited the adult service environment. Our study is still ongoing and, when completed, it will serve as a basis for future large-scale studies to validate our protocol and help to develop evidence-based transition guidelines.

Table 8. Post-transition stage: age 21–26.

- Transition will be completed by age 21
- **Adult Team**
 - i. Assume care of patient as primary team
 - ii. Continue to encourage maintenance of RISE competencies
- **Pediatric Transplant Team**
 - i. Will remain on as ancillary support for the adult team
- **Family**
 - i. Will remain with patient as support
 - ii. Will hand over health care responsibilities to patient
- **Transition Team**
 - i. 6-month post transition assessment
 1. Appointment adherence
 - a. Percentage missed will be measured and recorded
 - b. Reason for missing appointments will be recorded
 - i. Overt (willful)
 - ii. Covert (Forgetfulness or denial)
 - iii. Socio-economic (transport, finances, work-related, etc.)
 2. Medication adherence
 - a. Assessment by:
 - i. Self-report
 - i. Pharmacy refill information (Non-adherence=adherent <75% of time)
 - ii. Continue to monitor long term outcomes
 1. Transition provider survey for treatment, lab and adherence information at baseline, 6, 12 and 24 months
 2. Patient satisfaction survey at baseline and every 6 months
 3. Parent survey on transition at baseline and every 6 months
 - iii. Quality outcome assessment after 3 consecutive adult appointments
 - iv. Ongoing evaluation at 1, 2, 3, and 5 years

Limitations of the Study

Our survey sample size was small, but the study still provides insight into the current state of transition care in the United States. This may not represent the state of transition in other parts of the world. We recognize that there are limitations to our current model. The challenges in implementing the RISE to transition protocol are not realized, as this entails financial burden and mobilization of resources to bring all the services under one roof, especially in freestanding pediatric hospitals. This might be the biggest obstacle in developing countries due to limited resources. Other limitations of the protocol include geographical limitations for patients, physicians, and personnel involved in transition, as well as the time commitment required to complete transition. Our pilot study on implementation of the RISE to transition protocol at our facility is still ongoing and the final results are awaited. The RISE to transition protocol needs to be tested in multicenter and multinational trials before it can be validated for use in the United States and globally.

Conclusions

The transition period is a critical time for pediatric renal transplant patients. This period is complicated by the patient's psychosocial development and increases the chances of high-risk behavior and non-adherence. The current transition care is non-standardized, inconsistent in tool and personnel usage, and lacks effective communication, despite evidence of their utility. Through the use of dedicated clinics and a structured transition protocol, transition of pediatric renal transplant recipients can be improved. Our RISE to transition protocol focuses on 4 key components for a successful transition: Recognition, Insight, Self-Reliance, and Establishment of healthy habits. The implementation of this protocol aims to improve graft survival, rejection rates, adherence rates, quality of life, and other outcomes. The results of our pilot study may serve as a basis for further research and validation of the RISE to transition protocol, which could contribute to the development of evidence-based transition guidelines for pediatric renal transplant recipients.

Conflict of interest

None.

Supplementary Table

Supplementary Table 1. PRISMA 2009 checklist.

Section/topic	#	Checklist item	Reported on page #
TITLE			Page No.
Title	1	Identify the report as a systematic review, meta-analysis, or both	4
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number	2, 3
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known	3, 4
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS)	4
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number	No
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale	5
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched	5
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated	5
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis)	5
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators	5
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made	5
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis	Table 3
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means)	NA
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I ²) for each meta-analysis	NA
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies)	Table 3
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified	NA
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram	6
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations	Table 1

Supplementary Table 1 continued. PRISMA 2009 checklist.

Section/topic	#	Checklist item	Reported on page #
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12)	Table 3
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot	Table 1
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency	NA
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15)	Table 3
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16])	NA
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers)	5, 6 & Table 1
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias)	Table 3
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research	5, 6
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review	24

Moher D, Liberati A, Tetzlaff J, Altman DG, PRISMA Group: Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLoS Med*, 2009; 6(7): e1000097. For more information, visit: www.prisma-statement.org.

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