

# Solid-Organ Transplantation in Childhood: Transitioning to Adult Health Care

## abstract

Pediatric solid-organ transplantation is an increasingly successful treatment for solid-organ failure. With dramatic improvements in patient survival rates over the last several decades, there has been a corresponding emergence of complications attributable to pretransplant factors, transplantation itself, and the management of transplantation with effective immunosuppression. The predominant solid-organ transplantation sequelae are medical and psychosocial. These sequelae have a substantial effect on transition to adult care; as such, hurdles to successful transition of care arise from the patients, their families, and pediatric and adult health care providers. Crucial to successful transitioning is the ongoing development of a sense of autonomy and responsibility for one's own care. In this article we address the barriers to transitioning that occur with long-term survival in pediatric solid-organ transplantation. Although a particular transitioning model is not promoted, practical tools and strategies that contribute to successful transitioning of pediatric patients who have received a transplant are suggested. *Pediatrics* 2011;127:742–753

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### KEY WORDS

organ transplantation, pediatric, adolescent, outcomes, transition, barriers

### ABBREVIATION

QoL—quality of life

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The quandary of how and when to transition young adults from pediatric to adult medical care is a relatively new and exciting one. A little over a generation ago, so few children who had received solid-organ transplants survived past their teen years that a discussion of transitioning was irrelevant. Now, the majority of children with solid-organ transplants grow into adulthood. For example, 90% of patients aged 10 to 19 years who are on dialysis or have had kidney transplants can expect to live beyond their 21st birthdays.<sup>1</sup> Coping with a solid-organ transplant during young adulthood regardless of physical health is challenging. The added burden of transplantation appreciably increases anxiety to already stressed 18- to 24-year olds, for whom the rates of substance abuse, suicide, and mortality are twice those of 12- to 17-year-olds.<sup>2</sup> It is noteworthy that young adult and adolescent transplant recipients have the highest rates of acute rejection, death-censored graft loss, and chronic rejection that leads to graft loss, and nonadherence is a significant contributing factor.<sup>3</sup> It is important to note that although nonadherence represents a barrier to transitioning of the adolescent transplant recipient, accurate assessment of its prevalence is complicated by a lack of precise measures.<sup>4</sup>

Solid organ transplantation, similar to chronic illness, interrupts all aspects of normal development. The psychosocial, educational, and medical consequences of the underlying disease and transplant need to be addressed by pediatric care providers. Transfer to adult care should take place only after the adolescent/young adult has achieved targeted psychosocial, educational, and medical independence (assisted or unassisted).

Despite best efforts of the health care team and of young adults who have had a transplant, transition to adult

care does not always occur as smoothly or successfully as desired. The US Department of Health and Human Services (HHS) identifies transition leading to transfer of care as 1 of 6 primary goals for youth with special health care needs. Such children and their families represent an important underserved population,<sup>5</sup> as highlighted by the 2001 National Survey of Children With Special Health Care Needs, from which the core outcome "transition to adulthood" was reported as having the worst result (only 6% of children in the target population met this goal).<sup>6</sup> Although there are now policy statements and position papers<sup>7-9</sup> that call for a synchronized practical method to prepare young adults who have had a solid-organ transplant for a smooth transfer of medical care, current evidence suggests that many adolescents fail to meet this goal. A common need exists to improve the transition process, because many young adults are ill-equipped to receive care in the adult system. Moreover, adult providers may lack understanding and expertise to care for young adults who had a solid-organ transplant in childhood. In the United States, systems issues, such as inadequate health insurance coverage for 18- to 23-year-olds and a lack of transition services, also impede successful transitioning.

Solid-organ transplantation has become the standard of care and, in most cases, is the treatment of choice for end-stage organ disease.<sup>10</sup> Advances in surgical and organ-preservation techniques, improved immunosuppressive and antiviral regimens, and changes in donor-organ allocation have improved the success rates of solid-organ transplantation.<sup>11-13</sup> Transplantation, in essence, replaces end-stage disease with a more sustainable chronic disease state, and its consequences have substantial clinical and psychosocial

implications. The process of transitioning itself can be mired by complications that result from solid-organ transplantation.<sup>14</sup> The aims of this article are to (1) outline the consequences of solid-organ transplant during childhood and adolescence, (2) detail the hurdles that impede transition to adult care, and (3) provide practical advice for pediatric and adult caregivers to establish effective transition pathways for successful transfer of care.

## MEDICAL CONSEQUENCES

The medical consequences of solid-organ transplantation are related to the transplanted organ, posttransplant therapy, or the original disease, or they may be multifactorial. These consequences may serve to hinder transition of care during young adulthood (see Table 1). The psychosocial aspects of poor growth may have effects on transitioning<sup>15</sup>; short stature can result in negative social experiences.<sup>16</sup> Among adults who receive kidney transplants during childhood, short stature has been associated with less marriage, education, and employment.<sup>17</sup> Treatment with recombinant human growth hormone (rhGH) improves intelligence and psychosocial functioning in parallel with improved growth.<sup>18,19</sup> Indications for the optimal use of rhGH after solid-organ transplantation have been published.<sup>16</sup> Although the cardiovascular data from follow-up of pediatric transplant recipients into adulthood is limited, the multitude of risk factors places additional medical and psychosocial burden on these patients. Chronic kidney disease may occur after all pediatric solid-organ transplantation.<sup>20-23</sup> The etiology is multifactorial, can evolve before, during, or after the transplant, and compounds the development of other complications. Infectious disease is a major source of morbidity and mortality in all forms of pediatric solid-organ transplantation that may hinder timely

**TABLE 1** Medical Consequences of Solid-Organ Transplant and Suggested Interventions to Maximize Ability to Transition to Adult Care

Medical Consequence	Barriers Encountered	Suggested Interventions
Growth (poor catch-up growth, short stature, bone disease) <sup>15-19,24,30,80-82</sup>	Low self-esteem; psychosocial maladjustment	Maximize nutritional support; growth hormone therapy; minimize exposure to steroids; transplantation (especially at young age)
Cardiovascular (hypertension, coronary artery disease, accelerated atherosclerosis, arrhythmias) <sup>93-101</sup>	Low self-esteem; limited physical activity; increased physical symptoms; complex medical regimen (nutrition, lifestyle, medications); complex medical regimen	Minimize exposure to steroids and CNIs; control blood pressure to <75th percentile; dietary and lifestyle guidance and encouragement, minimize exposure to CNIs
Renal (acute, chronic) <sup>20-23,102-111</sup>	Increased physical symptoms; secondary organ failure; increased caregiver dependence (eg, multidisciplinary care)	Avoid CNI toxicity (acute and chronic); control blood pressure to <75th percentile; multiple organ transplantation; avoid ischemic or nephrotoxic injury when possible
Malignancy (PTLD, lymphoma, skin, other carcinoma) <sup>26-28</sup>	Infection; rejection; chemotherapy; complex medical regimen; multidisciplinary care; increased caregiver dependence; school absence	Continue to improve immunosuppressive regimens (CNI-free and steroid-free); low index of suspicion; prompt evaluation and treatment
Metabolic (dyslipidemia, hyperhomocysteinemia, diabetes mellitus, malnutrition) <sup>95-97,99</sup>	Complex medical regimen (lifestyle, diet, medications); insulin requirement; blood glucose monitoring; multidisciplinary care; risky consequences of nonadherence; increased physical symptoms	Multidisciplinary input (eg, dietician); minimize steroid exposure; minimize CNI exposure/toxicity; dietary and lifestyle guidance and encouragement
Infection (viral, bacterial, fungal, opportunistic, polyoma virus [renal treatment]) <sup>25,58,112-118</sup>	Instrumentation and invasive procedures (catheters, tracheostomy); multiple hospitalizations; prolonged hospitalizations; potential need for intensive care; multiorgan damage; allograft injury; PTLD; school absence	Prevention measures; minimize use of thymoglobulin; posttransplant prophylaxis; monitor for leukopenia/neutropenia; monitor viral load; monitor immune cell function; prompt treatment of suspected infection; prompt treatment of suspected PTLD
Neurocognitive <sup>29-34</sup>	Physical; cognitive; emotional; overprotective caregiver	Transplantation; nutrition; learning support; family therapy
Reproductive health (delayed puberty, delayed menarche, impaired fertility) <sup>35-40</sup>	Physical immaturity; cognitive immaturity	Counseling/patient education; adolescent or gynecologic care; increased awareness and training of primary transplant physicians; foster trust and openness in patient-physician relationship; provide confidentiality
QoL <sup>30,41-51</sup>	Physical limitations; cognitive limitations; family; friends; work; independent living	Medical, psychological, and social supports
Nonadherence <sup>36,41,54-56</sup>	Predominant cause of rejection and allograft loss; reduced QoL; loss of caregiver trust; lost sense of autonomy	Open communication with multidisciplinary team (psychologist, social worker, nurse, physician); stepwise patient education (use of images); gradual increases in patient responsibility; frequent assessment of patient comprehension; peer support/mentoring; simplify/tailor medication regimen; use alarms, calendars, and prompts as medication-taking strategies

All transplant recipients experience some adverse medical consequences after transplantation. Some consequences are associated with significant morbidity and, as a result, prevent those steps (ie, cognitive development, understanding of illness, independence, sense of responsibility, self-care) that are essential for successful transitioning to adult programs. In addition, a higher level of morbidity and a more complex posttransplant course may increase the patient's reliance on the family and medical team, increase attachment of the medical team and family to the patient, and decrease the ability of an adult program to adequately meet the needs of the patient. CNI indicates calcineurin inhibitor; PTLD, posttransplant lymphoproliferative disease.

transition.<sup>11,13,24,25</sup> Malignancy is a significant problem faced by pediatric recipients of solid-organ transplants<sup>26,27</sup>; its incidence has demonstrated a linear increase over time from transplant and is extrapolated at ~20% after 10 years.<sup>28</sup>

### NEUROCOGNITIVE CONSEQUENCES

Chronic disease considerably impacts cognitive development in children, particularly infants who are undergoing rapid neurologic growth. Developmental outcomes are influenced by various pretransplant factors such as disease-onset severity and morbidity before and during the transplant.<sup>29,30</sup> After re-

nal transplantation, intelligence levels have consistently been shown to reside in the low-normal range,<sup>29</sup> although most (~70%–80%) patients who have had a renal transplant receive mainstream classroom education. Transplantation has been found to improve deficits present during end-stage renal disease,<sup>30,31</sup> particularly physical growth,\* developmental quotient, and head circumference when measured 1 year after renal transplant.<sup>32</sup> Outcomes in liver transplantation indicate similar developmental delay; children who have had a liver transplant have been shown to have

lower intelligence than healthy children, especially when chronic liver disease occurred during infancy. Preliminary data from an ongoing Functional Outcomes Group study using patients in the Studies of Pediatric Liver Transplantation (SPLIT) registry indicate that full-scale IQ in patients who have had a liver transplant are low to normal.<sup>30</sup> Cardiac transplantation provides substantial developmental improvements, primarily for patients with early correction of cyanotic congenital heart disease.<sup>30</sup> Similar to data from other pediatric transplant populations, children who have undergone

cardiac transplantation have low-normal intelligence, and most of them attend mainstream school programs. However, a small but significant proportion of recipients of cardiac transplants (~10%) have neurologic injury that precludes functional testing.<sup>35</sup> Several studies have reported that cardiac transplant recipients have lower school performance and adaptive/behavioral concerns that include depression and attention problems. These studies also report deficits in measures of daily living, communication, adaptive behavior, and socialization skills.<sup>33,34</sup> Pretransplant morbidity contributes significantly to developmental outcomes. As an example, development is adversely affected in renal transplant recipients who have had hypertensive crises, seizures, or stroke. In heart transplant recipients, the length of hospital stay before transplant, need for cardiopulmonary bypass, embolic events, and circulatory arrest have negative effects on development<sup>30</sup> (see Table 1).

### REPRODUCTIVE HEALTH CONSEQUENCES

Sexual and reproductive health is a crucial component in the care of adolescent patients who have had a transplant. Puberty and menarche may be delayed or disrupted.<sup>35-37</sup> Young men may develop impaired fertility associated with end-stage organ disease that improves after transplantation.<sup>38</sup> Studies that specifically examined a transplant population identified a lower proportion having romantic relationships and sexual activity compared with matched healthy controls or those with chronic disease without organ failure.<sup>39,40</sup> Adolescent transplant recipients may underestimate their fertility or demonstrate a lack of knowledge regarding an increased risk of contracting a sexually transmitted infection because of immunosuppression.<sup>37</sup> Overall, sexually transmitted

infections in adolescent transplant recipients are more difficult to eradicate, and symptoms require immediate empiric treatment.<sup>37</sup> Sexuality and contraception are important topics to broach during the course of routine posttransplantation care of adolescents (see Table 1).

### HEALTH-RELATED QUALITY-OF-LIFE CONSEQUENCES

Transplantation has become a life-saving measure that prolongs the life of the recipient, but it also dramatically affects quality of life (QoL). QoL measurement can be variable and discrepant, depending on the measurement tool used, sample size, and whether the reporter is the child or parent. Self-reports are typically more positive than parental/caregiver reports.<sup>41-43</sup> QoL measures can be confounded according to both internal patient factors (anxiety, depression, cognitive difficulties) and external components such as disease course, medications, available social support, and interaction with the health care community.<sup>42</sup> Solid-organ transplant recipients generally have good long-term psychosocial outcomes with improved QoL in comparison to the pretransplant period and in relation to other patients with chronic disease.<sup>30,42</sup> Regardless, both liver and kidney transplant recipients have reported lower QoL compared with healthy peers.<sup>44,45</sup> Kidney transplant recipients commonly report physical and medication-related complaints, which in turn have been reported to contribute to nonadherence.<sup>42,46</sup> Depression, anxiety, and even frank psychiatric disorder have been reported to occur frequently among pediatric transplant recipients.<sup>47,48</sup> A major issue faced by many transplant recipients is difficulty with school reentry after protracted absence, which often strains peer relationships, dampens self-esteem, and adversely affects overall academic

achievement.<sup>42</sup> Problems with learning, attention, memory, and standardized test achievement often occur,<sup>42,49</sup> and there is a substantial minority of patients who require special educational programs.<sup>30</sup> On the basis of analysis of previous qualitative studies from which adolescent posttransplant experiences were reported, efforts should be focused on providing patients with support for fear, anxiety, low self-esteem, and difficulties with family and peer relationships.<sup>50</sup> Longer-term outcomes in transplant recipients entering adulthood have been examined, and higher rates of unemployment in relation to peers and stalled transition to independent living were reported<sup>17,51</sup> (see Table 1).

### NONADHERENCE CONSEQUENCES

Solid-organ transplantation requires lifelong treatment with complex medication regimens and multidisciplinary health care. A recent consensus report<sup>7</sup> on transitioning adolescent transplant recipients to adult care alluded to transitioning outcomes as "central to quality assurance." The authors called for a systematic approach to ensure the collection of data after the transfer. Previous reports suggested a consistent correlation between adolescent allograft loss and nonadherence<sup>52</sup>; as a result, nonadherence during transitioning may be a significant risk factor for allograft loss.<sup>53</sup> Although a majority of adolescent transplant recipients adhere to the prescribed posttransplant regimen, nonadherence is common<sup>36,54,55</sup> and may be a predominant cause of allograft rejection.<sup>36,41,54-56</sup> Nonadherence presents a substantial impediment to transitioning primarily by virtue of its adverse effect on transplant outcomes and QoL.<sup>54,56</sup> There are limited data on outcomes after transitioning that presently demonstrate contradictory results. Specifically, data from the Scientific Registry of Transplant

Recipients/Organ Procurement and Transplantation Network suggest that patient transfer is not associated with increase in allograft loss.<sup>53</sup> However, a retrospective review of 14 liver transplant recipients demonstrated a significant decrease in adherence to tacrolimus therapy (as measured by serum levels) after transition.<sup>52</sup> Another study of 20 adolescent patients transitioned after renal transplantation showed that allograft loss occurred in 8 patients, 7 of which (35%) were unexpected.<sup>57</sup> However, data from a larger cohort of renal transplant recipients recently indicated that there was no increase in allograft loss after transition to adult care.<sup>14</sup> These data highlight the need for further research into both nonadherence during transitioning and its effect on outcomes of transplant recipients after transition.

### **TRANSITIONING TO ADULT CARE**

Transitioning, according to the American Society for Adolescent Medicine, refers to the "purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems."<sup>59,60</sup> Transition to adult care should be gradual and continue until transfer. The complications that affect transplant recipients both in the short-term and long-term can result in a range of disability and chronic illness. The sequelae of transplantation that have been discussed can impede the normal processes of physical, sexual, cognitive, and psychosocial development.<sup>61</sup> The emergence of a sense of autonomy is crucial to successful transitioning, yet it is vulnerable to a multitude of potential posttransplant insults that can delay or prevent its occurrence. The more complicated the posttransplant course, and the greater the reliance of patients on medications, surgical interventions,

medical technology, pediatric practitioners, and caregivers, the more difficult it is to become independent or even to understand that independence is achievable.<sup>58</sup> Moreover, there are risks external to the patient, including overprotectiveness of caregivers, difficulty that the pediatric practitioner encounters in relinquishing care, and the reluctance of busy adult practitioners to take on the complex management issues that the young adult transplant recipient requires.<sup>61</sup> Posttransplant complications occur in all patients and require that transitioning be established as a gradual process over the course of years. Additionally, there should be flexibility within the health care system to allow for delays or changes in transfer of care, particularly during periods of acute illness.<sup>41</sup> Ultimately, transitioning barriers, especially lack of progress toward independence, should be detected early and minimized; the goal should be successful transfer between the ages of 18 and 23 years.

### **OVERCOMING HURDLES TO EFFECTIVE TRANSITIONING TO ADULT CARE**

Barriers to transition from pediatric to adult care traditionally emerge from 4 sources<sup>62</sup>: the patient; the family; the pediatric caregiver; and the adult caregiver.

Barriers to transition for the pediatric patient can be viewed according to the child's age at diagnosis. Chronic illness often leads to isolation, anxiety, depression, helplessness, shyness, and dependence. The earlier the diagnosis, the more dependent the child may be on his or her parents/guardians, which impinges on normal development. Chronic illness often disrupts the normal progression of developmental tasks associated with school-aged children.<sup>63</sup> Many adolescents

with chronic conditions are at a higher risk than their peers for unnecessary dependency, developmental difficulties, and psychosocial delay.<sup>64</sup>

A child's development occurs in stages, and many believe that a child must move through each stage successfully to reach his or her next developmental phase. Children with chronic illness may fail to do this successfully; many exhibit developmental delay. As children grow and experience the world around them, they develop a sense of autonomy, purpose, and competence, which leads to personal development in adolescence and young adulthood.

Through social interactions, young children develop a sense of pride in their accomplishments and abilities. Adult/parental encouragement is crucial for children to establish a feeling of competence and belief in themselves. During adolescence, children explore their independence and gain an identity. Those who receive encouragement and reinforcement through personal exploration develop a strong sense of self and feeling of control and independence.<sup>65</sup> Denial is a common coping strategy of children with chronic and life-threatening illness<sup>66</sup> and often leads to refusal to cooperate in necessary treatments. Allowing greater control in children's self-care and, consequently, their illness may have positive effects on their self-esteem and acceptance of their disease<sup>67</sup> (Table 2).

Many young adults personalize transition as a form of rejection. The transitioning young adult will likely have fears of anonymity, unfamiliarity, and insecurity about his or her new transplant program. The pediatric team can help the transitioning patient recognize that his or her best interest demands adult care when age appropriate. The pediatric team should

**TABLE 2** The Pediatric Patient

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Prepare the child to be responsible for his or her own health.
Begin at an early age to teach the child about his or her disease in concrete terms that can become more detailed as the child matures.
Encourage school attendance to give the child a sense of normalcy.
Address issues of fear and anxiety as soon as possible.
Ensure availability of mental health resources for the family.
Include choice of adult centers for transition.

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reassure the patient that all medical records and a complete medical and psychosocial summary will be sent before transitioning to the new adult providers; that designated point persons from each program will review the patient information; and that communication between the pediatric and adult team will continue after the transition as long as is needed. When transition is addressed regularly from the onset of disease by the pediatric team, these fears should be easier to alleviate. An interview between the social worker and adolescent to help guide the choice of adult transplant program and provider serves the same purpose as the student meeting with the high school guidance counselor to guide postgraduation plans. The pediatric social worker can determine the importance of the new provider's proximity to home, availability and types of transportation, insurance eligibility, appointment schedules, size of transplant program, and the expertise of the multidisciplinary facility.

The family is the most crucial system for the well-being of chronically ill children. The physical and emotional demands placed on caregivers of these children are immense. Time allotted to medical treatments at home frequently changes the dynamics of family life and places stress on parents, siblings, and the ill child. Parents of a child with chronic illness often have a

profound sense of loss and guilt. Acceptance of the impaired child rather than the idealized healthy child and future that every new parent envisions can take years and may never be complete.<sup>68</sup> The endless worry of monitoring a child's condition and being responsible for reporting symptom changes that could have major health implications takes its toll on caregivers.<sup>69</sup>

In an effort to protect their chronically ill child, many caregivers become over-protective and obstruct the development of the child's competency, sense of self, and independence. Sometimes parents of children with chronic illness have low expectations regarding the child's future employment and education.<sup>70,71</sup> The caregiver may have difficulty ceding control to their child for fear of medical consequences if their involvement lessens, which inadvertently gives children fewer opportunities to learn how to make autonomous choices and accept the consequences. For the most part, caregivers have invested time and energy in keeping their child as healthy as possible at the expense of daily family life. There are interruptions in school, family vacations, time spent with other siblings, and family events/traditions and changes in financial status. Most caregivers have developed a trusting relationship with the child's pediatric medical provider and staff. Leaving the hospital for adult care can seem like abandonment for many caregivers, and caregivers can actually sabotage efforts to transition the child. A transition program that supports the child's growth toward independence in care may help the parents/caregivers relinquish some of their control and encourage the child's development (Table 3).

The pediatric provider has an enormous investment in his or her patients. While in the pediatric care center, pa-

**TABLE 3** The Family

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Educate the child about his or her disease and treatment plan.
Encourage the child's inclusion in care from an early age.
Encourage independence in care as the child matures.
Facilitate education and communication between the family and medical staff.
Stress the need for a primary care physician.
Encourage financial counseling.
Provide education about issues of privacy and confidentiality.
Ensure availability of mental health resources for the family/siblings.
Include the family in making the choice of adult centers for transition.

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tients and families receive many supportive services that are not available in adult health care. Pediatric providers often place much of the responsibility of health care on the parents rather than patients for the same reasons as caregivers: fear of medical consequences if the parents' involvement lessens. Fear that their patient will be lost in the masses motivates many pediatricians to keep their patients longer than they should, which results in potential detriment to the patients' physical and emotional health. In addition, transitioning can be disrupted by the pediatrician's perception that the patient will not receive the same care from the adult provider as he or she has provided the patient.<sup>72</sup> It is unfortunate that, in some cases, the longer the pediatrician hangs on, the more difficult the transition often becomes (Table 4).

The adult provider may find it difficult to meet the psychosocial needs of young adults with transplants. Most adult providers lack training in the developmental and behavioral aspects of adolescent medicine, which makes it difficult for them to deal with these young patients.<sup>73</sup> The immaturity of some young adult patients presents multiple problems to adult providers, including the patients' readiness to assume decision-making responsibility,

**TABLE 4** The Pediatric Health Care Provider

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Institute a practice-wide transition policy.

Educate the child and parent(s) about the disease and treatment plan.

Educate the caregiver about child cognitive and psychosocial development.

Prepare the patient and caregiver(s) early for transition by giving small tasks to the patient to increase his or her independence.

Encourage patient involvement in care to increase ownership of his or her health care/condition.

Suggest that caregivers move into the role of coach.

Speak with patients alone after a certain age (early adolescence is suggested).

Discuss health care proxy and advanced directives at the age of 18 y.

Discuss confidentiality in regards to the patient's medical and mental health information.

Determine the patient's competency in making medical decisions.

Discuss insurance and financial issues.

Coordinate with other pediatric specialty care providers.

Designate someone from the health care team who, together with the patient and family, take responsibility for the transition process.

Develop Grand Rounds and joint conferences that include adult transplant providers in the area.

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their significant dependency needs, and their expectations for care.<sup>73</sup> Parents are frequently reluctant to let their young adult make decisions, are overly protective, and feel excluded from their adult child's care.<sup>73</sup> Treatment practices often differ between pediatric and adult providers. Pediatric providers are perceived to be more supportive and offer family-centered care that has a more psychosocial approach. Adult practices are centered more on disease, which effects how relationships are built between the patient and provider.<sup>72</sup> In addition, adult practices may not have trained ancillary staff or resources to help with young adult issues that are readily available in the pediatric practices. This lack of available resources is further complicated by the finding that pediatricians tend to transition nonadherent patients and patients with oppositional behavior earlier than their compliant patients<sup>60</sup> (Table 5).

**TABLE 5** The Adult Health Care Provider

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Designate someone from the adult health care team as a liaison who will take responsibility for the patient's transition process.

Encourage collaborative partnerships and transition-specific programs between pediatric and adult health care providers.

Obtain training in the developmental and behavioral aspects of adolescent medicine.

Increase the frequency of clinic appointments after the transition.

Stress the need for an adult primary care provider.

Provide the patient and family with all pertinent information regarding the new transplant program.

Provide the patient with a tour of the new facility.

Provide designated young adult transplant clinic days.

Advocate to provide uninterrupted insurance coverage for all young adults.

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### SYSTEMS ISSUES AND TRANSITION OF CARE

The success of transitioning depends heavily on the health care system in which it takes place. It is clear that without a definitive model for coordination of transition from pediatric to adult services, no orderly procedures can exist, and the process may fail despite the readiness of the patient to transfer care.<sup>74</sup> As an example, the transition process can be stalled when records are difficult to obtain or when patients who require more than 1 specialty care provider have difficulty coordinating services. Transitioning of young adults with chronic diseases can be further challenged by differences in perceptions of patient needs and concerns between pediatric and adult practitioners and by distrust of the pediatric practitioner toward the receiving adult practitioner and health system.<sup>75</sup> Transitioning clinics have been established in an attempt to provide smoother transfer of care into adult programs and, in some cases, even consist of collaborative adolescent/adult clinics staffed with both pediatric and adult transplant practitioners and ancillary staff. Such clinics can provide transitioning patients with

role-modeling and mentoring and may even enhance adherence.<sup>76</sup>

The financial aspects of medical care can complicate transitioning profoundly. Until recently, children's private health insurance that was linked to their parents' insurance usually ended between the ages of 18 and 23 years. Eligibility requirements for Medicaid programs either through Supplemental Security Income (SSI) or through chronic illness programs become more stringent after the age of 18 years.<sup>72,73</sup> Loss of health care coverage has been shown to be a predictor of allograft loss in the pediatric kidney transplant population.<sup>77</sup> Conversely, extension of coverage for immunosuppression in renal transplant recipients results in improved graft and survival outcomes.<sup>78</sup> The provision of adequate health care coverage should be a major goal for young adult transplant recipients, particularly during the vulnerable period of transitioning care.<sup>79</sup>

### CONCLUSIONS

The majority of children with solid-organ transplants now enter adulthood, which is why many pediatric settings have proposed and implemented transition models. Nevertheless, current evidence suggests that many young adults do not have a smooth transfer of care. This article was written to help identify confounding health consequences related to chronic illness and transplant, identify hurdles to successful transition, and provide practical advice to pediatric and adult health care providers (Table 6). Transitioning is a gradual process and should commence well in advance of the anticipated transfer of care. The transition program should be designed to help young people take responsibility for their own health care and provide tools to support the transition. Tools need to be developed that can be used, measured, and assessed

**TABLE 6** Proposed Age-Appropriate Roles for the Transplant Patient, Parent(s), and Pediatric and Adult Staff for the Successful Transition of Care<sup>41,119</sup>

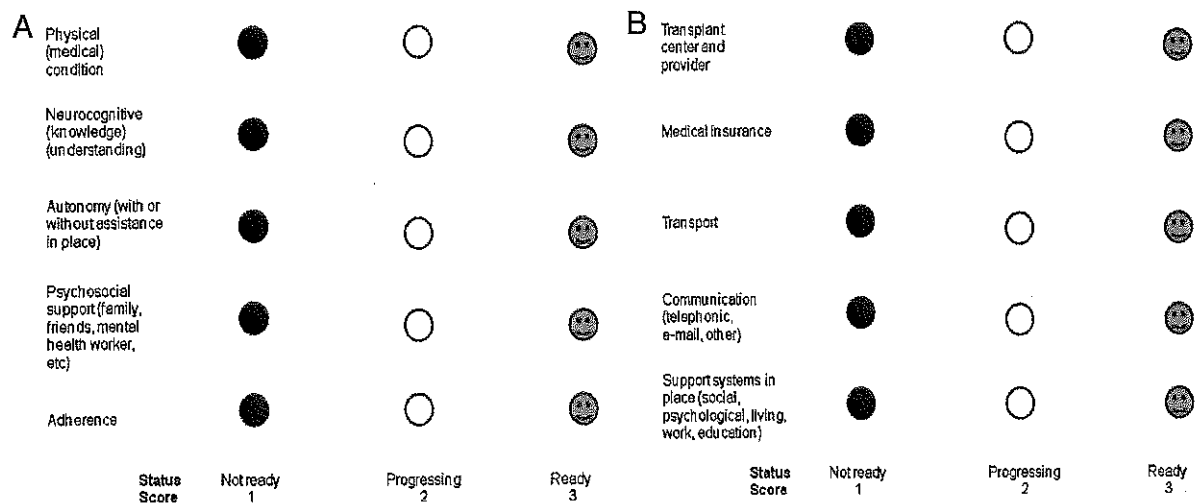
Roles	Childhood/Before Transplant/Early Posttransplant Period (Months)	Preteen Period/Early Adolescence	Adolescence/Young Adulthood
Patient	Learning: medical condition; need for treatment; need for medication; need for frequent follow-up	Increasing knowledge/responsibility: medication list; medication adverse effects; indications for medications; reasons for urgent care; awareness of medical consequences of treatment	Providing self-care: recite medications/indications; call for appointments/refills; identify/call for urgent concerns; effectively communicate health concerns; take medications on own; anticipate/accept eventual need for transfer of care
Parent	Learning: indications for medication; reasons for urgent care; potential medical consequences; medication adverse effects	Transition to supervisory role	Allow for autonomy of patient; allow for patient confidentiality; open communication
Pediatric transplant staff	Teaching/providing support: use of learning material (picture, video); reinforcement of key principles of care; identify barriers; identify systems problems; provide necessary support <sup>a</sup> ; encourage patient awareness/involvement	Ongoing teaching; provide techniques for increasing knowledge and adherence; reinforce key principles of care; identify barriers (medical, psychosocial, neurocognitive); identify systems problems; provide necessary support <sup>a</sup> ; encourage patient awareness/involvement	Discuss sexuality; ensure confidentiality; assess patient understanding and adherence; identify adult practitioners; communicate with adult programs; identify barriers (medical, psychosocial, neurocognitive); identify systems problems; provide necessary support <sup>a</sup> ; accept need for patient transfer despite close attachment; provide adult program with patient information/documentation; be available for questions during transitioning process and transfer of care
Adult transplant staff	Not yet involved	Not yet involved	Communicate with pediatric transplant staff; offer initial meeting/site visit; offer extended first visit; obtain necessary patient information; provide ongoing support when needed; consider involvement in joint-transitioning clinic

<sup>a</sup> Providing support may require referral to staff psychologist or social worker, close interaction with the patient's school or guidance counselor, using various support from family members, friends, or the community, and providing opportunities for peer support and mentoring (eg, transplant camps, etc).

for effectiveness of the transition process (Fig 1). From the time of diagnosis, it is important to stress to both the pediatric patient and family that the illness cannot be what defines the patient. Patients must be given the oppor-

tunity by their caregivers and pediatric providers to develop a sense of autonomy, purpose, and competence by participating in their care from the onset of diagnosis in developmentally appropriate ways. The end result should be a

patient who has developed a strong sense of self and a feeling of independence and control at the time of transition. The transition from pediatric to adult provider then takes on the same meaning as other normal transitions

**FIGURE 1**

A, Pediatric Transition Readiness Score (PTRS); B, Pediatric Acceptance Readiness Score (PARS). The transition program should be designed to help young people take responsibility for their own health care and provide tools to support the transition. Tools need to be developed that can be used, measured, and assessed for effectiveness of the transition process.



that occur in a person's life, such as graduating high school or college, starting a job, and beginning to live independently.

Partnerships between the pediatric and adult providers that serve to increase understanding of the medical

and psychosocial consequences of the young adult's underlying disease and transplant, and which support continuity of care during transition, will help to achieve the goal of collaborative, coordinated, and integrated services. Furthermore, comprehensive

health insurance that better serves this population of young adults is imperative. Development of widely applicable transition pathways will facilitate greater success in the passage of children with a solid-organ transplant from pediatric to adult care.

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