



Transition of the Adolescent Transplant Patient to Adult Care

Emily M. Fredericks Ph.D.,^{*,†} and M. James Lopez M.D., Ph.D.[‡]

Pediatric liver transplant recipients are surviving into adulthood at increasing rates, so attention is being focused on long-term outcomes, including the transition from pediatric transplant care to adult-centered transplant care.¹ The transition process can be a challenging phase for patients, families, and providers.² However, a routine assessment of transition readiness may lead to the early identification and remediation of potential barriers related to medical stability, regimen adherence, psychosocial functioning, insurance coverage, transportation, and the availability of an adult provider. Transition planning should be an integral component of the care of a pediatric transplant recipient.

Transition Versus Transfer

Transition is an active process that addresses the medical, psychosocial, and educational/vocational needs of adolescents as they prepare to move from child-centered health care to adult-centered health care, whereas *transfer* refers to changes in health care providers, clinic locations, or both.³ The transition process includes a shift of responsibility for health care tasks from the parent to the patient as well as preparation for the transfer to adult-centered care (Fig. 1). During adolescence, the management of a chronic illness typically shifts from a primarily parental responsibility to more independent self-management by the adolescent.⁵ According to a shared management model, during the late transition phase, the adolescent is the primary manager of health care responsibilities, whereas the parent's role shifts to consultancy.^{4,5} The actual transfer to an adult clinic is an important milestone, but this does not mark the end of the transition process. Rather, the adolescent/young adult continues to improve self-management skills after the transfer to adult care.

Nonadherence and Transition

The transfer to adult-centered transplant care is often associated with increased graft loss and mortality.⁶ However, graft loss during this period may be related to medication nonadherence rather than the transfer of care.⁷ Medication nonadherence is common among adolescent and young adult transplant recipients, and this is a particular concern as these recipients prepare to transfer their care to new providers within an adult clinic.^{4,8,9} Adolescence is a critical period for the establishment of both positive and risky life-long health-related behaviors. The developmental characteristics associated with adolescence, including the development of autonomy from family, assimilation with peers and separation from parents, and poorly developed abstract thinking and understanding of the long-term consequences of present actions, are often difficult to balance with the behaviors required for optimal medication adherence.¹⁰ Thus, it is recommended that pediatric providers have a strategy for assessing and promoting self-management skills to foster adherence in adolescent transplant recipients during the transition process.^{2,4,11,12}

Determining Readiness to Transfer Care

To date, there is not a universally accepted definition of a successful transition or transfer, nor are there standard guidelines regarding a patient's readiness to transfer care. Ideally, before transferring to adult-centered care, the adolescent should be able to describe his or her health condition, demonstrate responsibility for health management tasks, and have the capacity to independently manage his or her health care needs (Table 1).^{2,11} In adult care settings,

From the ^{*}Division of Child Behavioral Health; [†]Child Health Evaluation and Research Unit; and [‡]Division of Pediatric Gastroenterology, Department of Pediatrics and Communicable Diseases, University of Michigan, Ann Arbor, MI

The authors' work in pediatric liver transplantation is supported by the National Institutes of Health/National Institute of Diabetes and Digestive and Kidney Diseases (award K23 DK090202-02).

Potential conflict of interest: Nothing to report.

View this article online at wileyonlinelibrary.com

© 2013 by the American Association for the Study of Liver Diseases

doi: 10.1002/cld.243

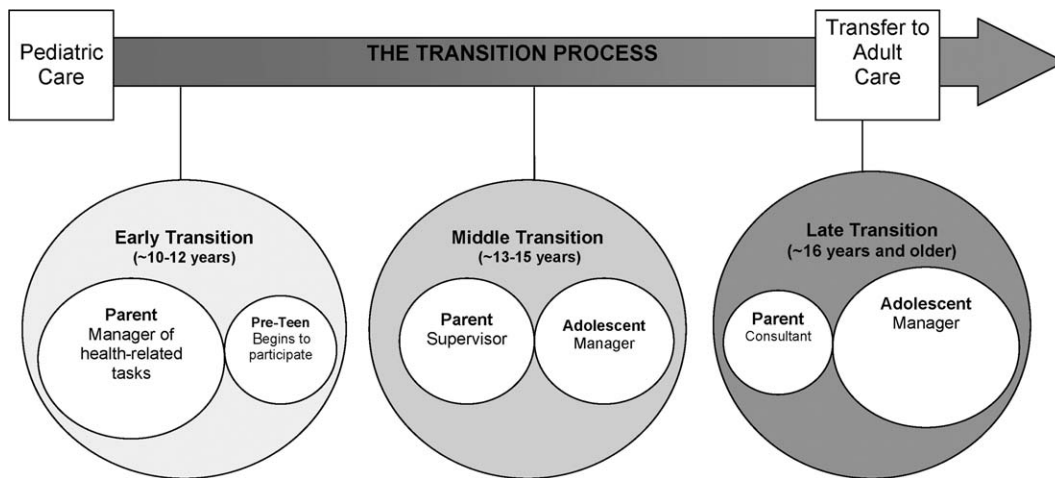


FIGURE 1 Transition process: the transition of responsibility for health management tasks and the transition from pediatric care to adult-centered care. Adapted with permission from *Pediatric Transplantation*.⁴ Copyright 2010, John Wiley & Sons, Inc.

TABLE 1 Recommended Tasks to Achieve Before the Transfer of Care

1. Understanding of and ability to describe the original cause of organ failure and the subsequent need for liver transplantation
2. Ability to describe long- and short-term implications of liver transplantation for overall health and other aspects of life
3. Demonstration of knowledge related to medications, including names, dose, function, timing, and side effects
4. Comprehension of the impact of illness/transplant on reproductive health and sexuality
5. Demonstration of responsibility for own health care, including management of medications and appointments
6. Ownership of medical information in a concise, portable medical summary
7. Adequate insurance coverage
8. Identification of a primary care provider
9. Expressed future goals, including academic/vocational aspirations
10. Stable emotional functioning and/or adequate mental health resources

This table has been adapted from *American Journal of Transplantation*.¹¹ Copyright 2008, American Society of Transplantation and American Society of Transplant Surgeons.

patients are expected to independently discuss medical care with providers, schedule and attend appointments, refill prescriptions, and adhere to medications and treatment recommendations.¹³ Thus, transition programs should encourage adolescent recipients to practice engaging in these behaviors before the transfer of care.

Because of the potential challenges associated with transition, it is recommended that pediatric transplant programs designate a health care provider to collaborate with patients and families in developing transition plans.¹¹ Most often, nurse practitioners take the responsibility for overseeing the transfer to adult care.¹⁴ However, pediatric and adult clinical transplant coordinators have an important role in the transition process, and they are equipped to take primary roles in transitional care programming. Clinical transplant coordinators can assist patients and families during the transition process, and they can serve as liaisons with adult transplant teams by facilitating the transfer of medical information.¹¹

In a recent survey, pediatric and adult liver transplant coordinators identified patients' knowledge of medications, independence and responsibility for medications, and adherence as important components of transition.¹⁵ Moreover, communication between pediatric and adult providers, including the transfer of information related to a patient's medical and psychosocial history, was considered to be critical in transition planning. The majority of clinical transplant coordinators believed that a standardized process would be beneficial in promoting self-management skills and responsibility for health care. Further work is necessary to define a successful transition and to identify key elements of transition programming.

Additional Considerations

There are disease-specific issues—particularly those that may lead to disease recurrence or have developmental considerations—that should be considered during the transition



process. Medication adherence is certainly important for all pediatric liver transplant recipients. However, for those with autoimmune hepatitis, for example, optimal medication adherence is essential and should be a key component of transition preparation. As with all recipients, barriers to medication adherence should be assessed and handled as part of routine clinical care. In addition, for the subset of pediatric liver transplant recipients who may have recurrent disease, such as those with primary sclerosing cholangitis, communication about disease activity and stability should occur with the receiving adult transplant team to ensure continuity of care.¹⁶

Anecdotally, patients who receive their transplant during adolescence appear to be at higher risk for poor health outcomes, and this is potentially due to the challenges associated with the adolescent developmental period. For this subset of patients, the promotion of regimen knowledge and self-management skills should be an area of emphasis, particularly with respect to the risk of disease recurrence.

Similarly, additional consideration should be given to pediatric liver transplant recipients with diseases associated with developmental delay, such as ornithine transcarbamylase (OTC) deficiency. Adolescent transplant recipients with significant emotional and cognitive delays may need additional support during the transition process, yet they should be given the opportunity to increase their independence and self-management skills to reach their optimal potential.¹⁷ Adolescents with developmental delays may not have the capacity to fully manage their health care independently and may require guardianship and continued parental support after the transfer to adult care. An assessment of these issues should occur during transition preparation and planning. These factors underscore the importance of the fact that the decision to transfer to adult care is multifactorial and should not be based on age alone.

Transition Resources

There are numerous practical tools available to pediatric providers to assist with health care transitions.¹⁸ A relatively

recent report outlines practice guidelines to support the transition from adolescence to adulthood within a medical home.¹⁹ This clinical report provides an algorithm to aid in transition decision making and includes timelines and checklists for pediatric providers. There are an increasing number of downloadable resources available to provide a framework for preparing pediatric patients and their families for the transfer to adult care. The National Health Care Transition Center developed the Six Core Elements of Health Care Transition, which includes detailed action items for the pediatric health care setting. Pediatric providers can download individual tools from the “Got Transition?” Web site²⁰ to assist with transition planning, transition preparation, and the transfer of care. The American Society of Transplantation Pediatric Community of Practice Joint Transition Work Group published a Web-based transition resource that is publicly available.²¹ In addition, there are psychometrically sound measures for assessing transition readiness, the allocation of responsibility for health management tasks, and self-management skills, which may be useful in developing interventions and programs to promote transition readiness.^{2,4,22-24}

Summary

The transition from pediatric transplant care to adult-centered transplant care has received increased attention because more pediatric liver transplant recipients are surviving into adulthood. Routine and standardized assessments of transition readiness may help in identifying a high-risk population for interventions both before and after the transfer to adult care. There remains a need for the development of evidence-based practices to guide the transition process and to identify predictors of successful outcomes.

CORRESPONDENCE

Emily M. Fredericks, Ph.D., Department of Pediatrics and Communicable Diseases, University of Michigan, 300 North Ingalls Street, Room 6E07, Ann Arbor, MI 48109-5456. E-mail: emfred@med.umich.edu.

References

1. Ng VL, Alonso EM, Bucuvalas JC, Cohen G, Limbers CA, Varni JW, et al.; for Studies of Pediatric Liver Transplantation (SPLIT) Research Group. Health status of children alive 10 years after pediatric liver transplantation performed in the US and Canada: report of the Studies of Pediatric Liver Transplantation experience. *J Pediatr* 2012;160:820-826.
2. LaRosa C, Glah C, Baluarte HJ, Meyers KE. Solid-organ transplantation in childhood: transitioning to adult health care. *Pediatrics* 2011;127:742-753.
3. Kennedy A, Sawyer S. Transition from pediatric to adult services: are we getting it right? *Curr Opin Pediatr* 2008;20:403-409.
4. Fredericks EM, Dore-Stites D, Well A, Magee JC, Freed GL, Shieck V, et al. Assessment of transition readiness skills and adherence in pediatric liver transplant recipients. *Pediatr Transplant* 2010;14:944-953.
5. Kieckhefer GM, Trahms CM. Supporting development of children with chronic conditions: from compliance toward shared management. *Pediatr Nurs* 2000;26:354-363.
6. Annunziato RA, Emre S, Shneider B, Barton C, Dugan CA, Shemesh E. Adherence and medical outcomes in pediatric liver transplant recipients who transition to adult services. *Pediatr Transplant* 2007;11:608-614.
7. Magee JC, Thomas SE, Fredericks EM, Guidinger MK, Port FK, Kalbfleisch JD, et al. Effect of recipient age and “transition” on graft loss in pediatric transplant recipients [abstract]. *Am J Transplant* 2006;6(suppl 2):214.
8. Dobbels F, Van Damme-Lombaert R, Vanhaecke J, De Geest S. Growing pains: non-adherence with the immunosuppressive regimen in adolescent transplant recipients. *Pediatr Transplant* 2005;9:381-390.
9. Shemesh E, Shneider BL, Savitzky JK, Arnott L, Gondolesi GE, Krieger NR, et al. Medication adherence in pediatric and adolescent liver transplant recipients. *Pediatrics* 2004;113:825-832.
10. Suris JC, Michaud PA, Viner R. The adolescent with a chronic condition. Part I: developmental issues. *Arch Dis Child* 2004;89:938-942.
11. Bell LE, Bartosh SM, Davis CL, Dobbels F, Al-Uzri A, Lotstein D, et al. Adolescent transition to adult care in solid organ transplantation: a consensus conference report. *Am J Transplant* 2008;8:2230-2242.



12. Annunziato RA, Parkar S, Dugan CA, Barsade S, Arnon R, Miloh T, et al. Brief report: deficits in health care management skills among adolescent and young adult liver transplant recipients transitioning to adult care settings. *J Pediatr Psychol* 2011;36:155-159.
13. Kennedy A, Sloman F, Douglass JA, Sawyer SM. Young people with chronic illness: the approach to transition. *Int Med J* 2007;37:555-560.
14. Betz CL, Redcay G. Dimensions of the transition service coordinator role. *J Spec Pediatr Nurs* 2005;10:49-59.
15. Lerret SM, Menendez J, Weckwerth J, Lokar J, Mitchell J, Alonso EM. Essential components of transition to adult transplant services: the transplant coordinators' perspective. *Prog Transplant* 2012;22:252-258.
16. Chapman R, Fevery J, Kalloo A, Nagorney DM, Boberg KM, Shneider B, et al. Diagnosis and management of primary sclerosing cholangitis. *Hepatology* 2010;51:660-678.
17. Kaufman M. Transition of cognitively delayed adolescent organ transplant recipients to adult care. *Pediatr Transplant* 2006;10:413-417.
18. Lemly DC, Weitzman ER, O'Hare K. Advancing healthcare transitions in the medical home: tools for providers, families and adolescents with special healthcare needs. *Curr Opin Pediatr* 2013;25:439-446.
19. American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, Transitions Clinical Report Authoring Group, Cooley WC, Sagerman PJ. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics* 2011;128:182-200.
20. National Health Care Transition Center. Got transition? <http://www.gottransition.org>. Accessed July 2013.
21. American Society of Transplantation. AST PCOP: Web resources on transition to adult care. <http://www.a-s-t.org/content/ast-pcop-web-resources-transition-adult-care>. Accessed July 2013.
22. Gilleland J, Amaral S, Mee L, Blount R. Getting ready to leave: transition readiness in adolescent kidney transplant recipients. *J Pediatr Psychol* 2012;37:85-96.
23. Ferris ME, Harward DH, Bickford K, Layton JB, Ferris MT, Hogan SL, et al. A clinical tool to measure the components of health-care transition from pediatric care to adult care: the UNC TR(x)ANSITION scale. *Ren Fail* 2012;34:744-753.
24. Sawicki GS, Lukens-Bull K, Yin X, Demars N, Huang IC, Livingood W, et al. Measuring the transition readiness of youth with special healthcare needs: validation of the TRAQ—Transition Readiness Assessment Questionnaire. *J Pediatr Psychol* 2011;36:160-171.