



STATE OF ART

Transitioning from pediatric to adult care after thoracic transplantation

Adam Putschoegl, DO,^a Anne I. Dipchand, MD,^b
Heather Ross, MD, MHsc, FRCPC, FCCS, FACC,^c Cecilia Chaparro, MD,^d and
Jonathan N. Johnson, MD, FACC, FASE, FAAP^{a,e}

From the ^aDivision of Pediatric Cardiology, Department of Pediatrics, Mayo Clinic, Rochester, Minnesota; ^bLabatt Family Heart Centre, Department of Pediatrics, The Hospital for Sick Children, Toronto, Ontario, Canada; ^cDivision of Cardiology, Department of Medicine, University Health Network, Toronto, Ontario, Canada; ^dDivision of Respiriology, Department of Medicine, University of Toronto, Toronto, Ontario, Canada; and the ^eDepartment of Cardiovascular Diseases, Mayo Clinic, Rochester, Minnesota.

KEYWORDS:

thoracic
transplantation;
heart transplantation;
lung transplantation;
transition;
adolescence;
adherence;
rejection

With improving outcomes after thoracic transplantation, more children are surviving to adulthood and requiring specialized adult care. A systematic and effective program is essential to transition these patients from a pediatric to adult health care setting. In this review, we discuss the concept of transition and the factors leading to an effective transfer to an adult care provider, including administrative support, patient/provider preparation, and the navigation of potential barriers. Notably, there is a paucity of data for many details of transition, making this a significant opportunity for future research.

J Heart Lung Transplant ■■■■;■:■■■-■■■

© 2017 International Society for Heart and Lung Transplantation. All rights reserved.

Since the first pediatric heart transplant was performed in 1967, > 11,000 thoracic transplants in children have been reported.¹ Numerous medical advances have allowed for improved survival of patients who undergo transplantation.¹ As with all children with chronic disease who survive into adulthood, transition from pediatric to adult providers can prove challenging. This review discusses challenges for heart and lung transplant recipients as they transition from pediatric to adult providers and provides guidance for an effective transition program. For this article, we define transition as a “purposeful, planned process that addresses the medical, psychological, and educational needs of adolescents and young adults with chronic physical and

medical conditions as they move from child-centered to adult-oriented healthcare systems.”²

Why is transition important?

Transitional care exists because although transplantation rates have been relatively stable, graft survival has improved with more children surviving to adulthood.¹ However, medium-term graft losses for adolescent and young adult transplant recipients are worse than for all other age groups (except for adults > 65 years old), mostly as a result of poor adherence, which is nearly universally present.^{3,4} We were unable to identify any articles that systematically examined outcomes of transition programs specific to pediatric cardiac or lung transplant recipients. However, this topic has been evaluated in other chronic diseases with clear benefits.^{5,6} Alternatively, when transition is not done effectively, studies show a decline in attendance to medical follow-ups to adult-centered clinics, with increased morbidity.^{7,8}

Reprint requests: Jonathan N. Johnson, MD, FACC, FASE, FAAP, Mayo Clinic, Gonda 6-138SW, First Street SW, Rochester, MN 55905. Telephone: 507-266-0676. Fax: 507-284-3968.

E-mail address: johnson.jonathan@mayo.edu

Are we transitioning?

The evidence suggests that transition programs are in their infancy. A survey of US transplant practices showed that >50% of programs transition their adolescent patients to an adult heart transplant program.⁴ This is not universal, with some pediatric centers continuing to follow adult patients post-transplant.⁴ Another review showed that only 47% of young adults with congenital heart disease were successfully transferred to adult care.⁹ It is estimated that there are approximately 250 adolescents per year worldwide who have had a prior heart transplants, will reach the age of 16, and begin transition.¹ Additionally, there were approximately 1,000 children 16 to 18 years old who underwent transplantation between 2000 and 2015.¹ These numbers emphasize the magnitude of work and preparation required to achieve a well-structured and effective transition program.

Factors specific to pediatric thoracic transplant recipients

Thoracic transplant recipients need regular visits with myriad health care providers. In some cases, patients may undergo multiple interventions early in their lifetime, necessitating long-term medication management and numerous follow-up visits with their health care team.¹⁰ A good example is patients who receive lung or lung-heart transplantation because of cystic fibrosis. Cystic fibrosis is a multisystem disease requiring periodic visits and treatments for extra-thoracic organ involvement. In these situations, patients will require a double transition: both to the adult transplant program and to the specific disease program (e.g., cystic fibrosis program). Conversely, a previously healthy adolescent may present suddenly and ultimately require transplantation. For these patients, this is an enormous change, and they have to learn how to manage a chronic medical condition, including medications, physician appointments, and recurring laboratory tests or imaging scans.

Timing of transition

Transition is not a single point in time. It is a process that involves many steps leading to the transfer of care to an adult provider (Figure 1).¹¹ The goal is to “provide uninterrupted health care that is patient-centered, age and developmentally appropriate, flexible, and comprehensive.”⁸ There is a paucity of clinical trials testing the efficacy of starting transition at different ages.¹² However, it is generally believed that earlier is better, with some advocating discussions with families shortly after birth and/or diagnosis.¹² Beyond this, consensus guidelines and other studies suggest that early adolescence is the ideal time to begin, with some advocating for age 12^{13–16}; however, flexibility should be emphasized based on psychosocial maturity.^{8,17} Other authors have recommended that a transition plan be put into writing by the time the patient is 14 years old.^{8,18} Webb et al¹⁹ suggested that if a patient has undergone transplantation as a teenager, the

discussions should begin as soon as the patient is stable as an outpatient. Importantly, transition should not take place during a medical crisis.²⁰ The final stage of transition, transfer to an adult provider, is recommended by the American Academy of Pediatrics to occur between ages 18 and 21. Flexibility may be offered in rare situations if needed to ensure the patient is able to navigate adult systems that demand increased responsibility and autonomy.¹⁶

Preparing patients for transition

The first step in preparation is helping the patient understand that a transfer of care will occur. The frequency of discussions of transition depends on psychosocial development, patient circumstances, and age at transplantation. As they grow older, children move from simplistic constructs to more complex analytic models of explanations and action in their long-term medical management.²¹ Major developmental milestones achieved during adolescence are often underdeveloped in children with chronic medical conditions.²² Meaux et al²³ concluded that the cumulative effects of physical changes, peer and family relationships, and academic challenges make adolescence a particularly vulnerable time for patients coping with chronic medical conditions.

Adolescents are more likely to take ownership of their chronic medical condition when they perceive a shared management between themselves, their parents, and their health care providers.²³ To foster this, institutions should select a patient-specific readiness-assessment tool to reveal areas of strengths and weaknesses so that education can be focused on gaps in self-management and lay the groundwork for transition.¹⁶ We recommend that 1 to 2 years before the anticipated transfer of medical care, the pediatric provider should inform patients and caregivers of the options for adult practices for ongoing care. Whether there are 1 or multiple options, the pediatric provider should prepare appropriate documentation and facilitate orientation and introduction to the adult practice and key team members.¹⁶ This approach has been shown to increase a patient’s sense of security.²⁴

Promoting self-management

Self-management is the “active, daily, and flexible process in which youth and their parents share responsibility and decision making for achieving disease control, health and well-being through a wide range of illness-related activities.”²³ Adolescents may have difficulties with medication scheduling, appearance changes, and interruptions in routine due to the medical regimen, creating a barrier to self-management.²³ In a study of heart transplant recipients, both the patients and their parents expressed a goal of transition to self-management.²³ A review of transitions demonstrated shared responsibility between parents and adolescents, with a gradual shift from parent-directed management to adolescent self-management. Younger adolescents needed help in managing medications, and older adolescents needed

Download English Version:

<https://daneshyari.com/en/article/5615798>

Download Persian Version:

<https://daneshyari.com/article/5615798>

[Daneshyari.com](https://daneshyari.com)