

Maintaining the Gift of Life: Achieving Adherence in Adolescent Heart Transplant Recipients

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ABSTRACT

Since the beginning of United Network of Organ Sharing data collection in 1987, a total of 8,333 pediatric patients have received a heart transplant in the United States. Because these patients now have longer graft success with improved care and immunosuppression, many of them are entering adolescence and young adulthood. Primary care pediatric nurse practitioners need to be alert to the prevalence of noncompliance with treatment in heart transplant patients, which continues to be highest in adolescence. Low compliance in adolescence increases morbidity, contributes to decreasing quality of life, and is the leading reason for graft failure and mortality in this age group. This article will review common barriers to treatment adherence in the adolescent heart transplant patient, discuss the role of the primary care pediatric nurse practitioner in preventing noncompliance, and review strategies that the primary care pediatric nurse practitioner can implement to improve compliance in this patient population. *J Pediatr Health Care.* (2017) ■, ■-■.

KEY WORDS

Adherence, adolescent, heart transplant, pediatrics

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BACKGROUND

In 2015, 423 patients in the United States under the age of 18 years received a heart transplant (U.S. Department of Health and Human Services, 2016). In total, since October 1, 1987 (the beginning of United Network of Organ Sharing data collection), 8,333 pediatric patients have received a heart transplant in the United States (U.S. Department of Health and Human Services, 2016). Thus, in the United States, there is the likelihood that a pediatric nurse practitioner may encounter a heart transplant recipient in practice. Because these patients now have longer graft success with improved care and immunosuppression (77.93% survival at 3 years after transplantation and 70.38% survival at 5 years after transplantation [U.S. Department of Health and Human Services, 2016]), many of these patients are entering adolescence and young adulthood. During this delicate time between childhood and adulthood, these patients have to make the challenging transition to self-care. Noncompliance with treatment continues to be highest in adolescent heart transplant recipients and is the leading reason for graft failure and mortality in this age group (Dharnidharka, Lamb, Zheng, Schechtman, & Meier-Kriesche, 2015; Dobbels, Van Damme-Lombaert, Vanhaeke, & De Geest, 2005; Shellmer, Dabbs, & Dew, 2011).

In the United States, there is the likelihood that a pediatric nurse practitioner may encounter a heart transplant recipient in practice.

This article will serve to aid the primary care pediatric nurse practitioner (PNP-PC) in encouraging compliance in adolescent heart transplant patients and facilitating the transition to self-care and self-management

by discussing the barriers to compliance and management strategies and by providing resources to improve outcomes.

PREVALENCE

Currently in the United States, there are 331 patients under 18 years of age who are listed as waiting for a heart transplant. Additionally, the survival rate under the age of 18 years according to the [U.S. Department of Health and Human Services Organ Procurement and Transplantation Network \(2016\)](#) is 86.35%, 77.93%, and 70.38% at 1, 3 and 5 years, respectively. There are varying reports on the prevalence of adolescent nonadherence. [Loiselle et al. \(2015\)](#) found that roughly 43% of teenage transplant recipients are noncompliant to their medication regimen, and [Meaux et al. \(2014\)](#) reported nonadherence rates for adolescents as high as 65%. Although health consequences of nonadherence in all solid organ transplant recipients are significant, patients with cardiac transplants are especially vulnerable to a catastrophic event due to rejection ([Oliva et al., 2013](#)). [Oliva et al. \(2013\)](#) studied Organ Procurement Transplant Network data from 1999 through 2007; they identified 2,070 pediatric heart transplant recipients and the evaluated the impact of medication noncompliance on survival in these patients. Oliva et al. found that nonadherence in this population was highest (18.3%) among adolescents and that among patients with more than two reported incidences of nonadherence and subsequent rejection, there was a 56% mortality rate within 2 years. These findings serve to underline the grave importance of this topic and highlight the overwhelming incidence of poor compliance in this adolescent patient population.

PATHOPHYSIOLOGY

Reason for Transplantation

Understanding why a patient received his or her transplant is an important part of care as a provider.

Cardiomyopathy

Patients receive transplants for diagnoses of both hypertrophic cardiomyopathy and dilated cardiomyopathy, with the most common indication for pediatric heart transplantation overall being dilated cardiomyopathy ([Thrush & Hoffman, 2014](#)). Both long- and short-term outcomes after transplantation for cardiomyopathy patients are impressive, with 1- and 10-year survival rates of 90% to 95% and 60% to 80%, respectively ([Kirklin, 2015](#)).

Congenital heart disease

Congenital heart disease continues to be the most common reason for cardiac transplantation in infants but has decreased as reparative and palliative surgical interventions have evolved ([Dipchand, Kirk, et al., 2013](#); [Kirklin, 2015](#)).

Retransplantation

Retransplantation is considered for patients with allograft failure due to acute rejection less than 6 months after transplantation, severe coronary allograft vasculopathy or moderate to severe systolic or diastolic dysfunction in the absence of rejection if there are no contraindications to retransplantation present such as a history of significant nonadherence ([Costanzo et al., 2010](#)). Repeat transplantation is rare and is associated with a worse outcome than primary transplantation ([Thrush & Hoffman, 2014](#)).

Graft Failure

There are multimodal ways in which rejection can damage the heart and affect morbidity and mortality. Cellular rejection is mediated by T lymphocytes that are mounted against the allograft tissue in the recipient and found in the cardiac muscle upon endomyocardial biopsy ([Costello, Mohanakumar, & Nath, 2013](#)). Antibody-mediated rejection is facilitated by B lymphocytes, which produce antibodies against the allograft called donor-specific antibodies, and typically occurs soon after transplantation but can occur later ([Pajaro et al., 2011](#)). Coronary allograft vasculopathy is a type of chronic rejection and refers to progressive, occlusive narrowing of the coronary arteries ([Pajaro et al., 2011](#)). This process generally occurs years after transplantation and is the current limiting factor in long-term graft survival ([Costello et al., 2013](#); [Dipchand, Kirk, et al., 2013](#)). PNP-PCs must remember to always assess for the signs of cardiac failure (fluid retention, fatigue on exertion, chest pain) in patients, especially if they are nonadherent, because although most early rejection is asymptomatic, these patients can show signs of early hemodynamic compromise ([Kirk et al., 2014](#)).

WHAT IS NONADHERENCE?

For the purpose of this article, the terms *nonadherence* and *noncompliance* will be used interchangeably. Different organizations have differing definitions of adherence/compliance with medical treatment, which are open to interpretation by reporting centers and thus may affect the reported rates of nonadherence ([Kirk, 2013](#)). The [World Health Organization \(2003\)](#) defines adherence as the “degree to which the person’s behavior corresponds with the agreed recommendations from the healthcare provider” (p. 3), which encourages inclusion of all aspects of nonadherence including medication noncompliance, missed appointments, missed blood draws, procedures, lifestyle modifications, and diet. This definition is important in the sense that all types of nonadherence can affect the health of the patient and the success of his or her graft, not solely medication adherence.

Nonadherence to or noncompliance with medical recommendations in the pediatric heart transplant recipient can encompass many aspects. The most common form of nonadherence in the adolescent patient

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