

National review: Non-adherence among teenage heart transplant recipients is widespread, often fatal

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After receiving an organ transplant, patients must follow a regimented medication routine to maintain the health of their graft (transplanted organ). Failure to do so, known as non-adherence (NA), can result in life-threatening illness. NA has long been a concern among adolescent patients, but a new study from Boston Children's Hospital demonstrates the problem may be more serious than previously understood.

The study, published online June 4 by the *Journal of Heart and Lung Transplantation*, looked at eight years' worth of data from the [Organ Procurement](#) Transplant Network (OPTN) and found that as many as 9 percent of all pediatric and adolescent heart recipients (ages 18 and under) in the US had an episode of NA that compromised their health within two years of receiving their transplant. Among patients who did not adhere to their medication, the risk of mortality was 26 percent within one year and 33 percent within two years.

"It is widely known that non-adherence is a particularly difficult problem among adolescent patients," says senior author Christopher Almond, MD, MPH, a [cardiologist](#) in the [Heart Transplant](#) Program at Boston Children's. "But prior to this study, the scope and gravity of the problem wasn't well understood. Regionally, we knew what we were seeing, but this makes it markedly clear how many kids are dying nationally from a problem that is sadly so preventable."

Researchers examined all 2,070 pediatric heart transplant cases between 1999 and 2007, including all reported incidents of NA related to post-transplant death. Of the 186 children who were reported to be NA, 48 died within a year of receiving their transplant, and 61 died within two years.

"With all the advances that have been made in [transplant medicine](#), non-adherence has become the leading cause of fatal [graft rejection](#) in [adolescent patients](#), and it's completely avoidable," says lead author Melisa Oliva, PsyD, formerly a staff psychologist at Boston Children's Pediatric [Transplant Center](#). "Teens may not understand the gravity of not adhering to their medications, including how they could lose their graft and affect their chances of receiving another transplant. We hope these data can help raise awareness of the seriousness of the problem and guide clinicians in identifying those most at risk, so interventions can be put into place early, before [adherence](#) issues develop."

Also drawing from the OPTN data, the researchers identified several key risk factors associated with an increased risk of NA in pediatric heart transplant patients including:

- Age – adolescence (12-17 years of age) was the greatest risk factor
- Medicaid insurance
- Race – African-American
- Ventilator or ventricular assist device support at transplant

Researchers are hopeful that the nation's most at-risk patients may be identified and receive targeted interventions, such as extra counseling and support services in an attempt to prevent future, potentially fatal, cases of NA.

"For so many patients to receive a life-saving transplant—only to die from something this preventable—drives home the seriousness of this problem," says Almond. "If the medical community can use these data to better identify and counsel at-risk patients as to what the real consequences of NA can be, we believe an important number of pediatric transplant deaths can be avoided going forward."

Provided by Children's Hospital Boston

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