Ethical Issues Surrounding Noncompliance in Organ Donation

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Within a few months of the controversial lung donation to a child who was placed on the adult organ donation waiting list by way of a judge’s ruling, the media has been buzzing about yet another controversial case.

15-year old Anthony Stokes received a heart transplant at Children’s Healthcare of Atlanta on August 20. Anthony had originally been denied a spot on the heart transplant list due to his noncompliance, one of the medical center’s contraindications for being listed for a heart transplant. Apparently, a doctor told Anthony’s family that his “history of noncompliance” related to his low grades and time spend in juvenile detention. A week later, Anthony’s doctors and the hospital reversed their decision, giving him top priority on the transplant list.

Anthony began having chest pain this summer, which led to his admission to the hospital and ultimate diagnosis of a weakened, enlarged heart that could not pump blood efficiently. Doctors estimated that, without a transplant, Anthony could have less than six months to live.

In the process of determining eligibility for organ donation, doctors and hospitals take many factors into account. Federal regulations direct the Organ Procurement and Transplant Network (“OPTN”) to develop policies for the equitable allocation of organs among potential recipients based on sound medical judgment and that achieve certain performance goals, including standardization of criteria for determining suitable transplant candidates. 42 CFR § 121.8. Criteria for adding individuals to and removing them from organ transplant waiting lists are to include “objective and measurable criteria” to the extent possible, but the regulations do not elaborate on these “objective” criteria. Furthermore, the OPTN’s Policy 3.7.4, Pediatric Candidate Status, focuses on the candidate’s medical urgency for transplant, without taking into account any history of noncompliance.

The definition of a “noncompliant patient,” as provided in an article by Rodriguez et al.,[i] is as follows:

a noncompliant transplant patient is a patient with poor attendance to clinics or to laboratory appointments, who delayed in the notification of problems, showed poor adherence to diet and/or consistent weight gain, and showed poor adherence to their drug schedule including minor deviations.

In the case of Anthony Stokes, his doctors originally expressed their concern that the patient would be unwilling or able to follow through with aftercare, which includes taking the required medication and attending follow-up appointments. In the event of “medical noncompliance” with aftercare intake of immunosuppressive drugs, the risks of rejection of the donated organ and death are very high. According to a study by Rovelli et al.,[ii] 91% of patients who were noncompliant with both follow-up and medications either rejected the graft or died. This is tragic not only for the recipient and his or her family; it can be tragic for others because the organ could have been donated to someone else, who instead may have died on the waiting list.

In Stokes’ case, the doctors determined there was sufficient risk of graft rejection to prevent his inclusion on the recipient list, apparently on the basis of objective analysis of the patient’s history of noncompliance. After receiving the rejection letter from the hospital, Anthony’s family sought help from the Southern Christian Leadership Conference, which drew wide media attention to the case.
The hospital has not commented on what led the doctors and hospital to overturn their original decision to deny Anthony a spot on the transplant list, leaving many unanswered questions. Does this case throw into doubt the appropriateness of using noncompliance as a factor in prioritizing potential organ recipients? Is pre-transplant noncompliance a reliable predictor for post-operative noncompliance? Is there a need for more research on pre-transplant noncompliance and its relationship to graft failure—e.g., do reasons for the noncompliant behavior make a difference? What are effective approaches for improving noncompliant behavior? Is “noncompliance,” as a reason for not listing a potential organ recipient, too subjective? Has it been used to mask other reasons? Ethical questions such as these have frequently surrounded organ donation: they highlight the difficulty in standardizing procedures and processes that often are, at least in part, emotionally driven.


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