

Disclosure of organ transplant risks: A question of when, not if

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University of Pennsylvania School of Medicine physicians and bioethicists are calling for a new, more standardized way for patients in need of organ transplants to be informed of the risks they face. If adopted, their policy recommendations could promote greater equity in how organs are allocated while restricting patients' abilities to "cherry-pick" the best organs.

Writing in the June 26 issue of the *New England Journal of Medicine*, a Penn team led by Scott Halpern, MD, PhD, of the Pulmonary, Allergy and Critical Care division, highlights the recent Chicago case in which four patients were infected with HIV and Hepatitis C following liver, heart and kidney transplants. Although the donor did not test positive for HIV at the time of his death -- all U.S. donors are screened for infectious diseases -- local organ procurement officials and the transplant surgeons knew the man had engaged in behaviors that boosted his risk of HIV. The recipients, however, were not made aware of this risk at the time the organs were offered, and as a result, at least one of the recipients is suing the transplant organization and hospital.

The Penn researchers argue that while patients do not have the right to know every detail about the specific donor their organ will come from, that the current system does not adequately protect patients' rights to make fully informed decisions regarding the risks they are willing to accept. Thus, Halpern and colleagues propose that the United Network for Organ Sharing (UNOS), the national clearinghouse for organ allocation, create a policy requiring transplant programs to disclose "all

foreseeable risks" of the surgery to potential recipients at the time that they are placed on the waiting list for an organ. They argue that all patients should be given the option of accepting or declining organs that would come from suitable but suboptimal donors – including donors with risks for infectious diseases, older donors, or donors after cardiac death whose organs might be less hardy because they were deprived of blood flow for short periods of time before transplant. Currently, UNOS requires only that kidney recipients be allowed to accept or decline organs from so-called "expanded-criteria donors" – those who are older or have diseases such as hypertension – and even this narrow requirement is unevenly adhered to across the nation.

In addition to encouraging more systematic disclosure of the general risks of transplantation when patients are listed, the researchers say it is wrong to disclose specific risks associated with a particular donor at the time an organ becomes available. "Allowing a patient to cherry-pick his organs by telling him everything about a potential donor creates the potential for discrimination, inefficiency, and inequity in how organs are allocated," Halpern says. "By contrast, notifying patients of all foreseeable risks of transplantation at the time they are placed on the waiting list protects their right to decide how much risk they will accept without any of these negative consequences for society."

A particularly sensitive issue – and one that makes this issue especially timely – is the remote but real possibility that HIV and other socially stigmatized infections might be transmitted through organ transplantation. Because of the nation's ongoing shortage of organs -- 10 percent of patients awaiting transplant die each year -- patients with behavioral risk factors for HIV are not barred from donating organs as they are from donating blood. In their paper, the authors provide new data indicating that more than five percent of organ donors are classified as "high risk" for undetectable HIV infection. Donors classified as "high risk" currently include homosexual men, people who have been jailed,

injection drug users, and people who have received certain blood products, although Halpern notes that officials at the Centers for Disease Control and Prevention (CDC) are currently reevaluating these definitions.

The researchers caution that telling patients about a specific donor's HIV risk factors, without emphasizing the greater risks associated with using organs from donors with hypertension or diabetes, could breed discrimination in how organs are allocated due to biases against homosexuals or drug users. "Permitting patients to evaluate specific donor characteristics could wrongly introduce social bias as a legitimate rationale for guiding the allocation of a public good," the authors write.

And since organs must be harvested and transplanted quickly, time spent deliberating stands to impede chances to find a properly matched recipient or perform a surgery free of complications "Even modest delays resulting from organ-specific consent would be difficult to justify in view of the strong moral bases and broad public support for maximizing efficiency in the allocation of scarce organs," they said.

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