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LIVING DONORS AND RECIPIENTS WANT MORE INFORMATION ABOUT EACH OTHERS' HEALTH BEFORE TRANSPLANTATION

Study's findings challenge current policies on information disclosure

Highlights

- Most donors and recipients support swapping health information before kidney transplantation, but there was low interest in sharing social information.
- Both donors and recipients wanted the transplant team involved in information disclosure.
- Most donors and recipients did not think the recipient had a right to know why a donor was excluded from donating.

Approximately 6,000 living donor kidney transplants are performed annually in the United States.

Washington, DC (August 13, 2015) — Both donors and recipients want more information about each others' health before participating in transplant surgeries, according to a study appearing in an upcoming issue of the *Clinical Journal of the American Society of Nephrology* (CJASN). The findings challenge current practices and policies on information disclosure for prospective living kidney donors and their intended recipients..

Patients in need of a transplant may want certain information about a potential living donor before accepting his or her organ. Likewise, a potential donor may want information about an intended recipient before deciding whether to offer the organ. It is mandatory to disclose to a candidate if the donor is at increased risk for hepatitis or HIV, but national and international living donor guidelines either do not address or are vague about what other information can be shared between prospective living donors and transplant candidates, as well as when to make such disclosures and who should make them.

To determine if the current policies about sharing of information in living kidney transplantation meets the needs of donors and recipients, Lainie Friedman Ross, MD, PhD (University of Chicago) and her colleagues surveyed 236 individuals, 160 of whom identified as potential or actual donors and 76 of whom identified as candidate or actual recipients.

Among the major findings:

- Overall, 79% of respondents supported providing donors with recipients' general health information that would affect post-transplant health, and 88% supported providing recipients with donors' general health information. Such information might include individuals' status related to smoking, heart health, and kidney function.
- There was little interest in sharing social information such as criminal record, sexual orientation, employment status, or religion.
- The closer the donor-recipient relationship, the more information donors and recipients were willing to share.
- Both donors and recipients wanted the transplant team involved in information disclosure.
- More than three-quarters of both donors and recipients did not think the recipient had a right to know why a donor was excluded from donating.

"Our finding that both donors and recipients support greater sharing of health and health-behavior information challenges the current approach to disclosure in organ transplantation. It is also clear that they want the transplant teams involved in these discussions," said Dr. Ross. "The current model of health care decision-making and information disclosure assumes an isolated autonomous individual who makes private health care decisions with his or her own physician, but this fails to capture the fact that donor and recipient outcomes are interdependent. A re-evaluation of current practices and policies should be considered."

Study co-authors include Leslie Mataya, Jacqueline Meadow, BA, J. Richard Thistlethwaite, Jr, MD, PhD, Didier Mandelbrot, MD, and James Rodrigue, PhD.

Disclosures: The authors reported no financial disclosures.

The article, entitled "Disclosing Health and Health Behavior Information Between Living Donors and their Recipients," will appear online at <http://cjasn.asnjournals.org/> on August 13, 2015.

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