

Clinician and patient preferences clash over information sharing before transplantation

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Most kidney donors and recipients are in favor of exchanging personal health information that may influence success before scheduling a living organ donor transplant, while healthcare professionals are more reluctant, according to a study appearing in an upcoming issue of the *Clinical Journal of the American Society Nephrology (CJASN)*. The results suggest that clinicians should consider supporting and facilitating more information sharing before transplantation.

Living [kidney donation](#) is a complex decision, with multiple medical, legal, and ethical aspects. In many situations it can be difficult to know what personal [health information](#) is important to share and what information should be kept confidential. For example, knowing that a donor has [high blood pressure](#) may affect a recipient's willingness to accept the gift, or a potential recipient who is HIV positive may worry that this information could change a donor's willingness to donate. The situation becomes even more complex during incompatible kidney exchanges when multiple incompatible donor-recipient pairs are matched with each other to produce compatible matches. In these cases, donors and recipients are usually strangers to each other and may be more reluctant to share personal health information.

Because there is currently no consensus on what information should be disclosed between potential transplant donors and recipients, Patricia Hizo-Abes (medical student), Ann Young (doctoral student) and Amit Garg, MD, PhD, FRCPC (all from The University of Western Ontario and Lawson Health Research Institute, London, Canada), and colleagues,

conducted a survey on the preferences of 43 potential kidney donors, 73 potential recipients, and 41 health professionals towards sharing personal health information. When considering traditional live [donor transplantation](#), 86% of donors and 80% of recipients said that a recipient's health information that could influence the success of transplant should be shared with the donor; 97% of donors and 89% of recipients said that a donor's information should be shared with the recipient. When considering incompatible kidney exchange, 85% of donors and 85% of recipients said that a recipient's information should be shared with all donors and recipients involved in the transplantation; 95% of donor and 90% of recipients said that a donor's information should also be shared with all involved individuals.

While the majority of kidney donors and recipients were in favor of exchanging information, transplant professionals' opinions varied greatly and tended to be more conservative. (For example, for incompatible kidney exchanges, only 61% of health professionals were in favor of sharing donors' information and only 47% were in favor of sharing recipients' information.) These findings indicate that not only do transplant professionals lack a consensus related to information sharing, but their preferences are also markedly different from those of their patients.

The authors noted that the rights of any donor or recipient opposed to information sharing must be respected, but clinicians should not assume to know how much patients value their confidentiality. In addition, transplant professionals should better facilitate the sharing of information within legal limitations. "Our results do not advocate for complete information sharing, but rather consideration for greater information sharing," said Dr. Garg.

More information: The article, entitled "Attitudes to Sharing Personal Health Information in Living Kidney Donation," will appear online on

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