Donor and Recipient Perspectives on Anonymity in Kidney Donation From Live Donors: A Multicenter Survey Study

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Background: Maintaining anonymity is a requirement in the Netherlands and Sweden for kidney donation from live donors in the context of nondirected (or unspecified) and paired exchange (or specified indirect) donation. Despite this policy, some donors and recipients express the desire to know one another. Little empirical evidence informs the debate on anonymity. This study explored the experiences, preferences, and attitudes of donors and recipients toward anonymity.

Study Design: Retrospective observational multicenter study using both qualitative and quantitative methods.

Setting & Participants: 414 participants from Dutch and Swedish transplantation centers who received or donated a kidney anonymously (nondirected or paired exchange) completed a questionnaire about anonymity. Participation was a median of 31 months after surgery.

Factors: Country of residence, donor/recipient status, transplant type, time since surgery.

Outcomes: Experiences, preferences, and attitudes toward anonymity.

Results: Most participants were satisfied with their experience of anonymity before and after surgery. A minority would have liked to have met the other party before (donors, 7%; recipients, 15%) or after (donors, 22%; recipients, 31%) surgery. Significantly more recipients than donors wanted to meet the other party. Most study participants were open to meeting the other party if the desire was mutual (donors, 58%; recipients, 60%). Donors agree significantly more with the principle of anonymity before and after surgery than recipients. Donors and recipients thought that if both parties agreed, it should be permissible to meet before or after surgery. There were few associations between country or time since surgery and experiences or attitudes. The pros and cons of anonymity reported by participants were clustered into relational and emotional, ethical, and practical and logistical domains.

Limitations: The relatively low response rate of recipients may have reduced generalizability. Recall bias was possible given the time lag between transplantation and data collection.

Conclusions: This exploratory study illustrated that although donors and recipients were usually satisfied with anonymity, the majority viewed a strict policy on anonymity as unnecessary. These results may inform policy and education on anonymity.

Complete author and article information provided before references.

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In the majority of live kidney donations, the recipient is emotionally and/or genetically related to the donor. However, over the past decades, other forms of live kidney donation have been developed, such as nondirected[1-3] and paired exchange[1,2] live kidney donation. In the European Platform on Ethical, Legal and Psychosocial Aspects of Organ Transplantation (ELPAT) classification for living organ donation, these types of donation are defined as "unspecified donation" and "specified indirect donation," respectively.[4] In the Netherlands and Sweden, anonymity is absolute both before and after donation for nondirected and paired exchange procedures.[5,6] Some countries (eg, the United Kingdom and the United States) do not require these procedures to be carried out anonymously or have a policy of conditional anonymity whereby donor-recipient pairs can meet after a certain period if both parties agree.[7,8] But what are the potential advantages and disadvantages of these varying policies?

The underlying rationale of anonymity is that it is presumed to protect donors and recipients against potential risks. Mamode et al[7] described the following assumed risks of revoking anonymity: disappointment when the reality differs from an idealized image of recipient/donor or outcome, feeling pressured to donate, possible withdrawal, infringement of privacy, and solicitation and commercialization. However, they also proposed that imposed anonymity could be experienced as paternalistic and may have a negative impact on donation rates. Not knowing the other party and/or surgical outcomes may also lead to anxiety/obsession. However, the pros and cons as they are experienced by anonymous donors and recipients have not yet been empirically investigated.

Previous studies of anonymity among exchange pairs suggested that the majority (69%) preferred anonymity between pairs.[5,9] In a study by Kranenburg et al,[9] reasons to prefer anonymity among exchange pairs included

avoidance of resentment (in the case of differing transplantation outcomes) and stress. Curiosity was the driving factor behind the wish to meet the other pair. A study among nondirected donors demonstrated that 17% wanted to meet the recipient.[10] Because these studies were conducted when nondirected and paired exchange donation programs were new, the samples were therefore small.

Thus, we are aware of no large-scale up-to-date studies about the experiences, preferences, and attitudes toward anonymity. In clinical practice, recipients and donors who participate in an anonymous transplantation program often ask for information about the donor or recipient. Therefore, the aim of this exploratory, multicenter, retrospective, mixed-methods, survey study was to investigate experiences, preferences, attitudes, and perceived pros and cons of anonymity among donors and recipients who donated or received a kidney anonymously. Differences between donors and recipients who participated in different transplantation programs were investigated because, for example, nondirected donors choose to donate in a strictly anonymous procedure, whereas paired exchange donors originally intended to donate to their known recipient. Given differences in culture and clinical practices, we also explored differences in attitudes and experiences between participants from Sweden and the Netherlands. Moreover, we explored whether time since the surgery influenced the opinion on anonymity.

Methods

Study Population and Design

Recipients and donors of 7 Dutch and 4 Swedish transplantation centers who received or donated a kidney anonymously (nondirected or paired exchange) were invited to complete a retrospective questionnaire on anonymity. Participants were required to have donated or received a kidney anonymously in the Netherlands (2009-2014) or Sweden (2004-2014); be 18 years or older; have sufficient command of Dutch, Swedish, or English; and reside in the Netherlands or Sweden. Due to the small number of procedures in Sweden, the inclusion period was longer. Seven hundred forty-three people donated or received a kidney anonymously in the Netherlands and Sweden during the study period. Of these, 329 recipients and 358 donors were invited to participate by letter from their transplantation team; see Figures 1 and 2 for reasons for exclusion.

In the Netherlands, it was possible to complete the questionnaire online or on paper. Swedish participants completed the questionnaire on paper. One reminder was sent to nonresponders. After they signed and returned the informed consent form, participants were sent the questionnaire by e-mail or post, depending on their preference. The study protocol was approved by the Regional Ethical Review Board in Gothenburg (347-14) and the Medical Ethical Committee of the Erasmus University Medical Center (MEC-2014-271). Local permission of the medical

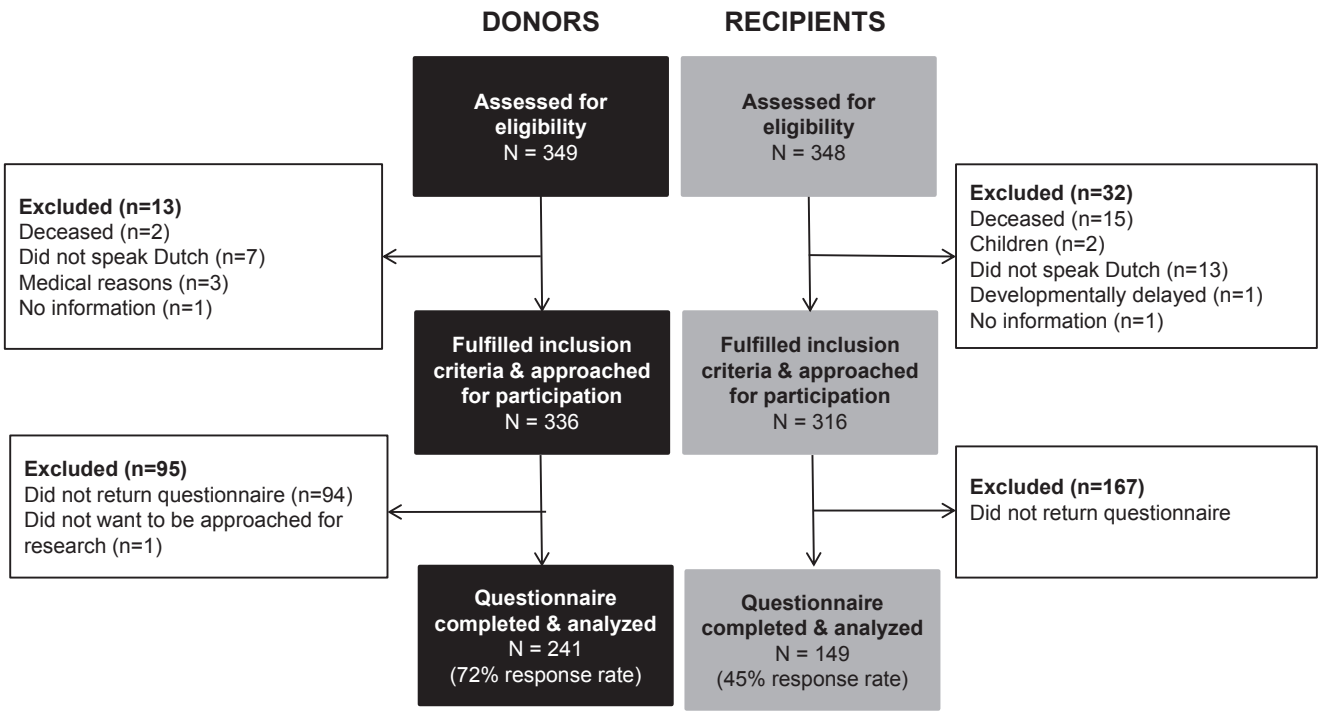

Figure 1. Flow chart showing inclusion/exclusion of Dutch participants.