ORIGINAL ARTICLE

Toward a conditional approach to anonymity? An explorative multicenter longitudinal study among anonymous living kidney donors and recipients

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SUMMARY

Anonymity between living donors and recipients is a topic of discussion among transplant professionals. This longitudinal study explored living kidney donors' and patients' perspectives on anonymity. Prior to surgery (T0) and 3 months afterward (T1), participants in unspecified or specified indirect donation programs completed a questionnaire on their experiences with and attitudes toward anonymity as well as demographic and medical characteristics. Nonparametric tests were used to assess group differences and associations. Participants were content with anonymity at T0 and T1. Fourteen and 23% wanted to meet at T0 and T1, respectively. If the other party expressed the wish to meet, 50% (T0) and 55% (T1) would be willing to meet. Most participants agreed that meeting should be allowed if both parties agree. Attitude toward anonymity did not differ between donors/recipients, nor between T0/T1 and unspecified/specified indirect donation programs. This study showed that most donors and recipients who participated in anonymous donation schemes are in favor of a conditional approach to anonymity. Guidelines on how to revoke anonymity if both parties agree are needed and should include education about pros and cons of (non-) anonymity and a logistical plan on how, when, where, and by whom anonymity should be revoked.

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Key words
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Introduction

Anonymity of donors and recipients in living donor organ transplantation is a recurrent topic of discussion among transplant professionals. This discussion has been stimulated by the introduction of specified indirect donation ((domino-)paired exchange programs), and unspecified kidney donation (nondirected donation) [1], as well as the use of publicly solicited organ donors [2]. In specified indirect donation and unspecified donation, anonymity between donor and recipient is typically maintained prior to surgery

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[1,3]. Policies on anonymity after surgery vary between countries. Some countries such as the USA [4] and the UK [5] use a conditional approach and allow meetings between donor–recipient pairs after surgery, under the condition that both parties agree. In other countries, such as the Netherlands and Sweden [6], anonymity is absolute. The main reason for transplant professionals and/or authorities to maintain anonymity between donor and recipient is to protect donors, recipients, and society against the risks of revoking anonymity. These risks are well described in an opinion paper by members of Ethical, Legal and Psychosocial Aspects of Organ Transplantation (ELPAT), a subsection of the European Society for Organ Transplantation (ESOT), and include commercialization of organs, and breach of donor/recipient privacy [3]. Nevertheless, the same paper concluded that, even though anonymity would be valuable before surgery, a conditional approach to anonymity should be possible after surgery [3].

However, policies on anonymity should not solely reflect the opinions of transplant professionals or authorities, but should also take into account the opinion of the donors and recipients concerned. The limited number of studies that have examined this revealed that in countries with an absolute approach to anonymity, most anonymous donors and recipients prefer anonymity while a small minority would like details on the identity of the other pair and/or would like to meet them [7–9]. In a recent study, Slaats *et al.* (in press) found that the majority of donors and recipients were in favor of a conditional approach to anonymity, rather than the absolute approach that is currently in effect in the Netherlands [10].

However, all but one of aforementioned studies were retrospective [7,8], and, in some cases, more than 10 years had passed since surgery. Additionally, these studies did not investigate potential changes in the opinion about anonymity in living donation over time (pre/postoperative). A prospective investigation of the opinion of Dutch specified indirect donors and their recipients about anonymity found no pre/postoperative differences [9]. However, this study was conducted 10 years ago, before the introduction of domino-paired exchange programs and unspecified direct donation in the Netherlands.

Both the course leading up to the surgery and the ensuing period differ largely between donors/recipients involved in specified indirect donation and unspecified donation. Contrary to recipients involved in specified indirect donation, recipients who receive a kidney from an unspecified donor often do not expect to receive a living donor kidney transplant and associated advantages in terms of graft survival. A study among deceased transplant recipients waiting for a transplant has shown that if such individuals were to receive a kidney from an unspecified living donor, their reaction may be twofold: some reported they would perceive anonymity as positive, because it would free them from any obligations and responsibilities toward the donor [11]. Others would be concerned about (having no information about) the (health of the) donor [11]. The latter group might be the patients observed in clinical practice who remain curious about their donor. In contrast, unspecified donors deliberately chose to participate in an anonymous procedure and the most commonly reported motivation is "to help others" [12]. For that reason, one might expect that these donors do not experience the need to know the recipient, as the very act of donating might be sufficient for them [11]. However, clinical practice reveals that a number of unspecified donors request to have contact with the recipient. To accurately inform policy, up-to-date longitudinal studies on the opinion of living donors and recipients about anonymity in current donation programs are needed.

Therefore, the first aim of this explorative multicenter longitudinal study was to investigate the experiences with and attitude toward anonymity among individuals who anonymously donated or received a living donor kidney, both before and 3 months after surgery. The second aim was to explore whether attitude toward anonymity differed between donors and recipients in different transplant programs (specified indirect versus unspecified) and was related to socio-demographic and medical characteristics, and the current health status of participants.

Materials and methods

Participants

All individuals over 18 years of age who anonymously donated or received a living donor kidney between July 1, 2015, and May 1, 2016, in seven of eight transplant centers in the Netherlands were considered for inclusion. This cohort included participants in unspecified and specified indirect donation programs, but excluded donor–recipient pairs involved in solicited specified donation [1]. Individuals who did not speak the Dutch language sufficiently or did not live in the Netherlands were also excluded.

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Procedure

All those approved for surgery were invited for the study by telephone or letter from their own transplant center. They were asked to complete a questionnaire (on paper or online) at the moment of invitation (T0; on average 2 weeks before surgery) and 3 months after surgery (T1). When no response was received at T0, the local investigator visited the donor/recipient on the day of admission to the hospital to invite them to participate. Consequently, the T0-questionnaire was completed at home or in the hospital (by 81.9% and 18.1% of participants, respectively). The T1-questionnaire was completed at home by all participants. All participants signed an informed consent form prior to participation. This study was approved by the institutional review board of the Erasmus MC, University Medical Center Rotterdam (MEC-2014-271).

Measures

Given the exploratory nature of this study and the lack of validated measure for the concepts examined, a number of closed and open-ended items were developed by the ELPAT Living Organ Donation and Psychological Care working groups. The questionnaire was refined by the Dutch research team consisting of nephrologists, psychologists, transplant surgeons, specialist nurses, and live donor coordinators. The questionnaire was pilot tested in the Netherlands among two donors and two recipients who were instructed to think aloud while completing the questionnaire in the presence of a researcher. Based on this feedback, the questionnaire was further refined. The self-developed questions that were analyzed for the current study are available as Appendix S1.

Socio-demographic and medical characteristics

Socio-demographic characteristics and medical characteristics of donors and recipients can be found in Table 1. All socio-demographic and medical characteristics were self-reported, except for transplant program, which was provided by the transplant centers.

Experiences with anonymity

Experiences with anonymity (Table 2) were measured with several items. Participants were asked how satisfied they were with being anonymous (T0 and T1) or not being anonymous (T1 only) to their donor/recipient (1 "completely dissatisfied" to 7 "completely satisfied"). They were also asked to indicate (yes/no/don't know) if they would want to meet the other party (T0 and T1). At T1, participants were asked to indicate (yes/no) if they had sent/received an anonymous card to/from their donor/recipient, and if they had any other kind of contact with their donor/recipient. If participants had met the other party they were asked to rate how they experienced the meeting (1 "very negative" to 7 "very positive") and to what extent they regretted the meeting (1 "not at all" to 7 "a great deal").

Using open-ended questions, participants were asked to elaborate on their reasons for (not) wanting to meet (T0), and their reasons for (not) sending a card to their donor or their feelings about (not) receiving a card from their recipient (T1).

Attitudes toward anonymity

Attitudes toward anonymity (Table 3) were measured with 10 statements (T0 and T1), such as "There must be anonymity between donor and recipient before/after surgery". Participants indicated to what extent they agreed with the statements on a 7-point scale (1 "completely disagree" to 7 "completely agree").

Current health status

Current health status (Table 1) was measured by the EQ-5D-5L health rating scale [13]. Participants had to indicate their current health on a visual analog scale, ranging from 0 "worst health you can imagine" to 100 "best health you can imagine". Permission to use this questionnaire was granted by EuroQol.

Statistical analyses

Data were analyzed with SPSS 23.0 (IBM Corporation, New York, NY, USA, 2015). Firstly, we examined whether participants differed from nonparticipants in terms of gender, age, and type of transplant program using independent *t*-tests and chi-square tests. Secondly, we used Spearman's correlations to examine whether there was a correlation between participants' scores at T0 and the immediacy of the operation (number of days between completion of T0 and the operation), and Mann–Whitney *U*-tests to examine whether participants' scores differed between method of completion (at home versus in the hospital).

Descriptive statistics were used to describe the participants' socio-demographic and medical characteristics, their experiences with anonymity and attitudes toward anonymity. Differences between donors' and recipients'

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Table 1. Socio-demographic and medical characteristics of participants.

	Donors (n = 72)		Recipients (n = 50)	
	n	%	n	%
Median age (range)	62.50 (21–79)			57.00 (25–75)
Gender				
Men	30	41.7	26	52
Highest level of education				
Primary/secondary school	23	32.4	24	51.1
Further education	48	67.6	23	48.9
Missing	1		3	
Transplant program				
Unspecified donor/waitlist recipient	47	65.3	23	46.0
Specified indirect donor/exchange recipient	25	34.7	27	54.0
Preemptive transplantation				
Yes	–		15	30.0
Median months on dialysis before transplantation (range)			13.50 (2–144)	
Previous transplantations				
0			40	80.0
1			8	16.0
2			2	4.0
Median hospital duration in days after surgery (range)	5 (2–9)		11 (5–93)	
Complications after surgery				
No	47	73.4	24	53.3
Yes, but no readmission was needed	14	21.9	7	15.6
Yes, readmission was needed	3	4.7	14	31.1
Missing	8		5	
The kidney I received from my anonymous donor still functions	–			
Yes, good			41	91.1
Yes, but moderately			2	4.4
No			2	4.4
Missing			5	
Current health status				
T0 Median (range)	90 (60–100)		62.50 (6–93)	
T1 Median (range)	90 (60–100)		75 (30–99)	
Method of completion of questionnaire (T0)				
At home	64	88.9	31	70.5
At the hospital ward	8	11.1	136	29.5
Median number of days between completion of T0 and day of surgery (range)*	7 (1–145)		3 (1–65)	

*A high number of days between completion of T0 and surgery was caused by surgeries being canceled and postponed.

scores were analyzed with Mann–Whitney U-tests or Pearson Chi-Square tests. When no significant group differences (donor/recipient) were found, descriptive statistics for the whole sample are given, referred to as participants. Descriptive statistics for donors and recipients separately can be found in Tables 2 and 3. Differences between T0 and T1 were measured with Wilcoxon signed-rank tests. Spearman's correlations were performed to describe the relationship between participants' attitudes on one hand and their socio-demographic and medical characteristics, and current health status on the other hand. Nonparametric tests were performed due to the skewed distribution of the data. Taking into account the large number of tests, we applied a Bonferroni correction, where a value of $P < 0.001$ was considered to be statistically significant.

Inductive coding was used to analyze the responses to the open-ended items. The responses were classified into categories, and similar categories were grouped into themes. Responses were independently coded in Microsoft Excel by two authors (MP, EM). Coding discrepancies were discussed until agreement was reached.

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Table 2. Experiences of anonymity in living kidney donation.

	Donors						Recipients					
	T0			T1			T0			T1		
	Mdn	Range	*n*	Mdn	Range	*n*	Mdn	Range	*n*	Mdn	Range	*n*
Satisfaction with anonymity BEFORE the operation*	6	1–7	72	7	1–7	64	6	2–7	45	7	1–7	45
Satisfaction with anonymity AFTER the operation*	–	–		6	1–7	65	–	–		7	1–7	44
	% Yes	% No		% Yes	% No		% Yes	% No		% Yes	% No	
I would have liked to meet my recipient/donor BEFORE the operation	7	76	72	3	85	65	26	59	48	18	57	44
I would have liked to meet my recipient/donor AFTER the operation	–	–		17	62	65	–	–		31	49	45
If the other party would like to have contact with me, I would be open to such a meeting	47	28	72	55	28	65	58	18	48	53	13	45

*This item was scored on a 7-point scale: 1 "completely dissatisfied" to 7 "completely satisfied".

Table 3. Attitudes of donors and recipients toward anonymity in living kidney donation.

	Donors						Recipients					
	T0			T1			T0			T1		
Statements*	Mdn	Range	*n*	Mdn	Range	*n*	Mdn	Range	*n*	Mdn	Range	*n*
There must be anonymity between donor and recipient BEFORE the operation	6	1–7	71	6	1–7	63	6	1–7	46	6	1–7	45
There must be anonymity between donor and recipient AFTER the operation	6	1–7	70	5	1–7	64	5	1–7	45	5	1–7	45
If both parties agree, donor and recipient should be allowed to meet BEFORE the operation	6	1–7	71	7	1–7	66	7	1–7	46	7	1–7	45
If both parties agree, donor and recipient should be allowed to meet AFTER the operation	6	1–7	71	7	1–7	65	7	1–7	46	7	3–7	45
The donor has the right to remain anonymous	7	1–7	71	7	3–7	66	7	2–7	46	7	1–7	45
The recipient has the right to remain anonymous	7	1–7	69	7	2–7	66	7	1–7	46	7	1–7	45
The donor has the right to know to whom he/she is donating a kidney	2	1–7	70	2†	1–7	62	4	1–7	44	5†	1–7	45
The recipient has the right to know from whom he/she is getting a kidney	2	1–7	71	1	1–7	63	4	1–7	45	4	1–7	45
Anonymity makes a donation altruistic	7	1–7	71	7	1–7	64	7	1–7	43	7	1–7	42
The donation should only proceed if the donor agrees to anonymity	3	1–7	69	3	1–7	65	3.5	1–7	44	4	1–7	44

*All statements were scored on a 7-point scale: 1 "completely disagree" to 7 "completely agree".

†Recipients agree with this statement significantly more than donors ($U = 844.5$, $P < 0.000$, $r = 0.35$). No other significant group differences (T0 versus T1 or donor versus recipient) were found at a P value of <0.001.

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Results

Participants

During the inclusion period, 92 donors and 92 recipients were approved for anonymous living kidney donation/transplantation. Three donors and 13 recipients were excluded (Fig. 1). Eighty-nine donors and 79 recipients were invited to participate, 46 declined participation (nonresponders). Seventy-two donors and 50 recipients completed the first measurement (response rates 81% and 63%, respectively). Notably, the participating donors and recipients do not all match up as couples (e.g., the donor may have participated, while the recipient refused). Three donors and five recipients dropped out during the study and did not complete the second measurement. There were no significant differences on T0 experience and attitude items between methods of completion, and there was no relationship with immediacy of the operation.

Socio-demographic and medical characteristics

Socio-demographic and medical characteristics are presented in Table 1. Participants (n = 122) were not significantly different from nonresponders regarding gender and age. However, nonrespondent donors were more often specified donors than unspecified donors ($\chi^2(1) = 11.55$, $P = 0.001$, OR = 8.15). This difference was not found among recipients.

Experiences with anonymity before and after surgery

Satisfaction with anonymity

Participants were satisfied with anonymity before (median = 6, range: 1–7) and after surgery (median = 7, range: 1–7) (Table 2). This did not significantly differ over time or between donors and recipients. Of all participants, 14% wanted to meet before and 23% wanted to meet after surgery. This did not significantly differ between donors and recipients. However, if the other party would want to meet, more participants would be open for a meeting (T0: 50%; T1: 55%). This did not significantly differ over time or between donors and recipients. In addition, we found no evidence that responses to any of these statements differed between unspecified donors and specified indirect donors, nor between waitlist recipients and exchange recipients (Tables S1 and S2).

Thirty-two recipients elaborated on their reasons for (not) wanting to meet their anonymous donor. Recipients did not want to meet their donor because they feared that this would provoke emotions or stress (n = 6), would lead to cancelation of the transplantation if the donor/recipient would be different than expected (n = 5), or that it would lead to an unequal

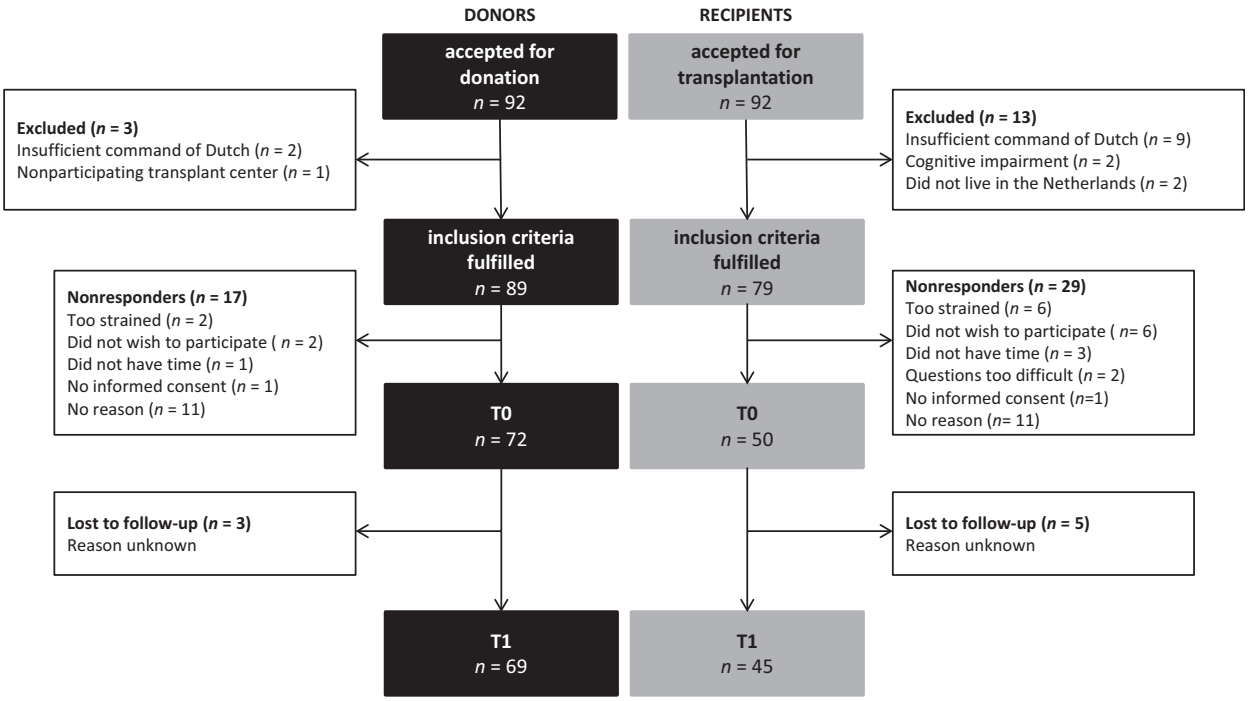

Figure 1 Flowchart of participants.

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relationship with the donor ($n = 3$). One recipient wanted to respect the donor's wish for anonymity, and another recipient found enough satisfaction in the contact with his exchange donor. Recipients who wanted to meet their donor wanted to know ($n = 5$) and thank the person ($n = 8$) who gave them such a generous gift. Some wanted to meet the donors' potential need for a meeting ($n = 7$) or share their experiences and improved quality of life with the donor ($n = 3$).

Sixty-five donors elaborated on their reasons for (not) wanting to meet their anonymous recipient. Most donors who did not want to meet (before surgery) feared that a meeting could influence their decision to donate ($n = 21$). Others made a conscious choice for anonymity and/or did not feel the need to meet the recipient ($n = 14$), feared that a meeting would provoke emotions or create a bond with the recipient ($n = 7$), feared an unequal relationship with the recipient ($n = 6$), or found enough satisfaction in the contact with the exchange recipient ($n = 5$). Most donors who wanted to meet expected that such a meeting could be important for the recipient and wanted to meet the recipient's need ($n = 18$). Some wanted to share experiences with the recipient ($n = 3$), expected that such a meeting would enhance their satisfaction about the decision to donate ($n = 2$), or were curious about the recipient ($n = 2$).

Donor–recipient contact

Two specified indirect donors accidentally met their recipient. One donor was completely discontent with the breach of anonymity and regretted the accidental meeting. The other donor was content with meeting his recipient, and even though he felt slightly uncomfortable, he did not regret the meeting.

Thirteen recipients (26%) had sent an anonymous card to the donor, and 31 (62%) had not. Six recipients did not complete this question. Analysis of the open-ended questions revealed the main reason for recipients to send a card was to thank the donor ($n = 11$). Recipients who had not sent a card to their donor were still planning to do so ($n = 9$), did not know about the possibility to send an anonymous card ($n = 7$), wanted to recover more first ($n = 6$), and/or did not feel the need to send a card ($n = 5$).

Sixteen donors (22%) had received an anonymous card from their recipient, and 50 (69%) had not. Six donors did not complete this question. Most of the donors who received a card reported that the card meant a lot to them and that they were happy to hear from their recipient ($n = 13$). One donor who received a card on the day of discharge reported regrets receiving the card so early in his recovery. Donors who did not receive a card either did not have a strong opinion on it ($n = 18$), felt disappointed ($n = 13$), or did not know about the possibility for recipients to send anonymous cards ($n = 8$).

Attitudes toward anonymity

The median attitudes toward anonymity are presented in Table 3. We found no evidence for differences in attitude between donors and recipients nor between T0 or T1, except for the statement "The donor has the right to know the other party". At T0, most participants somewhat disagreed with this statement (Median = 3, range: 1–7). No significant difference was found between donors and recipients. At T1, recipients (Median = 5, range: 1–7) agreed with this statement significantly more than donors (Median = 2, range: 1–7), $U = 844.5$, $P < 0.001$, $r = 0.35$.

Associations between attitudes and socio-demographic and medical characteristics

At T0, no significant associations were found. At T1, better self-reported graft functioning among recipients was significantly related to greater agreement with the statement that "The donor has the right to stay anonymous (T1)" ($r_s = 0.540$, $P < 0.001$). Also, the donor's age was significantly related to agreement with the statement that "There must be anonymity between donor and recipient after the operation (T1)" ($r_s = 0.395$, $P = 0.001$). No significant relationships were found between attitudes toward anonymity and gender, education, dialysis before transplantation, previous transplantations, duration of hospitalization, complications after surgery, and participants' health status. In addition, we found no evidence that attitudes toward anonymity differed between unspecified donors and specified indirect donors, nor between waitlist recipients and exchange recipients (Tables S1 and S2).

Discussion

This is the largest longitudinal study to date to explore the donor and recipient perspective on anonymity in living kidney donation. In line with the current policy on anonymity in the Netherlands, anonymity was maintained for 98% of participants. Most donors and recipients were satisfied with being anonymous to their recipient/donor and agreed that there should be anonymity before and after surgery. These results confirm

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the findings of previous studies on the perspective of donors and recipients on anonymity in living donation schemes [7–9]. Despite this high level of satisfaction with absolute anonymity, participants believed that, in general, (other) pairs should be allowed to meet if both parties agree. This contradictory result was also found in a retrospective study by Slaats *et al.* (in press) and seems to indicate that donors and recipients are in favor of a conditional approach to anonymity, rather than an absolute approach [10].

A minority of participants wanted to meet the other party. The reasons why participants wanted to meet include curiosity about the other or, for donors, the outcome of the transplantation and are similar to the ones found in a previous study [9]. Recipients mainly wanted to be able to thank their donor and some donors expected a greater sense of satisfaction if they would be able to see the impact of the donation on their recipient's life. Although the kidney was an anonymous gift, apparently it created a certain bond between giver and receiver; as explained by the Gift Exchange Theory [14]. According to Mauss [15], human beings have a sense of equity and reciprocity, and when there is no possibility to repay the gift, difficulties can arise (e.g. as expressed by deceased-donor–recipients [16]). Also, in clinical practice, it is often assumed that unspecified donors differ from specified donors and waitlist or exchange recipients in their attitude toward anonymity. However, our (short-term) results revealed that participants' experiences with, and attitudes toward, anonymity did not differ between donors and recipients and was not associated with type of transplant program.

Furthermore, participants were much more likely to be open for a meeting if the other party would want to meet them. These results indicate that participants tend to conform to the need of their recipient/donor when they know that the other person would like to have contact, even when this is not their own personal desire. Such individuals might be at risk of experiencing difficulties if the meeting is disappointing, because they may experience greater ambivalence about a meeting. However, this requires further research.

Finally, we found that participants' attitude toward anonymity in living kidney donation did not change over time. This is in line with findings of Kranenburg *et al.* [9]. In practice, if transplant coordinators were to assess desire for contact with the other party, these findings suggest that answers are not likely to change during the period shortly before or after surgery.

The findings of this and previous studies indicate that anonymity before and after donation should remain the norm. Despite this norm, transplant professionals should not simply prohibit the revoking of anonymity and deny contact for the minority of donors and recipients who desire this. This preference should be taken seriously, especially as some of these donors and recipients are not able to achieve closure [10]. A first step should be to standardize education on the possibility of anonymous correspondence between donor and recipient, as our findings showed that a number of donors and recipients do not know about this possibility and that some donors feel disappointed when they do not receive a card. Secondly, in agreement with Mamode *et al.* [3], we argue that a conditional approach to anonymity should be adopted. This means that if both parties requested to have contact with or meet their donor/recipient, they should be allowed to after surgery. The question remains whether, if one person has filed a request to meet, the other half of the pair should be actively approached with the question whether they would like to meet too. It is likely that such an active approach would encourage the tendency to conform to the other party's wishes [10]. To prevent this, we propose a passive, standardized approach to removal of anonymity in which transplant centers keep a record of donors' and recipients' requests to meet their recipient/donor. Only in case both donor and recipient have, independently, requested a meeting, their request should be approved. Education on this should then be included in the preoperative work-up.

However, such an approach would require effort from transplant professionals to educate patients and donors on potential advantages and disadvantages of nonanonymity and accurately register individuals' wish to meet. To guarantee a standardized procedure, we encourage the development of national guidelines on how to revoke anonymity. These guidelines should include educational recommendations, for example as developed by Slaats *et al.* (in press). These educational guidelines provide the most commonly reported reasons for donors and recipients (not) to want to maintain anonymity. Such information can help donors and recipients who are considering revoking anonymity to make a decision and help to manage their expectations. In addition, guidelines should describe the logistical procedures, for example how the wish to meet is to be independently assessed (active/passive) and registered (where, who), and how and when anonymity could be revoked, for example by exchanging contact details (which) or by arranging a potential meeting. The question remains: who is responsible for education on the potential risks (and benefits) of revoking anonymity, for

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the facilitation of meetings, and/or follow-up care. The reporting of experiences in countries with a conditional approach to anonymity would provide valuable information for making such policy decisions. Maple *et al.* [5] found that although 65% of nondirected altruistic (unspecified) donors in the UK had found out what happened to their recipient, only 12% of the donors reported to have further contact with their recipient, and less than 2% met in person. However, it is unknown how these donors experienced the contact or meeting with their recipient (and vice versa).

Despite the strengths of this study, such as the longitudinal multicenter design and high response rates, some limitations should be taken into consideration. Firstly, as this was an exploratory study, we did not perform a formal validity assessment of the questionnaire. Secondly, we examined the experience with, and attitudes toward, anonymity in the short-term. It might be that the curiosity about the other, or the outcome of surgery, grows over time. Future studies should use a longer follow-up period to investigate this. Thirdly, the exclusion of participants who did not speak Dutch sufficiently may have introduced bias, particularly among the waitlist recipient group. Fourthly, one-third of all donors and recipients accepted for surgery did not complete both measurements. We do not know to what extent the attitudes found are representative of the attitudes held among those who dropped out of the study. Finally, the results cannot be generalized to donors and recipients who have (deliberately) not participated in anonymous living donation schemes.

In conclusion, most donors and recipients who participated in anonymous donation schemes were satisfied with absolute anonymity. Nevertheless, the majority of participants believed that a meeting between donor and recipient should be allowed if both parties agree to that. This suggests support for a conditional approach to anonymity. Participants' attitude toward anonymity did not change over time. Guidelines on how to revoke anonymity if both parties agree are needed and should include education about pros and cons of (non-) anonymity and a logistical plan on how, when, where, and by whom anonymity should be revoked.

Authorship

MCP: participated in research design, data collection, data analysis and writing of the article. DS: participated in research design and writing of the article. JV: participated in research design, data collection and writing of the article. KAMIP: participated in research design and writing of the article. IMD: participated in research design and writing of the article. FJMFD: participated in research design and writing of the article. WW: participated in research design and writing of the article. JW: participated in research design and writing of the article. WCZ: participated in research design and writing of the article. EKM: participated in research design, data analysis and writing of the article.

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Conflict of interests

The authors have declared no conflicts of interest.

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SUPPORTING INFORMATION

Additional Supporting Information may be found online in the supporting information tab for this article:

Table S1. Differences between transplant programs on experiences, preferences and attitudes (measured at T0).

Table S2. Differences between transplant programs on experiences, preferences and attitudes (measured at T1).

Appendix S1. Anonymity in living kidney donation questionnaire.

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REFERENCES

1. Dor FJ, Massey EK, Frunza M, *et al.* New classification of ELPAT for living organ donation. *Transplantation* 2011; **91**: 935.
2. Frunza M, Van Assche K, Lennerling A, *et al.* Dealing with public solicitation of organs from living donors – an ELPAT view. *Transplantation* 2015; **99**: 2210.
3. Mamode N, Lennerling A, Citterio F, *et al.* Anonymity and live-donor transplantation: an ELPAT view. *Transplantation* 2013; **95**: 536.
4. Rodrigue JR, Schutzer ME, Paek M, Morrissey P. Altruistic kidney donation to a stranger: psychosocial and functional outcomes at two US transplant centers. *Transplantation* 2011; **91**: 772.
5. Maple H, Chilcot J, Burnapp L, *et al.* Motivations, outcomes, and character istics of unspecified (nondirected altruistic) kidney donors in the United Kingdom. *Transplantation* 2014; **98**: 1182.
6. Lennerling A, Fehrman-Ekholm I, Nordén G. Nondirected living kidney donation: experiences in a Swedish Transplant Centre. *Clin Transplant* 2008; **22**: 304.
7. De Klerk MLA, Luchtenburg AE, Zuidema WC, *et al.* Acceptability and feasibility of cross-over kidney transplantation. In: Gutmann T, Daar AS, Sells RA, eds. *Ethical, Legal and Social Issues in Organ Transplantation*. Lengerich: Pabst, 2004: 255–262.
8. De Klerk MZW, Kranenburg K, IJzermans JNM, Weimar W. Justification for anonymity in a kidney exchange program. In: Weimar W, Bos MA, Busschbach JJ, eds. *Organ Transplantation: Ethical, Legal and Psychosocial Aspects Towards a Common European Policy*. Lengerich: Pabst, 2008: 236–240.
9. Kranenburg L, Zuidema W, Vanderkroft P, *et al.* The implementation of a kidney exchange program does not induce a need for additional psychosocial support. *Transpl Int* 2007; **20**: 432.
10. Slaats D, Lennerling A, Pronk MC, *et al.* Donor and recipient perspectives on anonymity in living kidney donation: A multi-center survey study. *American Journal of Kidney Diseases* In Press.
11. Bailey PK, Ben-Shlomo Y, de Salis I, Tomson C, Owen-Smith A. Better the donor you know? A qualitative study of renal patients' views on 'altruistic' live-donor kidney transplantation. *Soc Sci Med* 2016; **150**: 104.
12. Massey EK, Kranenburg LW, Zuidema WC, *et al.* Encouraging psychological outcomes after altruistic donation to a stranger. *Am J Transplant* 2010; **10**: 1445.
13. EuroQol G. EuroQol – a new facility for the measurement of health-related quality of life. *Health Policy* 1990; **16**: 199.
14. Simmons R, Marine S, Simmons R. *Gift of Life: The Effect of Organ Transplantation on Individual, Family and Societal Dynamics*. New Brunswick, NJ: Transaction Books, 1987.
15. Mauss M. *Gifts-Forms and Functions of Exchange in Archaic Societies*. London: Cohen & West, 1954.
16. Schweda M, Wöhlke S, Schicktanz S. Understanding public skepticism toward organ donation and its commercialization: the important role of reciprocity. *Transplant Proc* 2009; **41**: 2509.

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