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The implementation of a kidney exchange program does not induce a need for additional psychosocial support

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Summary

The Dutch kidney exchange donation program started in January 2004. A literature review has shown that several factors of the exchange program could influence the psychological well being of participants, such as the loss of the possibility of a 'medical excuse' for unwilling donors and the issue of anonymity. However, these factors have not been the subject of empirical study yet. We therefore studied these factors to determine whether additional psychosocial support is necessary for donors and recipients in the Dutch kidney exchange program. We used structured interviews for all 48 donors and recipients that had undergone exchange donation/transplantation in 2004. A psychologist interviewed the participants before and 3 months after transplantation. We included a comparison group of 48 donors and recipients participating in the regular living kidney donation program. Donors did not experience additional pressure to donate due to the exchange donation. Most participants (69%) preferred anonymity between the couples. Ten percentage needed additional emotional support. In this respect the exchange group did not differ from the comparison group. We conclude that the psychosocial support offered to exchange couples can be comparable with the support normally offered to participants in the regular living kidney donation program.

Introduction

The Dutch living kidney exchange program started in January 2004. All seven Dutch transplant centers collaborate in this program [1]. Before embarking on the program, we published the results of a literature search on psychosocial and ethical issues related to kidney exchange [2]. We identified five topics: the influence of 'donation via strangers' on the motivation and willingness of donor-patient couples, the question of anonymity, the loss of 'medical excuses' for unwilling donors, the view that exchange donation is a first step to commercial organ transplantation, and the interference with existing organ donation programs [3–6]. At that stage, we concluded that in theory neither of these issues, nor the combination of them seemed to propose an objection to the introduction of the exchange donation program in the Netherlands. However, we felt the need to study a number of these issues empirically, for two reasons. First, a number of studies on kidney exchange donation have been published [7–9]. Although these studies claim that psychosocial implications of kidney exchange programs are important for both the donors and recipients, so far empirical studies on psychosocial implications of kidney exchange programs are lacking. Secondly, empirical data on psychosocial aspects of the kidney exchange program will help us evaluate, and if necessary, adjust our existing protocol for psychosocial support.

Materials and methods

Participants

We included all 48 donors and recipients (24 couples) who were the first to participate in the Dutch kidney exchange program in 2004. We included a comparison group to make comparisons on need for additional psychosocial support. The comparison group consisted of 48 donors and recipients (24 couples) participating in the regular living kidney donation program. Patient and donor characteristics are summarized in Table 1. All participants in the Dutch kidney exchange program were included, and participants to the regular directed living kidney donation program were selected at random from the registers of the seven participating transplant centers. Anticipating local differences, we matched the exchange group and the comparison group for transplantation center. For instance, if there were six donor–recipient couples in the exchange program coming from Rotterdam's transplant center, we also selected six donor–recipient couples from Rotterdam in the comparison group. All participants were included before donation/transplantation, and they had completed all of the necessary pretransplant medical procedures. Besides the 24 couples who actually donated/were transplanted within the kidney exchange program, we also included 16 of the 18 donors and recipients (eight couples) who registered for the exchange program for at least half a year, but who had so far not been selected for transplantation.

The Dutch law on human medical research (WMO) does not require an official approval of the Institutional Review Board, because this study concerns noninvasive, questionnaire-based research with a low frequency of administration [10]. The informed consent procedure took place as follows: the local transplant coordinator let the potential participants know that a study would be taking place and that the researchers involved in the study would approach potential participants with a letter clarifying details of the study together with an accompanying telephone call. When we telephoned the potential participants to our study, all were willing to participate and gave their verbal consent.

Materials

Interview data were collected at two different time points; before (T1) and 3 months after donation/transplantation (T2). At both T1 and T2, the donors and recipients underwent a structured interview. At T1 they also completed a questionnaire on coping styles. A psychologist interviewed all participants. Interviews took place at the participants' home or in the hospital. Donors and recipients were interviewed separately. The structured interview consisted of questions with set response categories, and several open questions. Participants were asked to explain their answers to the set response categories. The psychologist summarized these explanations, and the responses to the open questions. The psychologist and the subject then verified these summaries for accuracy and completeness. The interview consisted of all topics that were mentioned in the literature as potentially influencing patients' and donors' psychosocial outcomes: the decision-making process on entering a new kind of donation procedure, the loss of the possibility of a 'medical excuse'

Table 1. Donor and recipients characteristics.

	Exchange donors	Exchange recipients	Comparison donors	Comparison recipients	Total
N	24	24	24	24	96
Male/female	10/14	11/13	4/20	14/10	96
Median age	54	49	52	45	
Median waiting time (SD; range; years)		1 (1.2; 0–4)		2 (1.7; 0–7)	
Partner	17	17	7	7	48
Mother	4	–	5	–	9
Father	–	–	2	1	3
Daughter	–	2	–	6	8
Son	–	2	1	1	4
Sister	1	1	5	2	9
Brother	–	–	–	3	3
Sister-in-law	1	1	–	–	2
Brother-in-law	–	–	–	–	0
Aunt	–	–	–	–	0
Uncle	–	–	–	1	1
Niece	–	–	1	–	1
Cousin	–	–	–	–	0
Friend	1	1	3	3	8

Table 2. Decision-making, loss of 'medical excuse', limited contact possibilities, and anonymity in the exchange donation group.

Questions before donation/transplantation	Response categories	Exchange donors	Exchange recipients
1) You decided to participate in the exchange donation program. To what degree was this either a difficult or an easy decision?	1. Very easy	14 (58%)	10 (46%)
	2. Easy	10 (42%)	5 (23%)
	3. Difficult	0	6 (27%)
	4. Very difficult	0	1 (5%)
2) What was your main reason to participate?	Open question		
3) […] Do you feel pressured or coerced to donate?	Open question		
4) In the exchange program anonymity is maintained. How do you feel about that?	1. I prefere anonymity	17 (71%)	16 (67%)
	2. Indifferent	2 (8%)	4 (17%)
	3. I would have preferred to get acquainted	5 (21%)	4 (17%)
Questions before donation/transplantation			
5) Was it troublesome for you that you could not see your donor/recipient directly after the operations†?	1. Very troublesome	3 (15%)	5 (26%)
	2. Somewhat troublesome	6 (30%)	5 (26%)
	3. Not really troublesome	3 (15%)	2 (11%)
	4. Not troublesome	8 (40%)	7 (37%)
Was your experience better or worse than expected?	1. Better	10 (50%)	10 (53%)
	2. Worse	3 (15%)	5 (26%)
	3. As expected	7 (35%)	4 (21%)
6) You did not directly donate to/receive from your partner, sister, etc. but indirectly, through a third person. Which of the following descriptions suits your experience of the exchange donation? (Please explain your answer)	1. To me it is as if I directly donated to/received from my partner, sister, etc.	13 (54%)	10 (43%)
	2. The idea is a bit awkward, but is a minor detail, in the end it is all about the recipient getting a transplant	6 (25%)	6 (26%)
	3. I experience it as a problem that another couple is involved in 'our' transplantation	0 (0%)	0 (0%)
	4. Actually I feel quite comfortable donating/receiving through a third person	1 (4%)	3 (13%)
	5. None of the above	4 (17%)	4 (17%)

*Missings occurred once a person could not clearly choose for/be assigned to a specific response category.
†Numbers for item 4 do not add up to 24, because four couples were operated in the same hospital. Consequently, this item 4 was not applicable to them. The number of exchange recipients does not ad up to 20 because we lost one recipient due to nontransplantation-related complications.

for unwilling donors, the influence of anonymity on the well-being of participants, the limited contact possibilities between couples after transplantation, and psychological distress in case of a longer waiting time than anticipated (Table 2). Some of these questions had already been tested in an earlier pilot study on exchange donation [6]. In order to take into account topics that may be of influence as well but were not addressed during the interviews, we ended the interview with an open question asking for any need for additional psychosocial support. To measure coping styles, we used a validated coping list, the Utrechtse Coping Lijst (UCL) [11,12]. We included the questionnaire on coping styles, because we anticipated that coping styles might be associated with the amount of additional psychosocial support needed [13,14]. The questionnaire consists of 47 self-report items, comprising seven subscales (those subscales are not presented to the participant): active confronting, palliative response, avoidance, seeking social support, depressive reaction pattern, expression of emotions, and comforting thoughts. On a 4-point scale, the respondent has to identify how often in general he/she reacts to problems or difficult situations in the way described.

The group of 16 donors and recipients who registered for the exchange program but had not yet been selected for transplantation were interviewed by different means than the other 96 participants in our study. This was inherent to the nature of their situation; we considered it inappropriate to ask them about issues such as anonymity as they had no prospect for donation/transplantation in the short term. Therefore, we developed a specific interview for them. This interview focused on their experience of not being selected for transplantation in the last period of time, their attitudes toward the exchange donation program and their need for additional psychosocial support (Table 3). These 16 donors and recipients were interviewed over telephone by the psychologist. The psychologist read out loud the possible response categories to the participants. For most questions, an explanation of the choice for a specific response category was asked. Once the participant had provided an explanation, the psychologist wrote down a summary of this explanation, and then read out the summary to the participant in order to verify the summary for accuracy and completeness.

Statistics

We used SPSS 11 frequency counts for the data presented in Tables 2 and 3. In order to investigate the relationship between coping styles and the reported need for support we used Spearman's test. For variables specific to exchange donation (i.e. variables where no comparison could be made between exchange condition versus tradi-

Table 3. The group donors and recipients who had registered for the exchange program for at least half a year, but were not selected for transplantation (yet).

Question	Response categories	Donors	Recipients
1. Do you experience distress/tension in the period during which attempts are made to find a match for you? (Please explain your answer; in case of 1, 2, 3: How are you dealing with this distress?)	1. Yes, a lot	1	2
	2. Yes	1	1
	3. Some	2	2
	4. Not really	3	2
	5. Not at all	1	1
2. More generally, you have now participated in the program for over half a year, but until now you could not be successfully matched. How do you experience this situation?	Open		
3. Thinking of your present situation, how do you evaluate the exchange program? (Please explain your answer)	1. Positive	8	7
	2. Less enthusiastic, but still positive	0	1
	3. Negative	0	0
	4. Other	0	0
4. Again, thinking of your present situation, do you consider withdrawal from the program? (Please explain your answer)	1. No	8	6
	2. Yes, but would not	0	2
	3. Yes	0	0
	4. Other	0	0
5. In case another donor–recipient couple would consult you whether or not to participate in the program; what would your advice be?	1. Positive	8	8
	2. Negative	0	0
	3. Other	0	0
6. […] We can imagine that it may be difficult to accept that a match was not found in the short term, and that you may prefer to talk this over with a professional. […] Do you wish psychosocial support from the hospital? (Please explain your answer, if 4. with whom?)	1. No, I can handle this myself/with my family	6	5
	2. No, because…	2	3
	3. Not at the moment	0	0
	4. Yes	0	0

tional condition), we used the method of Cohen's kappa for correspondence (statistics software AGREE [15]) to take into account the fact that each individual was part of a certain donor–recipient dyad. The items with a ranking in response categories were analyzed by using squared weighted Cohen's kappa. Statistical significance, when using Cohen's kappa, suggests no differences between conditions. For comparisons between the exchange and the comparison group, we used Fisher's exact test. For more complex comparisons between the exchange and the comparison group, we applied the method of latent transition analyses (statistics software M PLUS [16]). We created a class variable for the relatedness of donors and recipients, both before and after transplantation. This enabled us to test the difference between the exchange and traditional condition while explicitly taking into account the pairedness within the structure of the data set.

Results

Factors that could explain a greater need for psychosocial support in exchange donation

Decision-making process

A large proportion of participants in the exchange donation group were partners (Table 1). At an earlier stage they had already decided positive about living kidney donation, but then learnt they were incompatible. For them the decision to participate in an exchange procedure was easily made because both donors and recipients experienced the new possibility of exchange donation as a great opportunity for improving their quality of lives. To quote a male donor donating to his wife 'Once you're married, it goes without saying. Both our quality of lives will improve'. Of course, the novelty and complexity of the exchange procedure were mentioned with regard to the decision-making process, but these issues were of lesser importance than the will to donate or get transplanted. The 15% that had experienced difficulties in deciding whether or not to participate in exchange donation were all recipients (Table 2). Nevertheless, Cohen's κ for correspondence between donor and recipient was statistically significant ($\kappa = 0.31$; $P = 0.01$). Reported worries concerned the future health status of the donor and relationship with the donor after donation/transplantation. These kinds of worries are also found for the recipients in our comparison group, and therefore not specific to exchange donation.

Loss of the possibility of a 'medical excuse' for unwilling donors

We asked all exchange donors whether they felt additional pressure or coerced into donating within the exchange donation program. All but two responded that this was not the case. Rather, they were pleased to find out about the possibility of exchange donation. Two exchange donors felt pressured; however, when asked to clarify their response they indicated that the pressure came from themselves, in terms of their own conscience, rather than feeling pressurized by the hospital or family members. In the comparison group, none of the donors reported feeling any kind of pressure from external sources.

Influence of anonymity or acquaintance on the well-being of participants

Before donation/transplantation 69% appreciated the anonymity of the Dutch exchange program, and 19% expressed preference to get acquainted with the other couple (Table 2). The main explanation given for the preference for anonymity was the fear for grievances between couples in case of disappointing or differing transplant outcomes. Another explanation given was that they considered the predonation/transplantation period already as stressful, and getting to know the other couple would most likely only have increased those stress levels. Cohen's κ for correspondence was statistically significant for interactions between condition (donor or recipient) and time (before or after transplantation, $\kappa = 0.42$; $P < 0.001$). After donation/transplantation, an explanation often given for the interest in meeting the other couple was curiosity. Reason for not wanting to meet was the wish to preserve the experience of the procedure as if it were a directed donation. This last finding is confirmed by the findings presented in Table 2: half of the participants report experiencing the exchange donation as if it was a directed donation. For this variable we found a statistically significant correspondence between donors and recipients ($\kappa = 0.46$; $P < 0.001$).

Limited contact possibilities between couples after transplantation

In the Dutch exchange donation program, the original donor and patient couple are separated: the donor is operated in the hospital of the other patient. There was diversity into what extent donors and recipients reported difficulties with being hospitalized in different transplant centers. Experiencing difficulties varied from 38% with no difficulties at all, to 41% in between, and 21% reporting difficulties (Table 2). There was a statistically significant correspondence between donors and recipients (Cohen's $\kappa = 0.60$; $P = 0.04$).

After donation/transplantation, on the whole the separation was experienced as less distressing than expected; for this variable we found no statistically significant correspondence between donors and recipients (Cohen's $\kappa = 0.29$; $P = 0.10$).

Psychological distress in case of not being selected for transplantation

Sixteen donors and recipients who had registered for the exchange program for at least half a year, but were not selected for transplantation, were included in this part of the investigation. Most of them did indeed report experiencing psychological distress, for instance worrying about the future. This was especially true for patients (rather than donors), and for the time period around receiving the results of the matching procedure. Despite reporting distress, none of them indicated a need for additional psychosocial support, because they felt capable in dealing with the situation themselves. Furthermore, we found that the longer waiting time did not result in devaluation or a planned withdrawal from of the exchange kidney donation program. All of the respondents would recommend the exchange program to others in the same situation. In giving this recommendation, many respondents mentioned that with more couples in the program their chances of finding a match would improve. These results are summarized in Table 3.

Reported need for additional psychosocial support

Need for additional psychosocial support provided by the hospital

Before donation/transplantation, we asked all donors and recipients in our study whether they felt the need for additional practical or emotional support. Twenty-six percentage reported a need for additional practical support and 4% reported a need for additional emotional support. Donors and recipients in the exchange group reported more need for practical support before donation/transplantation compared with the comparison group (latent transition analysis, $P < 0.001$). The reported needs often comprised practical assistance, for instance help with insurance or domiciliary care. This difference between the exchange group and comparison group in need for additional practical support was not found after donation/transplantation. There was no difference in need for emotional support between the exchange group and comparison group, either before or after donation/transplantation. Of all 96 donors and recipients, four persons reported a need for additional emotional support before donation/transplantation, and six after donation/transplantation. These were eight different persons (exchange group: two donors, two recipients; comparison group: four recipients). Two of them were already seeing a psychiatrist. There was one couple with relationship problems, and had in fact been referred to a mental health institution. Six persons indicated needing additional support because of the emotional impact of the procedure and/or support for coping with complications. We found no correlation between the UCL subscales and the need for additional psychosocial support (for all seven subscale correlations were: $r < 0.18$; $P > 0.10$).

Psychological complaints after donation/transplantation

After donation/transplantation, 16 participants in our study reported psychological complaints (exchange group: four donors, four recipients; comparison group: two donors, six recipients). Psychological complaints composed of getting over the past event, memory problems, worries about one's health status, and depressive symptoms. Despite the occurrence of these complaints in 16 participants in our study, only half of them reported a need for additional emotional support. We found no statically significant difference in the frequency of occurrence of psychological complaints between the exchange and the comparison group (Fisher's exact test; $P = 0.645$). We found very weak correlations between the UCL subscales 'expression of emotions' and 'seeking social support' and the experience of psychological complaints (respectively, $r = 0.23$; $P = 0.023$ and $r = 0.24$; $P = 0.024$).

Discussion

In the literature, concerns about the psychosocial aspects of exchange donation focus on the emotional aspects of the procedure. However, we did not find any differences between the participants of the exchange program and the comparison group with regard to need for additional emotional support. The exchange group needed more practical support than the comparison group before donation. Practical support consisted of help with planning and logistics of domiciliary care, appointments, visiting hours, etc. This additional need for practical support could be explained by the additional arrangements the exchange group had to make, as the donor would be in a different hospital. In the Netherlands, psychosocial support of living kidney donors and recipients normally comprises a consultation with both a transplant coordinator and a social worker. Social workers and transplant coordinators need to be aware of and should acted upon a possible need for additional practical support before exchange donation/transplantation. Taking into account the nature of the additional practical support requested, this support can easily be provided during the standard consultation with the social worker or the transplant coordinator. Consequently, we think that there is no need to intensify the existing protocol for psychosocial support. This may have been different if there was no strict anonymity between couples. Reports from the Korean exchange donation program suggest that additional

emotional support is required in case of conflicts between donors' or patients' families, if there were a significant discrepancy in transplant results [17]. For the Dutch situation, wherein anonymity is maintained, the need for additional emotional support does not seem to be determined by the specific donation program (either directed or exchange), but rather by situation-specific factors (e.g. occurrence of complications) or person-specific (e.g. suffering from depression) factors. In expecting person-specific factors to be of influence we included a questionnaire that measured coping styles. However, we found no relationship between the person-specific factor 'coping style' and the need for additional support provided by the hospital. This may possibly be due to the fact that very few needs for additional support were reported, resulting in too little variance to detect such a relationship.

A large proportion of the exchange couples in our study were partners (Table 1). Partners generally are highly motivated for living kidney donation [18]. Possibly because of this determination, they are likely to register for exchange donation, if it turns out that direct donation is not feasible. One reason why direct donation between partners may not work occurs in case the female recipient has developed antibodies toward her husband as a consequence of previous pregnancy. Therefore, there may be relatively more male donors in the exchange donation group (Table 1). Notably, we included all 24 couples that were selected for donation/transplantation during the first year of existence of the exchange donation program. Given this high response rate, one could say that the sample is highly representative. On the other hand, one could argue that the positive attitude of this population toward the exchange program is inherent in the 'early adopter' status of this first group, and cannot be generalized to all future donors and recipients. As part of the quality control of the developing exchange program, further research could test if the positive attitude found among the early participants is indeed present among future candidates for exchange donation.

Conclusion

The first-year evaluation of the psychosocial support in the Dutch kidney exchange donation program suggests that the amount of psychosocial support that is offered to exchange couples can be equal to the amount of support normally offered to participants in the regular living kidney donation program.

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References

1. de Klerk M, Keizer K, Claas F, Witvliet M, Haase-Kromwijk B, Weimar W. The Dutch national living donor kidney exchange program. *Am J Transplant* 2005; **5**: 2302.
2. Kranenburg LW, Visak T, Weimar W, *et al.* Starting a crossover kidney transplantation program in the Netherlands: ethical and psychological considerations. *Transplantation* 2004; **78**: 194.
3. Ross FL, Rubin DT, Siegler M, Josephson MA, Thistlethwaite JR, Woodle ES. Ethics of a paired-kidney exchange program. *N Engl Med J* 1997; **336**: 1752.
4. Thiel G, Vogelbach P, Gurke L, *et al.* Crossover renal transplantation: hurdles to be cleared! *Transplant Proc* 2001; **33**: 811.
5. Sanner MA. Transplant recipients' conceptions of three key phenomena in transplantation: the organ donation, the organ donor and the organ transplant. *Clin Transplant* 2003; **17**: 391.
6. de Klerk M, Luchtenburg AE, Zuidema W, *et al.* Acceptability and feasibility of cross-over kidney transplantation. In: Gutman T, Daar AS, Sells RA, Land W, eds. *Ethical, Legal, and Social Issues in Organ Transplantation*. Lengerich: Pabst. Publishers, 2004: 255–262.
7. Stegall M, Dean P, Gloor J. ABO-incompatible kidney transplantation. *Transplantation* 2004; **78**: 635.
8. Delmonico F, Morrisey P, Lipkowitz G, *et al.* Donor kidney exchanges. *Am J Transplant* 2004; **4**: 1628.
9. Ross LF, Zenios S. Practical and ethical challenges to paired exchange programs. *Am J Transplant* 2004; **4**: 1553.
10. Medical Research Involving Human Subjects Act. Central Committee on Research Involving Human Subjects (CCMO). CCMO-gedragswetenschappelijk onderzoek. http://www.ccmo-online.nl/hipe/uploads/downloads/notitie_gedrags.DOC (in Dutch).
11. Schreurs PJG, Van de Willige G, Brosschot JF, Tellegen B, Graus GMH. *De Utrechtse Coping Lijst: UCL*. Lisse: Swets & Zeitlinger, 1993.
12. Evers A, van Vliet-Mulder JC, Groot CJ. Utrechtse Coping Lijst, UCL, 1988/1993. In: Evers A, van Vliet-Mulder JC, Groot CJ, eds. *Documentatie van tests en testresearch in Nederland*. Assen: Van Gorcum, 2000: 56–57 (in Dutch).
13. Jadoulle V, Hoyois P, Jadoul M. Anxiety and depression in chronic hemodialysis: some somatopsychic determinants. *Clin Nephrol* 2005; **63**: 113.
14. Kim Y, Valdimarsdottir HB, Bovbjerg DH. Family histories of breast cancer, coping styles, and psychological adjustment. *J Behav Med* 2003; **26**: 225.

15. Popping R. *AGREE: Version 6.0 iecProGAMMA Computing Agreement on Nominal Data*. Groningen, the Netherlands: ProGamma, 1995.
16. Muthén LK, Muthén BO. *Mplus Statistical Analysis with Latent Variables Users Guide*. Los Angeles, California: Muthen & Muthen, 2004.
17. Park K, Moon JI, Kim SI, Kim YS. Exchange donor program in kidney transplantation. *Transplantation* 1999; **67**: 336.
18. Thiel G. Emotionally related living kidney donation: pro and contra. *Nephrol Dial Transplant* 1997; **12**: 1820.