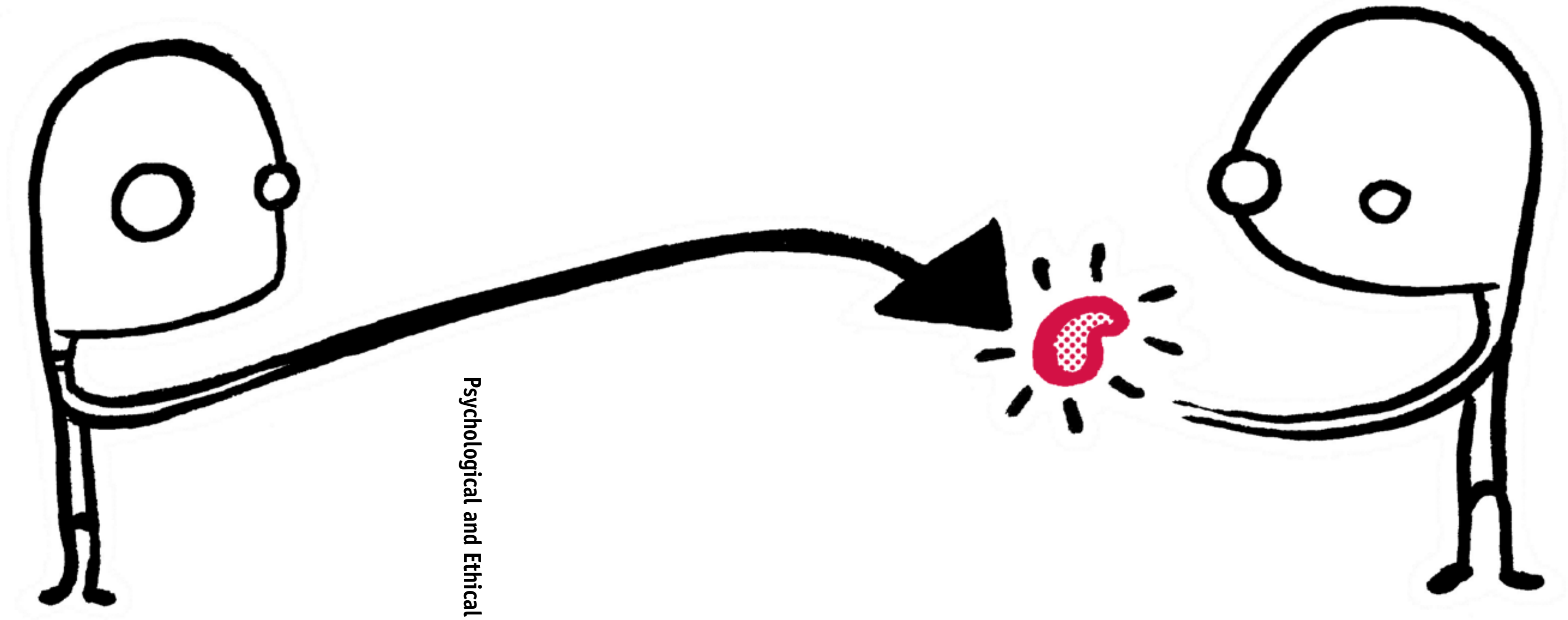

Psychological and Ethical Aspects of Living Kidney Donation

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Psychologische en ethische aspecten van nierdonatie bij leven

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Chapter 1

Introduction

LIVING KIDNEY DONATION

The preferable treatment option for patients with end stage renal failure is a kidney transplantation (1). However, there is a shortage of deceased donor kidneys for transplantation. In the Netherlands, average waiting times for deceased donor kidney transplantation have increased, and range from 2 years for patients with blood type AB to 5 years for patients with blood type O (2). Patients waiting for a deceased donor kidney are dependent on dialysis treatment. Although dialysis is a life saving treatment, patients on dialysis are confronted with lowered quality of life (3, 4) and an increased risk of morbidity and mortality: approximately 25% of all patients die while waiting for a transplant (5). Living kidney donation offers a realistic alternative to patients with end stage renal failure. In living kidney donation, a living donor donates one of his/her kidneys to the patient. Donor risks for potential life threatening or severe complications are reported to be approximately 0.2% (6, 7), and donor mortality risks are estimated at 0.03% (8). The quality of life of living donors after donation is likely to return to pre-donation levels (9), and is reported to be even higher than that of the general population (10, 11). Since the first living kidney donation from a mother to her son in the Netherlands in 1966, the number of living kidney donations has increased to 275 for the year 2005 (2). This means that in the Netherlands currently over 40% of all kidneys transplanted come from living donors. In the past, only the patients' close relatives were considered suitable as living donors for immunological reasons, but over the last decades non-related living donor kidneys have proved to give similar good outcomes (12, 13). In addition, surgical techniques have improved (14), resulting in better outcomes for living kidney donors. At present the laparoscopic donor nephrectomy is advocated as the preferable surgical approach, because of the beneficial effect on the quality of life and the earlier return to work of the donors (9, 15). It is partly because of these findings that the practice of living kidney donation has rapidly developed over the past decade.

Below I will outline three major developments. Firstly, the knowledge that kidneys from non-related donor kidneys function equally well compared to kidneys from related donors, has increased the chances of finding a suitable living donor. Spouses or partners, second-degree family members, friends etc., all became, in principle, eligible for living donation. It emerged that spouses especially were enthusiastic about donating to their ill partner, because the emotional bond may be stronger and it provided both with the potential for a better quality of life (16). Our Centre's data show, that the proportion of partner donations has increased from three partner donations in 1986-1990 to 77 in 2002-2006. The trend of relatively more partner donations can also be seen in other countries (17, 18). A second development in the field of living kidney donation is kidney exchange donation (19). Kidney exchange donation offers an opportunity for recipients who cannot receive directly from their original donor, due to blood type incompatibility or a positive cross-match. Incompatible donor-recipient couples can register for an exchange donation procedure, wherein patients exchange donors in order to receive a compatible kidney. A third development is the growing acceptance of Samaritan kidney donors; people who are willing to donate a kidney to a patient they do not know (20). Over the last years, the reluctance in regard to Samaritan donors seems to be decreasing: recently some transplant centers have started to publish their first results using Samaritan donation (21). The reluctance to accept the offers of Samaritan donors may not be based so much on medical grounds but more on psychological grounds; as for a long time there were concerns that such donors might become mentally unstable (22).

PSYCHOLOGICAL AND ETHICAL ASPECTS

Although the rapid development of living kidney donation over the past decade represents a medical success story, one can identify several ethically and psychologically dilemmas and complications. In making this observation, it should be noted that it is somewhat artificial to strictly separate 'medical', 'ethical' and 'psychological' perspectives: such strict separation wrongly implies that moral and psychological considerations are not routinely part of basic (transplant) medicine. Indeed ethical and psychological considerations have been part of transplant medicine from the beginning. The regular citing of the works of Simmons, Fellner, and Sadler in 'medical' transplant journals provides clear evidence for this (for instance 23-25, cited in resp. 26-28). Their work dates back to the early seventies. During this period questions about violating the "do no harm principle" by taking one kidney from a healthy person was a central theme. Nowadays the surgical practice of living kidney donation is generally not viewed as "doing harm" but is justified by the increased survival chances of the patient and low incidence of complications and by the psychological benefits for the donor (29). The donor benefits by improving survival chances and quality of life of his/her loved one. In addition, especially in case of partner-donations, there is a good chance that the donor's own quality of life will improve as well. After transplantation they will be able to undertake more activities together, without the worry of dialysis: they will be able to go out more, to go on holiday etc. Furthermore, there are reports of increased donor self-esteem after donation (30). Another issue that aroused controversy in the early days of living kidney donation was the fear for donor coercion, i.e. the fear that a donor may not in fact be a willing participant but instead had been forced to donate against his/her will (31). Donor coercion has serious moral and psychological consequences such as the violation of the donor's autonomy and freedom of choice. Psychologically, acting against one's will evokes negative feelings and regrets, or disproportionate guilt may occur in case of non-donation. Nowadays, the underlying theme of donor coercion is still present as can be seen from recent questions from members of the Dutch parliament about this issue (32) and in discussions on exchange donation (33). In clinical practice, 'donor coercion' is sometimes controlled for by the establishment of separate 'donor advocates' (34, 35), health care professionals who take care of the interests of the donor; and report cases of hesitating or ambiguous 'donors' to the physician. In these cases, if necessary, the physician may provide a 'medical excuse' by saying the donor is not suitable for donation (for medical reasons). In this way doctors protect the unwilling donor from precarious interpersonal situations.

As stated at the beginning of this Introduction, new developments have taken place in the field of living kidney donation. These developments raise new ethical and psychological questions. This thesis focuses on the ethical and psychological questions that arise from recent developments in the field of living kidney donation. Below I will set out the ethical and psychological questions, and explain how they fit in this thesis.

Thesis outline

This thesis focuses on the ethical and psychological implications of recent developments in the field of living kidney donation. In studying these implications, we have continuously worked from a multidisciplinary point of view: psychology, ethics and medicine were closely interwoven all the time. Research questions anticipated on or followed the recent developments in the field of transplant medicine. Therefore, the studies presented in this thesis have a somewhat pragmatic character.

The thesis consists of four parts. Part one “direct(ed) donation” comprises studies on donations from living kidney donors to someone they know, with whom they have a genetic and/or emotional relationship. This first part refers to the first recent development in the field of living kidney donation that is described above, i.e. the enlargement of the pool or availability of potential living donors. It is no longer necessary to focus on parents or siblings as a donor. Nowadays anyone, be it your partner, friend or maybe even your neighbour is eligible as a living donor. At first sight, this seems promising, because it improves the chances of finding a living donor. But do the patients view this development positively? What do they think of the current availability of treatment options? In the past, spouses or partners often acted as patient advocates, trying to find a living donor within the family for their ill partner (36). But nowadays they are themselves eligible as donors, and probably the first person who is implicitly expected to donate. This raises questions about how a donation affects equity in the partner relationship, and how donors and recipients handle their feelings of debt and gratitude. Another question is how the knowledge of being eligible as a living donor impacts on the potential donors. How should a person behave if he/she does not want to donate? And finally, how does the increase of availability of potential living donors impact on the physicians who want to provide their patients with the best treatment. If almost anyone within the close environment of the patient can be a living donor, why would physicians not try to reach these potential donors? The question here is to what extent, and for what reasons interference in the personal relationship and private life of the patient can be morally justified.

The second part of the thesis is entitled “indirect donation”. Indirect donations are possible through the implementation of several kidney exchange donation programs. This is the second recent development in the field of living kidney donation that is described above. Living kidney exchange donation raises moral concerns such as: the loss of possibilities to use ‘medical excuses’ for unwilling donors; about the view that ‘exchange‘ donation may be a first step to a commercial organ trade; and about the interference with existing organ donation programs. Psychologically, there are concerns such as: whether or not participants in an exchange procedure should be allowed to meet each other; how the attitude towards donation by a stranger influences the motivation and willingness of donor-patients couples to participate in exchange donation; and how donor-recipient couples cope with a possible scenario wherein they register, but are repeatedly not selected for an exchange procedure. These specific features of an exchange donation program may psychologically affect participants in an exchange donation program. We investigated whether more psychological complaints occurred in participants in an exchange donation program (compared to participants in a ‘regular’, direct donation program), and whether psychosocial care for participants in an exchange donation program should be intensified. Part two of this thesis also addresses ‘altruistically unbalanced’ exchange donation. This is an exchange procedure wherein one donor-recipient pair is incompatible (e.g. A-donor > O-recipient) and the other pair is compatible, but not identical (e.g. O-donor > A-recipient). Exchanging these kidneys would result in two compatible living donor kidney transplants. This procedure raises questions such as whether it can be morally justified to ask a compatible donor-recipient pair to participate in an exchange donation procedure, merely to increase the overall number of transplantations? Further, would compatible pairs be willing to participate in such a procedure?

In the third part of this thesis “non-directed donation”, I will address the third recent development in the field of living kidney donation described above, the decreasing reluctance towards Samaritan kidney donors. Questions about the motivation and mental stability of these donors are central in this part. Allocation issues are also addressed. For example, should Samaritan kidney donors be allowed to direct their kidneys, or should they be permitted to donate them only to the first patient who has been waiting the longest? Should directed donation by Samaritan donors be interpreted as discrimination, or as their basic right?

The fourth part of this thesis is entitled “future directions?”, and addresses the controversial issues of financial incentives for living kidney donation and xenotransplantation, the transplantation of genetic modified pig’s kidneys into humans. We studied public opinion on the acceptability of the idea of introducing financial incentives to increase the number of kidney transplants. We also studied patient’s attitudes towards xenotransplantation. From an ethical point of view, xenotransplantation implies the weighing of individual benefit versus collective risk. Psychologically this futuristic type of transplantation raises issues about human identity. For example, do patients feel they might exhibit animal behaviour after such a transplant or do they conceive this idea as mere science fiction?

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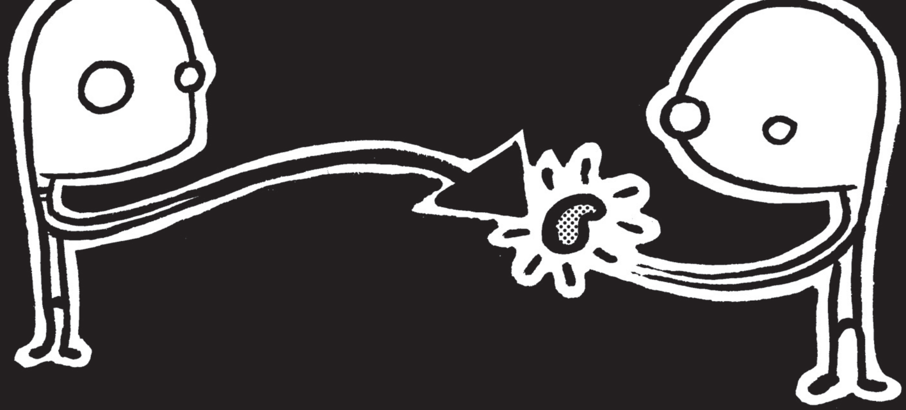
PART I: DIRECT(ED) DONATION

In living kidney donation, a distinction can be made between direct donation and directed donation.

Direct donation refers to the situation in which the donor donates directly to the intended recipient, for example to his father. Indirect donation, on the other hand, is used to describe the situation in which the donor does not donate directly to the intended recipient, but via an exchange procedure. Indirect donation procedures are described in part II of this thesis.

Directed donation refers to the situation in which the donor directs his kidney to a specified person, for example to his father. Directed donation is different from non-directed donation, which occurs when the donor does not specify the recipient. Non-directed donation is described in part III of this thesis.

Part I comprises studies on living kidney donations that are both direct (without a third party involved) and directed (to a specified person).



Chapter 2

Postmortal or Living Related Donor: Preferences of Kidney Patients

Kranenburg L, Zuidema W, Weimar W, IJzermans J, Passchier J,
Hilhorst M, Busschbach J.

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Transpl Int. 2006; 19(7): 600.

SUMMARY

We studied the willingness and motives for accepting a living kidney donation in 61 kidney patients on the waiting list by a semi structured interview and a questionnaire on two occasions. Between both moments of measurement patients received general information on transplantation options. We tested whether demographic data, medical status data or quality of life correlated with treatment choice. Our results showed that 61% of the patients preferred living kidney donation to postmortal donation. Their main motivation for this choice was the better quality of the living kidney. The most often named reasons to choose postmortal donation were unwillingness to burden a loved one and fear of psychological problems in relation to the donor after transplantation. There was no statistical significant change of preference between both moments of measurement; however there seemed to be a tendency in favor of living kidney donation. Fewer years spent on renal replacement therapy correlated statistically significant with the choice for living kidney donation. These findings encourage the development of new strategies to facilitate the living kidney donation program, and confirm the need for the standard option of psychosocial support for patients.

BACKGROUND

The decision-making process of the donor is evaluated in psychological studies on living kidney donation, in order to prevent an involuntary, pressed 'donation'. Research has shown that the decision to donate is most likely to be made in a voluntary manner. In fact, it is usually hard to influence the donor decision, as donors often make the principal decision before detailed information on the transplantation procedure is available and without consulting significant others, such as spouses (1). As so much research is focused on the decision-making process of the donor, it almost seems like the acceptance of a living kidney donation by the patient is taken for granted. This is grounded in the normative view on decision making according to which the patient is assumed to make a rationalistic and calculating treatment decision. Indeed, in weighing gains and benefits for living kidney donation and postmortal donation, living kidney donation would result in higher 'utility' for the patient, as for instance can be expressed in Quality Adjusted Life Years (QALYs) (2). However, empirical research efforts that focus on the patient's willingness to accept the offer of a kidney by a loved one, show that patients may not be as rational and calculating as suggested. One study showed that 80% of 115 recipients actually refused to consider a transplant from their family (3), and in another study less than half of those patients who were offered a living-related kidney donation were willing to accept it (4). Furthermore, a recent study has shown that patients on dialysis do change their mind regularly about remaining on dialysis or opting for transplantation (5). Our research question therefore becomes: what determines the willingness to accept a living-related kidney donation and how stable are these patients' preferences?

METHODS

Patients

Sixty-one patients on the waiting list for a kidney transplant completed a questionnaire on transplantation options and a ranking exercise. The mean age was 50 years and 35 of the 61 patients were male. The interviews took place at the faculty or the university hospital, and occasionally at the patients' homes. The University Medical Ethical review board approved this study and patients were sent full information on the study before they agreed on participation.

Procedure and materials

Patients completed a questionnaire consisting of 'yes–no' questions on the acceptance of various forms of transplantation (6) and a short quality of life questionnaire, the EuroQol EQ-5D (7). In a semistructured interview, patients were asked to imagine that they could choose between various treatment 'options' for ESRD: postmortal transplantation, living-related donation, a commercial donor and xenotransplantation (in the imaginative situation that this would be a possible treatment option). They had to rank these options according to their personal preferences after which they had to motivate their ranking extensively. In this article, we will focus only on the actual and legally allowed treatment options: postmortal donation and living-related donation. In the interview, patients were also questioned about their perception of the risks of transplantation for themselves and the donor. Furthermore they were asked if they already had sought information on transplantation options themselves, and whether they felt the need for additional information and support on living kidney donation. There were two moments of measurement. In between these measurements, patients received general information about the kinds of transplantation that were named in the ranking exercise. The average time between two measurement moments was 2 weeks. We tested the difference between the two measurements in preferences for the donation options and whether demographic data, medical status data or quality of life (as measured with EQ-5D) correlated with the choice for either treatment option.

Statistical analysis

We used chi-squared exact testing, two-sided for binary variables and logistic regression analysis for continuous variables. For the measurement of change between the two measurement moments we used Wilcoxon signed ranks test, two-sided.

RESULTS

Preferences

When patients completed the yes/no questions of the questionnaire for the first time 49 (80%) stated that they would accept a kidney of a living, genetically related person and 50 (82%) stated that they would accept a kidney of a living, genetically unrelated person. The second time they

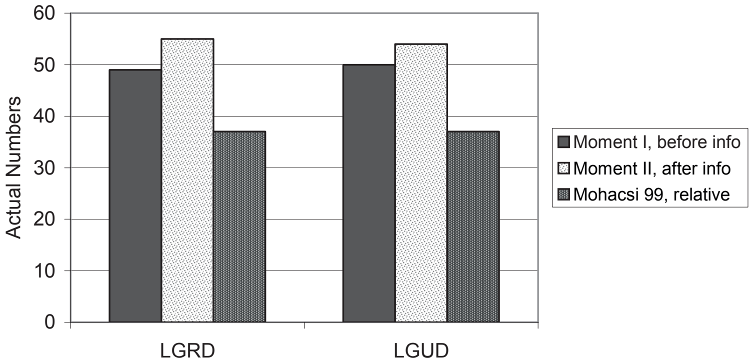

Figure 1. Statements on accepting a living genetically related donor (LGRD) or a living genetically unrelated donor (LGUD) in actual numbers, compared with the findings of Mohacsi [6] (percentages transformed into actual numbers for comparison with our findings). Moment I indicates the period before information was given in our study, at moment II information has been given and read (approximately 2 weeks later).

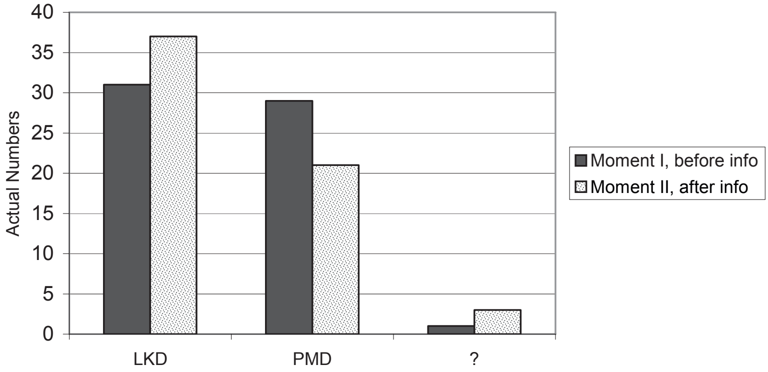

Figure 2. Results ranking exercise: LKD, living kidney donation; PMD, postmortal donation; ?, undecided. Moment I indicates the period before information was given in our study, at moment II information has been given and read (approximately 2 weeks later).

filled out this questionnaire, 55 (90%) stated that they would accept a kidney of a living, genetically related person and 54 (89%) stated that they would accept a kidney of a living, genetically unrelated person. There were 43 (70%) patients who at both measurement moments stated that they would accept any living kidney donation (see Fig. 1). The results of the ranking exercise at the time of the first measurement were: 31 (51%) preferred a living kidney donation, 29 (47%) preferred a postmortal donation and one (2%) was undecided. At the time of the second measurement the preferences were distributed as follows: 37 (61%) preferred a living kidney donation, 21 (34%) preferred a postmortal donation and two (5%) were undecided (see Fig. 2).

Motivations

The most often named first reactions in favor of living kidney donation at the time of the second measurement were: the better quality and expected outcomes of living kidney donation (23/37) and familiarity with the donor as positive aspect of the donation (nine of 37). The most often named first reaction in favor of postmortal donation was unwillingness to burden a loved one. In like manner, the remark was made that “a dead one won’t need his kidney anymore”, what indicates fear for a decline in the health status of the donor (11/21). Also the fear of psychological problems, especially feelings of guilt and responsibility towards the donor were named as motivation for the choice for postmortal donation (nine of 21). A further, closer examination of the answers and remarks of the patients during the semi structured interview, showed that a substantial part of all respondents were concerned about their future personal relationship with the donor. Especially the fear for inequality in this relationship after transplantation was present, as the following citations illustrate: “you don’t run the risk of obligations, expectations back, demands, psychological damage” “a psychological burden, even if nothing goes wrong some sort of obligation”; “eternal gratefulness, certain expectations from the side of the donor that won’t be fulfilled”.

Correlation between preference and personal characteristics

Fewer years spent on renal replacement therapy correlated statistically significantly with the choice for living kidney donation (p = 0.04). Age, sex, nationality (Dutch or non-native), religion (any or not religious; Christian or other), treatment method, being transplanted before, quality of life (as measured with EQ-5D) and risk-perception (whether or not naming operation risks or psychological risks) did not correlate with treatment choice.

Change of treatment choice between the two moments of measurement

In filling out the yes/no statements of the questionnaire for accepting a living genetically related kidney donation, five patients changed from disagree to agree, one from agree to disagree, and two from filling out nothing to agree between the two measurement moments. In filling out the yes/no statements of the questionnaire for accepting a living genetically unrelated kidney donation, six patients changed from disagree to agree, two from agree to disagree and one from filling out nothing to agree. These changes were not statistically significant. For the ranking exercise, nine patients changed their mind in that they first preferred postmortal donation, and later living related kidney donation; two changed their mind from postmortal donation to undecided about treatment choice of preference; and three patients changed from living related kidney donation to postmortal donation. The main motivation for the changing preferences in favor of living related donation was the better quality of the kidney (nine of 11) and the shorter waiting time (one of 11). The main motivation for changing preferences in favor of postmortal donation was the fear of feelings of guilt in case anything would happen to the donor, being unable to find a willing donor and not wanting to ask the children. The extent of change between both measurements for the ranking exercise was not statistical significant, however there was a tendency towards preference of living kidney donation (p = 0.07).

Need for additional information and support

Seventy percent of the patients explicitly stated that they had already sought information themselves at the time of the first measurement (Internet; in the hospital; documentation of the

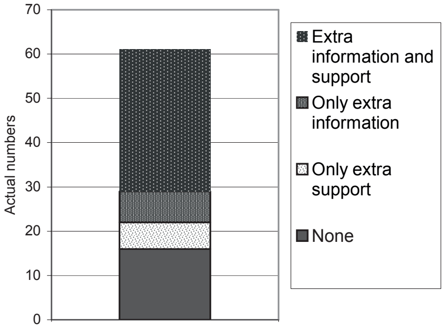

Figure 3. Need for additional information and support.

Dutch Kidney Foundation). Fifty-one per cent (32/61) of the patients stated that they felt the need for extra information and/or additional support on living kidney donation (see Fig. 3). The main topic where patients wanted more information was general information about living kidney donation; information on the procedure, especially on what to expect after transplantation and about (donor) risks. Considering extra support, patients stated that they appreciated to have the option to get extra support when needed. Two major topics were named in this respect: (i) general support, for example, for questions that they forgot to ask or came up after their consult with the specialist, and (ii) the need for emotional support, either for themselves or for the donor/other intimates. The need for additional information or support did not correlate with treatment choice.

DISCUSSION

Our results show a higher percentage of patients who would accept a living kidney donation compared with other studies (3,4,6). This difference might be explained by the fact that living kidney donation became more common over the last years in the Netherlands. This trend is generally accepted with a positive attitude towards living kidney donation by the government and the medical centers. For instance, since the year 2000 new patients in our center indicated for transplantation receive an information booklet and a video on living kidney donation. Therefore these new patients are more likely to follow this development in their treatment choice. To quote a patient in this respect “it [living-related kidney donation] happens often”. Furthermore, in Gordon’s study (4) there was a large group of 30/79 (38%) who choose not to undergo transplantation at all. In our study all patients were willing to undergo transplantation (only three of 61 had serious hesitations). When looked at the part of her study population who were willing to accept living kidney donation, the results are comparable. Nevertheless, one needs to bear in mind that this study is based on the answers of only 61 respondents. About one-sixth of our respondents were already involved in a living kidney donation procedure at the time of our investigation. As can be expected, all of them stated that they would accept a kidney of living donor. However, we do not think that the participation of these respondents distorted our results in insuperable way, as a minor part of them (25%) did not prefer living kidney donation to postmortal donation during the ranking exercises. These reluctant responses seem indicative for the doubts and worries they experience in going along with the living kidney donation procedure. These doubts mainly focus on the effect of the transplantation on the health status of the donor; because “a dead one doesn’t need his kidney anymore”. The fact that shorter time spent on dialysis correlated with the choice for living kidney donation, can also be seen as consequence of the above named recent developments: new patients are more likely to accept living kidney donation as a common, ‘normal’ treatment choice, compared with patients that are longer on dialysis. Furthermore, patients who spent shorter time on dialysis have a worse perspective on receiving a postmortal transplant (4 years waiting time on average), which also explains their focus on alternative treatment options. Additionally, most patients who are on dialysis now for a longer period, once also had the option of living kidney donation. Explained from the theory of cognitive dissonance reduction, changing their choice might be hard to accept. Following this theory, one automatically starts to appreciate the option you have chosen to the option you dropped, especially when you have already made some efforts or investments in the chosen option (in this case: invest waiting time being on dialysis). There was a tendency to change preference in favor of living kidney donation after information was given, as measured with the ranking exercise. One could indeed assume that this tendency is the result of the information that was given after the first measurement moment. However, we are cautious with this explanation because 43/61 (70%) explicitly stated that they had already sought information themselves before the information was given through the Internet, in the hospital, documentation of the Dutch Kidney Foundation and patient organization. Furthermore it is reasonable to assume that the other 30% might have heard at least some information or experiences with (living kidney) transplantation from patients and staff during their hospital visits. A more likely explanation for the change in preference is that it is not so much the contents of the information given that has caused a change, but rather the fact that information was given and that the topics addressed in the information were discussed in an interview. This may have caused a reconsideration of (already known) arguments and consequently the change reflects not so much a black-andwhite change of mind, but rather indicates the doubts on mutual contradictory arguments kidney patients have about their treatment choice. This explanation would be consistent with the findings of Gordon that kidney patients regularly change their treatment choice (dialysis or transplantation) (5). An argument that seemed important at the second moment of measurement to change preference towards living kidney donation was the better quality of the kidney. It might be so that this medical reason ‘quality’ is seen as a legitimate and possible decisive argument for accepting that a loved one participates in living kidney donation. Finally, the finding of patients’ fear for an unequal, disturbed relationship with the donor after transplantation is also reported elsewhere recently as a “debt of gratitude” (8).

Conclusion

Kidney patients prefer a living related donor compared with other treatment options, such as a postmortal donor. The most often named reason for this is the better quality of a living kidney, what is also the main reason given as a motivation for change of preference. However, living kidney donation is often accompanied by worries of the patient on the health status of the donor and inequality in their future relationship with the donor. In conclusion we think that these results encourage the development of new strategies to facilitate the living kidney donation program, and confirm the need for the standard option of offering psychosocial support to patients.

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POSTMORTAL OR LIVING RELATED DONOR: PREFERENCES OF KIDNEY PATIENTS. AUTHORS' REPLY.

We would like to thank Martínez-Alarcón et al. (1) for their comments on our study, especially for their efforts to make an international comparison. With regard to the differences found in both our studies, we agree that the shorter waiting time for a kidney cadaver transplant in Spain could be a possible explanation. In that respect, compared with other European countries, Spain may be the exception rather than the rule when it comes to cadaver kidney transplant waiting lists.

In reply to the authors' question on waiting time in the Netherlands, currently the average waiting time is 4.5 years. More specifically, the median waiting time for the participants in our study was 2 years (0–15 years). In our study, a shorter time spent on the waiting list correlated significantly with a positive attitude towards living kidney donation (2). As pointed out in our article, from the perspective of 'the longer waiting patient', a negative attitude could be explained by cognitive dissonance theory; and the positive attitude of the 'new patient', by a large reduction in waiting time and avoidance of the morbidity and mortality of dialysis. Furthermore, it may be that 'new' patients are more likely to be influenced by the relatively recent 'pro-living kidney donation' transplant professionals' policies in the Netherlands: information booklets and videos are offered as standard, and attention is paid to the better graft survival rates of living kidneys. In this respect, we wish to comment on the reference made by Martínez-Alarcón et al. that Spanish transplant professionals have positive attitudes toward living kidney donation (3,4). It is well known that attitudes often are not predictive of behavior. As Ríos et al. and Conesa et al. indeed suggested elsewhere this favorable attitude might not necessarily be followed by a real request for living donation (3,4). Their reference to the study of Arias is important here (5). This study shows that although most Spanish hospitals do not have objections to living kidney donation, it was not systematically offered to patients. Apparently, it makes a difference whether transplant physicians are telephoning family members to invite them for a consultation on living kidney donation as a standard procedure (as is the case in Norway), or whether transplant professionals are merely willing to start procedures once the patient (or his family) raises the topic of living kidney donation. Strikingly in this respect is Martínez-Alarcón et al.'s remark at the beginning of their letter that 'opinion studies of this type are indispensable if we wish to encourage living kidney donation'. In Spain, the question still seems to be 'if', or whether, to encourage living kidney donation, whereas in the Netherlands the question seems now to have become 'how' to encourage living kidney donation.

To conclude, it would be helpful for further understanding these matters to hear other countries' comments on the acceptance of living kidney donation, and, moreover, on how this translates into transplant centers' policies on the encouragement of living kidney donation.

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Chapter 3

Psychological Barriers in Expanding the Living Kidney Donation Program

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Submitted.

SUMMARY

Background: This is the first large scale interview study carried out in patients and potential donors who seem unwilling or unable to pursue living kidney donation. By investigating these groups we explored whether further expansion of the living kidney donation program is feasible.
Methods: We interviewed 91 patients on the waiting list for a kidney transplant who did not pursue living kidney donation, and their potential donors (n = 53). We also included a comparison group. All respondents underwent an in-depth interview by a psychologist about topics that could influence their willingness to pursue living kidney donation
Results: 78% of the patients on the waiting list were willing to accept the offer of a living donor. The main reason for not pursuing living kidney donation was reluctance to discuss the issue with the potential donors. This was also found in the comparison group. Both groups indicated that if there was no donor offer, they tended to interpret this as a refusal to donate. This interpretation not always holds: more than one third (19/53) of the potential donors were open to consider themselves as a potential donor. On the other hand, an in size comparable group of potential donors (21/53), was reluctant about donation. Main reason for donor reluctance was fear for their health after donation.
Conclusion: The majority of patients on the waiting list are willing to accept a living kidney donor, but adopt an awaiting attitude towards their potential donors. Offering those patients professional assistance should be considered.

INTRODUCTION

On the first visit to an outpatient clinic, a considerable proportion of patients indicated for kidney transplantation are accompanied by a number of willing living donors. This positive attitude towards donation however is not always the norm, as other patients never bring along a living donor to the appointment. In The Netherlands, patients without a living donor have to wait an average of four years before a deceased donor kidney transplant becomes available (1). As they will be dependent on dialysis treatment during this time they are at risk of a lowered quality of life and increased morbidity and mortality (2, 3). Given this patient burden, we decided to study the barriers to living kidney donation, and to investigate whether and how these barriers can be overcome.

The current study focused on the knowledge and acceptance of living kidney donation in the group that was eligible for living kidney donation and transplantation; the patients on the transplant waiting list and the persons in their close environment, i.e. the potential donors. By investigating these groups we hoped to explore whether barriers to living kidney donation can be overcome. We formulated two hypotheses. The first hypothesis was that the patient might be keeping potential donors away from donation. Evidence for this hypothesis was found by Gordon, who showed that patients were more concerned with the potential donors’ well being rather than their own; they did not want donors to “suffer for them” (4). Patients also seemed to worry about their relationship with potential donors and were especially concerned that they would feel indebted to the donor (5, 6). In other cases, where patients were willing to accept an offer from a potential donor, they were however reluctant to discuss the topic of live kidney donation with their potential donors (7). A second hypothesis was that it was not the patients who were reluctant to pursue the living donation option, but the potential donors who refused to donate. Remarkably, substantial research into the motivation of these presumed unwilling potential donors is lacking. A study by Hiller et al. amongst living kidney donors listed the common concerns of donors, e.g. the effect of donation on future health, absences at work, the ability to return to doing the same activities as previously, and pain They suggested that the same issues might apply to potential donors who are reluctant to commit to living kidney donation (8). A study by Stothers et al has shown that there was a lack of information among potential living kidney donors (9). However, they wondered whether improvement of knowledge about living kidney donation would lead to increased donation rates, because most donors did not appear to deliberate over organ donation before making a commitment. Furthermore, factors including gender and ethnicity were associated with the attitude of potential donors towards living kidney donation (10, 11).

MATERIALS AND METHODS

Patients

All patients seen in our outpatient clinic without a living donor in the period from January 2004 until January 2006 were asked to participate in the study. Included were patients referred for the first time as well as those already on the waiting list for transplantation. Patients were given written information on the aim of the study. If patients were willing to participate, they had to return a reply card. Subsequently, an appointment was made for an in-depth interview on the topic of living kidney donation. During this interview, we asked the patients for permission to approach one or more persons in their personal environment who could be considered as potential donors. These potential donors received written information and if they agreed to participate, an appointment for an in depth-interview was made. One week after the interview, we phoned all respondents to ask if they had any questions, remarks or needs as a result of the interview.

We included a comparison group. This group consisted of patients and their donors who planned to undergo living kidney donation and transplantation in the near future. These patients and donors were randomly selected from the registries. The physician asked these donors and recipients whether they would allow the researchers to contact them and explain the study. If they agreed, researchers contacted them to provide further information. After informed consent was given, they were interviewed regarding living kidney donation.

Respondents were divided into four groups: 1. Patients without a living donor (‘study patients’); 2. The people in their environment, i.e. their potential donors (‘study donors’). These two groups (1 and 2) collectively are referred to as ‘study group’ 3. Patients with a living donor (‘comparison patients’) and; 4. Their living donors (‘comparison donors’). These two groups (3 and 4) collectively are referred to as the ‘comparison group’. All respondents were interviewed at their place of preference; either in the hospital or at home. Most respondents preferred to be interviewed in their homes. Respondents who had insufficiently mastered the Dutch language were interviewed with the help of an interpreter and all respondents signed the informed consent forms. The Institutional Review Board of the Erasmus University Medical Centre approved this study.

Materials

All respondents were interviewed by means of a structured interview. The interviews were structured around several topics that have been suggested in the literature as important determinants of the willingness to undergo living kidney donation / transplantation. These topics were: sociodemographic and medical variables; knowledge and information; risk perception; willingness to pursue living kidney donation; communication with the specialist and the potential donors; and expectations regarding the personal relationship between patient and donor. Table 1 summarises the interview topics, together with a number of examples of questions for that topic. Most questions were asked in multiple-choice format or in the format of a Visual Analogue Scale (VAS). In all situations, respondents were asked to comment on their specific answer. The interviewer

Table 1: Interview topics and example questions

Topic	Example question
Sociodemographical and medical variables	For all respondents: what is your highest level of education? Score: interviewer circles one of eight categories ranging from primary school to academic degree For all patients: how much time have you spent on the waiting list for a deceased donor kidney? Score: interviewer notes waiting time in years / months
Willingness to pursue living kidney donation	For all respondents in group of interest: what is your personal stance towards living kidney donation for yourself? Score: patient chooses one of four response categories ranging from 'very negative, I would never accept a kidney from someone I know' to 'very positive, I would definitely accept a kidney from someone I know'. This question was rephrased for 'study donors', e.g. 'donate' instead of 'accept' For 'study donors': one can think of many reasons why one would not donate a kidney to someone you know with ESRD. This list names many different reasons not to donate a kidney to someone you know. Can you circle those reasons that you agree with and / or are applicable to your personal situation? Score: 'study donors' were offered a list of 21 objections to pursuing living kidney donation themselves. Examples of such objections are:' I would rather not donate a kidney, because I fear I will develop kidney problems in the future'; 'I would rather not donate a kidney, because my relationship with recipient is not good enough'; 'I do not know whether I would donate a kidney, because I lack information about what living kidney donation actually comprises'. A comparable list with reasons either or not to accept the offer of a living kidney donor was offered to the patients in the group of interest.
Information and knowledge	For all respondents: do you consider yourself well informed with regard to living kidney donation? Score: respondent chooses one of four response categories ranging from 'yes, definitely' to 'no, I do miss a lot of information' For all respondents: do you know what is the average graft survival rate of a living kidney? Score: respondent chooses one of five response categories, ranging from 1-4 years to >17 years. The sixth response category is 'I do not know" / cannot answer the question'.
Risk Perception	For all respondents: how do you estimate the chance that the donor will develop severe complications (such as having to undergo dialysis himself) as a consequence of the donation procedure? Score: respondents had to mark on a Visual Analogue Scale ranging from' very small chance' to 'very high chance' how they estimated this chance
Communication	For all 'study patients: would you ever actively approach and ask someone for living kidney donation? Score: patients choose one of four response categories: yes, not likely, no, otherwise For all respondents: in the Netherlands, it is common for the physician to discuss living kidney donation with the patients. Afterwards, it is up to the patient either to discuss living kidney donation (or not) with his potential donors. In Norway, the approach is different. The physician asks the patient about potential donors. Afterwards, if the patient agrees, the physician telephones the potential donors to invite them over for a consultation about living kidney donation. What do you think of this Norwegian approach? Score: respondents first give their first reaction, after that the pro's (saving patients a difficult conversation, the physician is better able to directly answer questions about living kidney donation) and con's (possibility of pressure on potential donors, too much interference in personal lives) are discussed. Then the respondent gives his/her final response in terms of favourable or not favourable.
Donor-recipient relationship	For all patients: do you agree with the following: if you accept someone's offer of a living kidney you owe this person forever' Score: respondents had to mark on a Visual Analogue Scale ranging from' totally disagree' to 'totally agree' to what extent they agreed with this statement. This question was rephrased for 'study donors' and actual donors.

summarized and wrote down their explanations. The interviewer and the respondents both verified the written summaries for accuracy and completeness. This way of interviewing offered the opportunity to gain in-depth information about underlying thinking and associations that were motivating respondents' choice for a specific response.

Statistics

We used SPSS 11 for analysing the data. To compare the study group and the comparison group and to compare donors and recipients, we used the Mann-Whitney U test and X^2 test, both exact testing; α was set at 0.05. We systematically compared 1. 'study patients' and 'comparison patients'; 2. 'study donors' and 'comparison donors'; 3. 'study patients' and the people in their environment, the 'study donors'; and 4. 'comparison patients' and 'comparison donors'. Results of these comparisons are reported only if they were statistically significant.

RESULTS

Inclusion of respondents

We approached 158 patients on the waiting list for transplantation. Of those, 91 were willing to participate in our study. The main reasons for not wanting to participate were the emotional burden of talking about the topic of living kidney donation or lack of motivation in participating in a study. There were no statistically significant differences between the included (n =91) and non-included patients (n=67) with respect to gender, age and birth country (resp. p = 0.33; p= 0.30; p = 0.75). Of the patients included in our study, 59/91 (65%) named one or more potential donors who we could approach for this study. In total, 97 potential donors were nominated and eventually 53 were found who were willing to participate. The inclusion rate in the comparison group was higher: 53 of the 60 patients and 51 of the 60 living kidney donors we approached were willing to participate. The main reason for non-participation in the comparison group was 'lack of interest in scientific psychological research'. Respondents' social and medical characteristics are given in table 2.

Willingness to pursue living kidney donation

We asked all respondents in our study group to give us their personal opinion on pursuing living kidney donation; whether they were positive or negative about this treatment option (the exact question is phrased in table 1). Of the 'study patients', 71/91 (78%) were willing to accept the offer of a living kidney from someone they knew (response category 1: very positive or 2: positive); 3/91 (3%) were in doubt; and 17/91 (18%) were negative about accepting a kidney from someone they knew (response category 3: negative or 4: very negative). We also asked the 'study donors' how they felt about living kidney donation and whether they would be willing to donate. We found that 21/53 (40%) of the 'study donors' were negative about being a living kidney donor.

Table 2: Respondent characteristics

	Study group		Comparison	
General	Patients	Donors	Patients	Donors
N	91	53	53	51
Median age (range)	54 (18-75)	44 (24-73)	50 (21-74)	50 (20-74)
Gender (Men / Female)	55 / 36	24 / 29	40 / 13	10 / 41
Median time on waiting list	2.3 years		0.5 years	
Mean time on waiting list	2.5 years		1.1 years	
Country of birth				
Netherlands	42	32	42	44
Surinam	11	6	2	3
Antilles	8	3	4	1
Morocco	7	7	1	1
Turkey	5	1	2	1
Indonesia	4	2	0	0
Other	14	2	2	1
Education				
Low	45	10	15	10
Average	37	22	20	31
High	9	21	18	10
Religion				
None	26	21	27	20
Christian	38	17	22	27
Muslim	18	10	3	2
Hindu	5	2	1	1
Buddhist	1	1	0	0
Other	3	2	0	1
Relation to patient				
Partner		14		21
Parent		4		7
Child		21		5
Sibling		8		11
Other		6		7

The other 60% varied in their reasoning from being willing to consider the idea but had serious hesitations to being positive about being a living donor.

Reasons for not pursuing living kidney donation

All respondents in the study group were asked to explain their reasons for not pursuing living kidney donation. They frequently gave more than one explanation. At a later stage during the interview, they were given a list that stated possible reasons for not pursuing living kidney donation (table 1). They had to select the reasons they considered applicable to their personal situations and viewpoints. The reasons they selected were consistent with the explanations they provided spontaneously at an earlier stage during the interview. ‘Study patients’, who were in principle positive about living kidney donation most often selected the next two reasons (both reasons were selected by 39/71 of the patients). The first reason was: "I would be willing to accept a kidney from someone I know, but only if the donor offers". 'Study patients' explained this by stating that they wanted to be sure that the offer was made completely voluntarily. Volunteering was perceived as a condition for proceeding with the donor-recipient relationship as the 'study patients' said that they would feel more reassured that they were not at fault if the decision to donate had been made voluntarily by the donor. This issue is related to the topic "donor-recipient relationship" discussed below. Another reason for not asking was the fear of receiving a negative response. This was viewed as being a painful experience and/or compromising the relationship as the following quotation shows "If I ask they may get angry, or try to avoid me. I do not want that, I really need them ". The second most often selected reason was "I would be willing to accept a kidney from someone I know, but nobody wants to donate (because they fear the operation, they fear health problems after donation, or because our personal bond is not strong enough)".

'Study patients' who were in principle negative about living kidney donation most often selected "I would probably not accept a kidney from someone I know, because I would fear for the donor's health after donation (selected by 13/17 patients); and [...] if something adverse happens to the donor as a consequence of the donation, I would feel guilty" (selected by 11/17 patients).

'Study donors' were most likely to select "I would probably not donate, because I fear health problems as a consequence of donation" (selected by 18/53 of the 'study donors'),"I would probably not donate, because I dread the operation" (selected by 16/53 of the 'study donors') or "I would probably not donate, because I have to take care of others (children, partner), and therefore I want to avoid any risk" (selected by 15/53 of the 'study donors'). Fourth and fifth 'study donors' also selected "I would donate, but the patient refuses my offer" (14/53) and "I may donate, but I lack information on what living kidney donation comprises"(12/53).

Knowledge and Information

We asked all respondents whether they considered themselves well informed in regard to living kidney donation (table 1). 65/91(71%) of the 'study patients' and 27/53 (51%) of the 'study donors' considered themselves reasonably or well informed. In comparison, 45/53 (85%) of the 'comparison patients' and 39/51 (77%) of the 'comparison donors' considered themselves well informed about living kidney donation from the moment they decided to continue living kidney donation. 'Study donors' considered themselves less often well informed compared to all three other subgroups ($p = 0.006$ ('study patients'), $p < 0.001$('comparison patients'), $p = 0.007$ ('comparison donors')). With regard to knowledge, nearly all 248 respondents knew that a living kidney donor did not necessarily need to be genetically related to the recipient. Only 5 thought the donor should be genetically related. Furthermore, we asked respondents whether they thought a deceased donor kidney and a living kidney would differ in quality. 'Study patients' were less likely to know about the superior quality of a living kidney, compared to 'comparison patients' ($p < 0.001$). The same was true for 'study donors' as compared to 'comparison donors' ($p = 0.016$).

Risk Perception

All respondents were asked "How do you estimate the chance that the donor will develop severe complications (such as having to undergo dialysis him/herself) as a consequence of the donation procedure?" Respondents had to indicate where they estimated this by marking on a Visual Analogue Scale ranging from' very small chance' (0) to 'very high chance' (100). Median estimations were: 'study patients': 23; 'study donors': 24; 'comparison patients': 13; and 'comparison donors': 16. We found statistically significant differences between 'study patients' and 'comparison patients' (p = 0.024); and between 'study donors' and 'comparison donors' (p = 0.049). To further explore risk perception with regard to patient risks, we asked: "imagine 100 patients on dialysis. None of them receives a transplant. How many of them, do you think, will be alive in four years time?" Median estimation of 'study patients' was 60%; 'study donors' 65%; 'comparison patients' 70%; and 'comparison donors' 75%. Differences between subgroups were not statistically significant.

Communication

73/91 (80%) of the 'study patients' stated that they would not (57/91) or probably would not (16/91) approach and ask a potential donor themselves (table 1). To quote two patients: "I would not dare. You do fear an answer that might hurt you. You do not know what that answer will be, that makes it difficult to ask" and "We did not really discuss it. It is not something we talk about". All but three 'comparison patients' did not initiate serious a conversation, but were offered the kidney by the donor. This is consistent with the findings among the 'comparison donors'. All but two of the 'comparison donors' stated that they were the ones who came forward and offered the kidney. We also investigated how respondents would appreciate the "Oslo experience" (12; table 1). Following this procedure, the physician asks the patients for their permission to approach their potential donors to invite them for a conversation on living kidney donation. In this way,

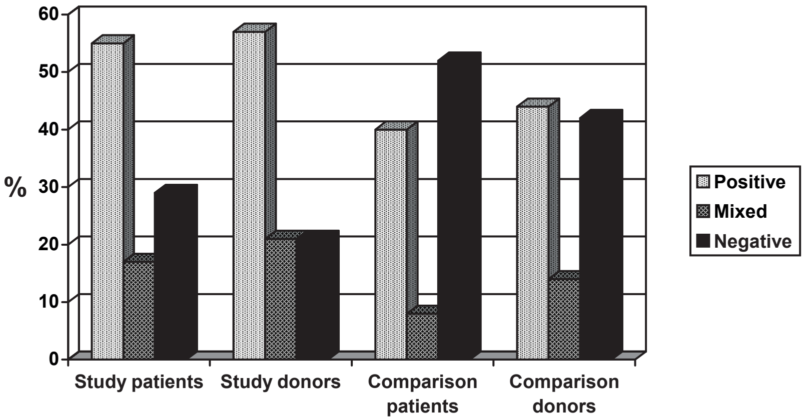

Figure 1. Respondents' appreciation of the "Norwegian Method" where the physician has an active role in finding the patient a living kidney donor.

it is not the patient but the physician who approaches and discusses living kidney donation with potential donors. ‘Study patients’ and ‘study donors’ were more likely to approve of this method than ‘comparison patients’ and ‘comparison donors’. Differences between ‘study patients’ and ‘comparison patients’ were statistically significant (p = 0.035), but not between ‘study donors’ and ‘comparison donors’ (p = 0.085). Proponents of this method made comments that stressed the lightening of the patient’s situation ”I think it is a good idea, it saves the patient a difficult task and you can speak more freely to a doctor, it is less emotional”. Opponents of this method were more likely to stress the danger of donor coercion: “I do not know, maybe they [the potential donors] would not dare to say no anymore”. Results are summarised in Figure 1.

Donor- recipient relationship

‘Study patients’ were less often sure that a donation would have a positive impact on the donor-recipient relationship compared to the persons in their environment, the ‘study donors’ (p= 0.002); and compared to the ‘comparison patients’ (p = 0.002). All respondents were asked whether they agreed with the statement: ”if you accept someone’s offer of a living kidney you owe this person forever.” Respondents had to mark on a Visual Analogue Scale ranging from ’totally disagree’ (0) to ‘totally agree’(100) how they felt about this statement (table 1). Median scores were: ‘study patients’: 27.5; ‘study donors’: 0.0; ‘comparison patients’: 17.5; and ‘comparison donors’: 1.0. There were statistically significant differences between ‘study patients’ and ‘study donors’ (p < 0.001); and between ‘comparison patients’ and ‘comparison donors’ (p = 0.049).

DISCUSSION

This study aimed to investigate the discriminatory variables between patients who pursue living kidney donation and patients who do not. For various variables, we found statistically significant differences between those two groups. ‘Study patients’ were less likely to know about the superior graft survival of a living kidney donor; were more likely to think that the donation procedure would negatively impact on the donor’s health; were more likely to be supportive of a more leading role of the physician (the ’Norwegian approach’); were less often sure that a donation would have a positive impact on the donor-recipient relationship; and were more likely to agree with the statement of “owing the donor”. In addition, ‘study donors’ differed from the ‘comparison donors’ with respect to the following variables: ‘study donors’ were less likely to feel well-informed about living kidney donation; knew less often about the superior graft survival of a living kidney donor; and were more likely to think that the donation procedure would negatively impact the donor’s health. Considering this large number of statistically significant findings, the question arises as to which of these findings is most relevant. If one wants to overcome psychological barriers for living kidney donation, what interventions would be helpful? Below we will discuss our results within the framework of possible interventions. During conversations with our patient respondents we found that the large majority of patients were willing to accept a living kidney donor's offer. These findings are consistent with earlier findings (5), and support the second hypothesis described in the introduction, i.e. that it is not that patients are reluctant to pursue the living donation option – but more that they (presume) unwillingness at the side of potential donors. One common finding arising from our conversations with patient respondents was their cautious attitude towards finding or 'arranging' a living donor. Surprisingly, this was almost the only variable where 'study patients' did not differ from 'comparison patients'. Both patients groups were waiting for the donor to take the initiative. This suggests that deciding whether to pursue living kidney donation is dependent on whether a kidney is being offered (or not). Patients may cautiously try to talk about their illness and need for a transplant in general, but they appeared almost never to ask directly for a donation. This lack of communication however was not the only issue. Other issues such as risk perception, information, and feelings about the donor-recipient relationship were important too. However, these latter issues can only be addressed within a specific context, e.g. in a conversation with the potential donors. But how can the optimal conditions for such a conversation be created? One option is the organising of information meetings on living kidney donation, and to encourage patients to bring their family members and friends to these meetings. This however may be subject to alteration: our experience shows that these meetings are mainly attended by patients and donors who have already decided to pursue living kidney donation. Another option would be to adopt the more direct 'Norwegian approach', where the physician takes a leading role. Data from the 'study group' showed that there was support for this option. Respondents appreciated that in this way patient were relieved from the difficult task to ask for a kidney. Furthermore, the proponents of this approach mentioned that potential donors could speak more freely (or refuse) to a doctor than to the patient. Next, the doctor is better capable to answer the questions of the potential donors. There were also negative comments from the study group respondents, in that they feared donor coercion. They were concerned that the donor would be afraid to refuse. This was also the main objection found in the comparison group, where respondents were generally negative about adopting the 'Norwegian approach'. However, it may have been easier for the comparison patients to answer in a socially desirable way, because they were in the lucky position of being offered a kidney without hospital assistance. Also from the side of the comparison donors, a feeling of pride that they offered without professional involvement may exist. Furthermore, if patients really fear for donor coercion, they are free to refuse the physician's request for approaching their family members. We think that patients might benefit from professional assistance to help them find a living kidney donor. The patient's physician would not necessarily be the one to fulfil this active role. Other counsellors may be more independent or may have more expertise in handling social and psychological issues (13, 14). In conclusion, we think that a more active role by the transplant centre should be considered.

CONCLUSION

The majority of patients on the waiting list were willing to accept a living kidney donor. We found a number of differences between patients on the waiting list (the study group) and patients who pursue living kidney donation (the comparison group), for instance, differences in risk perception and expectations about the future relationship. A notable similarity between the two groups was that the patients waited for the donor to initiate the communication about kidney donation. Understandably patients were reluctant to raise the topic themselves. If no donor spontaneously offered to donate, the patient was likely to interpret this as a refusal. This interpretation can be correct in some instances, as we found that some potential donors were negative about donation. Reasons given were fear for their own health and (lack of) relationship with the recipient. On the other hand, we found that several potential donors were in a pre-contemplation phase and therefore still open to considering themselves as potential donors. As both the health and the personal relationships of patients are at stake, they may profit from professional assistance to find a way of dealing with this complex situation that best suits their personal needs.

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Chapter 4

Avoiding the issue: patients' (non)communication with potential living kidney donors

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SUMMARY

Living kidney donation has proven to be an excellent solution for patients on the waiting list for transplantation. Though this is the preferred treatment from a medical point of view, in many situations a living kidney donor cannot be found. The purpose of this study is to investigate how kidney transplant candidates may or may not, find a living donor. We compare a group of 42 patients who did not find a living donor with a comparison group of 42 patients who did. All respondents were interviewed in-depth. We found that although almost all patients recognized the advantages of living kidney donation and were willing to accept the offer of a living kidney donor, many found it very difficult to ask a potential donor directly. This was true for both groups. Some patients who did not find a living donor had tried to discuss the topic cautiously, but often received no clear response from their potential donors. Patients were likely to interpret this as a refusal to donate and further discussion got blocked. Following this, patients tended to create narratives to give meaning to these situations. Although serving important functions, this process may result in missing the chance of the (medically) better treatment. Therefore, patients may gain from professional support to find ways to deal with this situation that best balances their medical needs and their personal relationships.

INTRODUCTION

Living kidney donation

There is a widespread shortage of kidneys for transplantation for patients with end stage renal failure. In the Netherlands, average waiting time for a deceased donor kidney is between 2.5 and 5 years (1). During the waiting period, patients are dependent on kidney dialysis that is associated with a decline in health and quality of life (2, 3). There is a 25% chance that a patient will die while on the waiting list (1). Living kidney donation has proved to be an excellent solution to help patients on the waiting list: their waiting time is significantly shortened, and the kidney survival rates for living donations are significantly better (4). Knowing this, it is not surprising that we found that many patients indeed prefer a living to a deceased donor kidney transplantation (5).

Who is eligible as a living kidney donor?

In the past, for immunological reasons only first-degree family members were thought to be suitable as donors, but over the last decades donations from other donors have proved to give equally good results (6). Data from our own centre show that family and close friends are most likely to volunteer as living donors. The role of partners in living kidney donation has undergone an interesting change over the past decade. Our centre's data show, that the proportion of partner donations has increased to 30% (22/74) of all donations in 2006. This trend is also seen in other countries (7-9). Often the spouse is more enthusiastic about donating to their partner than to other relatives, because the emotional bond may be stronger and it may give both of them the potential for a better quality of life (10). Furthermore, females are more likely to donate than men; in our series we have 344 females and 269 male donors. This is consistent with evidence from other countries (11-13).

Difficulties in finding a living kidney donor

Despite being the preferred treatment from both a medical and a patients' point of view, in many situations a living kidney donor is not found. Research dating back to 1971 has shown that finding a living kidney donor can cause 'formidable stress' in family relationships (14). Sometimes the patient is confident that a donor can be found in the family, but then fails and experiences bitterness about their siblings' refusals. Lack of discussion in the family has also been reported (15). It was found that patients felt that they should not ask for a donation. If patients tried to talk about donation, they received little or no response from potential family donors. A lack of response by relatives can be very difficult for the patient as it is hard to interpret and can be seen as a rejection. In these cases the patients found themselves cut off from family support at this very difficult time of being seriously ill and they appeared to be quite hurt by this isolation. Family tensions in the situation of finding a living donor have also been reported by more recent studies (16). Donations from parents to children seem to be relatively free of problems, whereas (potential) sibling donations tend to cause more difficulties (17, 18). A recent study suggests that lack of discussion in the family may still be a problem today and found that a third of potential family donors had not talked about donation with the patient (19).

Study aims

As we have discussed, the question of approaching family members and whether or not they will donate may have major implications for a patient's personal relationships. Even if patients and his relatives / friends decide to avoid the question of donation, things will change, as there is now a taboo subject for discussion. This means that the question of the kidney disease and donation inevitably affects family and other personal relationships. The purpose of our study is to investigate how kidney patients who are eligible for transplantation deal with searching a living kidney donor. We were especially interested in the group of patients without a living donor, as they might tell us which barriers they encounter and what professionals might do to overcome these.

METHODS

Patients

The medical ethics board of the Erasmus University Medical Centre gave approval for the study. All participants in our study signed written consent forms. We limited our analyses to native Dutch patients.

Study group: patients on the waiting list

We approached all patients without a living donor that had an appointment at our outpatient clinic in the period from January 2004 until January 2006. Some of these patients were new to our clinic and were about to start dialysis treatment. Other patients were already on the waiting list for transplantation, and visited our clinic for their annual check-up. During an appointment, all patients were given a letter informing them about this study. If patients were willing to participate, they returned a reply card and an appointment was made for an in-depth interview about living kidney donation. One week after this interview, we phoned all the participants to ask if they had any questions or issues to raise as a result of the interview. We approached 158 patients on the waiting list for transplantation. Of those, 91 were willing to participate in our study. Of those, 42 were native Dutch. The main reasons for not wanting to participate in the study were the emotional burden of talking about the topic of living kidney donation or lack of motivation in participating in a study. There were no statistically significant differences between the included (n =91) and non-included patients (n=67) with respect to gender, age and birth country (resp. p = 0.33; p= 0.30; p = 0.75). Respondents' characteristics are summarised in Table 1.

Table 1. Respondents characteristics

General	Study group Patients	Comparison group Patients
N	42	42
Mean age (range)	55 (19-76)	52 (22-75)
Sex (M / F)	27 / 15	34 / 8
Born in the Netherlands	42	42
Educational level		
Low	19	10
Average	19	17
High	4	15
Religion		
None	23	23
Christian	18	18
Other	1	1
Donor characteristics		
Partner (M / F)		3 / 18
Parent (M / F)		2 / 4
Child (M / F)		1 / 1
Sibling (M / F)		4 / 4
Other (M / F)		2 / 3

Comparison group: patients with a living kidney donor

We included a comparison group. This group consisted of patients who planned to undergo living kidney transplantation in the near future. These patients were randomly selected from the registries. The physician asked these patients whether they would allow the researchers to contact them and explain the study. If they agreed, researchers contacted them to provide further information. After informed consent was given, they were interviewed regarding living kidney donation. We approached 60 patients who planned to undergo living kidney transplantation in the near future. Of those, 53 were willing to participate in our study. Of those, 42 were native Dutch. Respondents' characteristics are summarised in Table 1.

Procedures

We conducted in-depth interviews about the same topics for both the study and comparison groups. These topics were: demographic variables, knowledge, information, attitudes towards living kidney donation, conversations with (potential) donors, doctor-patient discussions, and perceptions and expectations about the future relationship with the (potential) donor(s). We will focus on the communication with (potential) donors about living kidney donation. The interview questions are given in table 2. Participants were asked to explain and elaborate on their answers to these questions. The interviewer summarized what was said, and then the interviewer and the participants together checked these summaries for accuracy and completeness.

Table 2. Interview questions (translated from Dutch)

Group	Questions asked
Study group patients	Attitude towards living kidney donation 1.a How do you feel about living kidney donation? Would you accept a living kidney from someone (you know)? 1.b If negative, how negative (f.i. I may accept an offer at some point, I will not accept an offer, I will never ever accept any offer)?
	Asking and offering 2. Would you ever directly ask someone for a kidney?
	Family relationships and donation 3.a Do you have a partner?; Since when?; Do you live together (are you married)?; Do you know how he / she feels about living kidney donation?; Are you sure / have you talked about it? 3.b Are your parents still alive? Do you know how they feel about living kidney donation?; Are you sure / have you talked about it? 3.c Do you have children?; How many - what are their ages / sexes?; Do you know how they feel about living kidney donation?; Are you sure / have you talked about it? 3.d Do you have siblings? How many - what are their ages / sexes?; Do you know how they feel about living kidney donation?; Are you sure / have you talked about it? 3.e Are there any other people in your life that are important to you (friends, colleagues,..)?; For how long have you known each other? Do you know how they feel about living kidney donation?; Are you sure / have you talked about it?
Comparison group patients	Asking and offering 1.a How did your donor get to know about the option of living kidney donation? 1.b Did the donor offer him / herself? Or did the doctor ask him / her, or did you ask?
	Family relationships and donation Were there any other people than [name donor] who were eligible as a living kidney donor? (For all of the following questions first was asked whether the respondent had partners, children, siblings and significant others and whether parents were still alive) 2.a Was your partner eligible? Why (not)? 2.b Were your parents eligible? Why (not)? 2.c Were your children eligible? Why (not)? 2.d Were your siblings eligible? Why (not)? 2.e Was the partner eligible? Why (not)? 2.f Was one (or more) of them actually tested for becoming a living kidney donor?
	2.g. Why did [name donor] become your donor in the end?

RESULTS

Patients' views of donor eligibility

The way the situation of end stage renal disease and the (pending) donation question affect patients and their personal relationships, depends on who they think would be acceptable as a living donor. We found three patterns that we will discuss below. Characteristics of patients in these three categories are summarized in table 3.

1. Living kidney donor not wanted

Only 3 of the 42 patients who were on the waiting list for transplantation said that they did not want a living donor. This reflected their perception of the risks of donating. Even though all of them knew that the risks to the donor are low, these risks were too high for them to accept. In

Table 3. Donor eligibility for patients' on the waiting list

	N	M / F	Mean age (range)	Education low / medium / high	Religion None / Chr / other
1. Nobody considered eligible as a living donor	3	3 / 0	41 (18-73)	0 / 2 / 1	2 / 1 / 0
2. Some considered eligible as a living donor	10	6 / 4	58 (42-74)	4 / 5 / 1	3 / 7 / 0
3. Everybody is considered eligible as a living donor	29	18 / 11	54 (37-75)	15 / 12 / 2	18 / 10 / 1

addition, all of them said that they would feel guilty and would find it hard to forgive themselves if something should happen to the donor; ”I just could not live with it if something happened to them”. When asked whether they could think of anything that would change their mind about accepting a living donor kidney, one respondent said he would never accept any offer of donation, another would only accept if it became a matter of life and death, and the third would if it concerned a donor who was younger (than his partner and siblings who were in their early seventies) or a so-called Samaritan donor, someone who is willing to donate a kidney to anyone on the waiting list (see for instance 20).

2. Those willing to accept living donors

Ten of 42 patients in our study group were willing to accept an offer from some living potential donors, but had excluded others beforehand. Six of the ten patients excluded their children. One patient would not accept her husband's offer, because they had a son who might develop kidney failure in the future (an inherited condition ran in the family) and the patient wanted to save her husband's kidney for her son. Two patients felt their wives should not donate, because they were taking care of their young children. These patients were afraid that if something happened to the donor, the child could end up with both parents being ill. One mother excluded her daughter who had offered to donate, because the patient thought the loss of a kidney would complicate future pregnancies. This mother was willing to accept a kidney from her son, but had not discussed this with him. Another patient refused his sister's offer. This sister went through the medical testing necessary for donation, but her brother withdrew because he wanted to protect his sister who, in his opinion, was taking the donation too lightly. Finally, one patient got a serious offer from his neighbour whom he did not know too well. But because he suspected this offer was related to his neighbour's depression he refused it. There was one other case of a neighbour offering. This was refused because the patient “would feel ashamed of his family” in accepting as no-one in his own family was willing to donate.

3. Those willing to accept any living donor

Twenty-nine patients were happy to accept any living kidney offer; “even from my worst enemy”. Of these patients, 22 had children and neither the children or other potential donors were excluded from donation on beforehand.

Donors for those in the comparison group

All patients in the comparison group had a living donor, and had accepted their offer. Sixteen of the 42 patients had more than one donor medically tested for donor suitability. When asked why a particular person became the donor in the end, the patients reported that this selection process had proceeded smoothly. Some possible donors were excluded on the basis of blood type incompatibility and/or a positive crossmatch. Although it is still possible for these donors to donate via an exchange donation procedure (21), it may logistically and emotionally be more convenient for the patient to turn to a alternative living donor who can donate directly. Furthermore, it may depend on the specific personal circumstances of the potential donors who became the donor in the end. Sometimes it was the potential donors who decided among themselves who would be the donor, without the patients being involved.

Communication: waiting for someone to offer

All but one of the patients in the study group said that they would not (33/42), or probably not (8/42) ask directly for a kidney from someone they knew. Many felt that the donor should take the initiative in this. If the donor offered, they could be sure the offer was made voluntarily; “You would feel guilty, they would not dare to say no, and then, if something happens, you would feel even more guilty”; “If people do not offer I will not ask. It [a kidney] is not a small gift.” Another reason for not bringing up the topic directly was not knowing how to start a conversation or not daring to start the conversation on living kidney donation. Patients were afraid of rejection, and consequently disappointment, or of damaging their personal relationships: ”I was alarmed by my daughter’s reaction. [after that] I have not asked anyone else. I might lose them”. In the comparison group, all but three patients had a direct offer of a kidney from a donor. The donors took the initiative and offered a kidney. Some patients added with a sense of relief, “I would not have dared to ask”, and even “It is a code of honour not to ask”. More than once the donor’s offer was not accepted immediately, often patients wanted repeated reassurances that the donor was certain about donating ”I kept wondering whether my wife offered to donate because she really wanted to or because she felt obliged to donate. She has reassured me that she really wants to donate.”

Communication patterns in the study group

In the situation where no donor comes forward spontaneously, there are four common patterns of (non)-communication.

1. Some patients did not try to discuss living kidney donation, and as a consequence did not know what the potential donors thought about it: ”I would not dare. You are afraid of an answer that might hurt you. You do not know what that answer will be, that makes it difficult to ask” and “We did not really discuss it. It is not something we talk about”. In total 6/42 patients had not discussed the issue of living kidney donation with any of the persons in their close environment (see Figure 1).

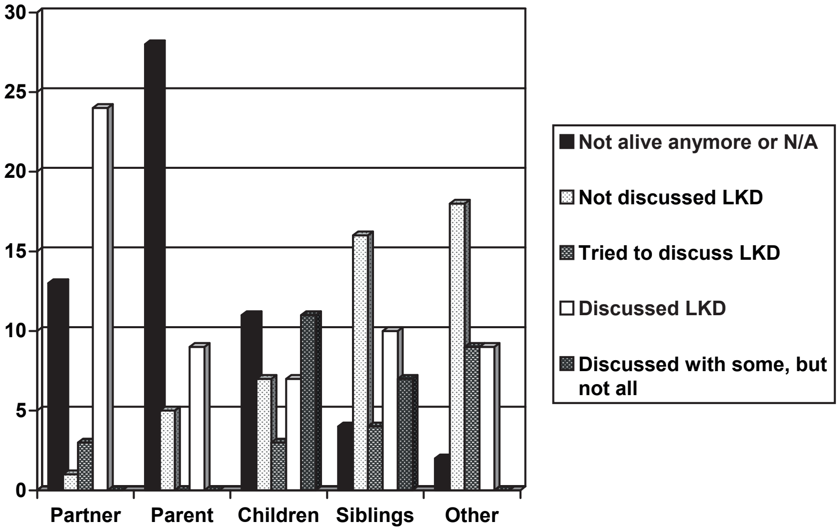

Figure 1. Patients' communication patterns with the persons in their close environment.

2. Other had attempted to explain about living kidney donation to potential donor(s) but had not got any clear response, or felt there was a negative reaction. In these situations patients had decided not to speak further about it and assumed that their potential donor would refuse a donation. Some typical statements from the interviews: "I try to talk about it, but I get no response. That makes you reluctant to bring it up again"; "You notice that they want to change topics, try to talk about something else" and "She [the neighbour] did watch the information video [on living kidney donation], but she never said anything about it anymore". This pattern was most often seen in situations where the patient had tried to discuss the issue with significant others (Figure 1). It should be added that in a minority of these cases patients did get a response, but this was always negative. Sometimes this led to severe disappointment: "I will not let this situation spoil my relationship with my family (I am really going to need them in the future), but I am disappointed." For some acceptance was the main reaction. There was a case of a niece who offered but then changed her mind. This patient commented: "I knew she would start questioning. Her change of mind was harder for her than for me to accept".

3. Discussing the topic with potential donors. We found that 19/42 of the patients had discussed the issue of living kidney donation with only one person/party. Patients were most likely to discuss the topic of living kidney donation with their partners: 24/ 42 of the patients had discussed the topic with their partners (13/42 did not have a partner). People were less likely to discuss the issue with their parents, children, siblings or significant others (but, note that most patients' parents had already died; Figure 1). The other patients (17/42) had discussed the issue of living kidney donation with at least two parties (for instance, with their siblings and their partner).

4. A special situation occurred when we asked the patients whether they had discussed the issue of living kidney donation with their children, and with their siblings (Table 2, questions 3.c and 3.d). We found that quite some patients had discussed the issue with some of their children, but not with all, or with one sibling, but not with the others (Figure 1). To cite a patient: ”I discussed it with one brother, we may register for an exchange donation procedure, but not with the other brother, because I know that he will say no, which I accept”.

Discussion

We found that most patients were willing to accept a kidney from a living donor. Only 3/42 rejected any living donation offer. We found that patients were cautious in discussing living donation with the people around them. This was true for both the study and comparison groups. In the study group, we found that patients interpreted and tried to make sense of their specific situation. They attached meanings to the fact that people didn’t step forward as a living donor. For example, in the situation where the patient has tried to bring up the topic, and does not get any clear reaction from their friends or family members: “I think she [my sister] is negative about donation, if she would have wanted to she would have let me know”. Some of these explanations can be characterized as a ‘if he could, he would’ justification. Previous research on moral obligations in kin relations has shown that indeed justifications of the type ‘would, or would perhaps, but can not’ (instead of ‘could, but does not want to’) are common in all sorts of give-and-take kin relationships (22). An example of this reasoning is: “My son can not donate because he has a busy job”. In this example, it may be easier for the patient to accept that his son cannot donate than that he may not want to make him that offer. Perhaps an even more striking example is: “They might want to donate, but I’d rather not accept”. At first sight, this looks like clear reasoning, but it may not be that simple, as the following example may illustrate “I don’t want to accept it from her, she has a young family, and what would happen if she gets the same disease, I would feel guilty. Although she gave blood for testing, and maybe I would accept if she steps forward herself and insists on donating.” In this example, the story of the patient “They might want to donate, but I’d rather not accept” is converted to “If she offers, I will accept”. These kinds of stories, narratives, or justifications do serve an important function. By creating accounts like the ones quoted above, patients may try to make the situation more acceptable for themselves. In the situation of end stage renal disease, it is already difficult to adjust one’s life story in ways that includes the illness. Things that might have contributed to their personal identity, such as work, or sports, may no longer constitute identity. Identity is shaped not only by how one sees oneself in for instance professional life, but also by and through personal relationships (23). If it turns out that nobody seems willing to donate, it might become hard to maintain identity based on the value given to these specific social relationships. Patients may try to solve this by thinking of good reasons why the potential donor is unable to donate (such as a busy job). This allows them to retain their mutual identity as good friends, favorite sisters etc. In addition, creating and communicating justifications for non-donation to potential donors serves an important function in maintaining personal relationships. The meta-communication of a phrase like “I can understand that you cannot donate because of your job”, or more indirect “People with busy / important jobs should not donate” is: “I accept that you do not donate a kidney to me”. The potential donor is reassured that the patient accepts that he/she does not donate. It also suggests that the topic will not be discussed unless the donor will initiate the conversation. It is not likely that the potential donor will be confronted with the ″the donation question″ any longer, as a justification for non-donation is already provided by the patient. This may cause relieve at the side of the potential donor, who then no longer needs to avoid serious conversation, or even contact with the patient. Thus, if the patient provides a justification for non-donation, he makes possible that his personal relationship with the potential donor can be continued.

Both the patient ‘s health and his personal relationships may be at stake in the situation of seeking a living donor. To protect their personal relationships, patients may have found a solution by making up reasons why others will not donate (as we discussed above). Although this may be a valid strategy from the perspective of the patient, the question is whether this really is in the patient’s best interest. By avoiding the conversation, or by saying out loud that he would not accept a kidney anyway, the patient may reduce the chances of a potential donor coming forward. As patients find themselves in this difficult situation where both health and personal relationships are at stake, they may benefit from transplant centre’s support in finding a living kidney donor. An important ethical question here is to what extent it may be justified to intervene in the patients’ personal lives and relationships. Elsewhere, we have described the dangers of such intervention, and we have argued that in the case of living kidney donation this should be limited to patient empowerment (24). Offering patients professional support is appropriate only if patients are willing to explore the extent their ideas about their relatives‘ willingness to donate may correspond to these relatives’ willingness to donate. Together with a health care professional they can develop ways of establishing their relatives’ feelings about living donation, and how to handle the consequences of these strategies.

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Chapter 5

Should Health care professionals Encourage Living Kidney Donation?

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SUMMARY

Living kidney donation provides a promising opportunity in situations where the scarcity of cadaveric kidneys is widely acknowledged. While many patients and their relatives are willing to accept its benefits, others are concerned about living kidney programs; they appear to feel pressured into accepting living kidney transplantations as the only proper option for them. As we studied the attitudes and views of patients and their relatives, we considered just how actively health care professionals should encourage living donation. We argue that active interference in peoples' personal lives is justified – if not obligatory. First, we address the ambiguous ideals of non-directivity and value neutrality in counselling. We describe the main pitfalls implied in these concepts, and conclude that these concepts cannot account for the complex reality of living donation and transplantation. We depict what is required instead as truthful information and context-relative counselling. We then consider professional interference into personal belief systems. We argue that individual convictions are not necessarily strong, stable, or deep. They may be flawed in many ways. In order to justify interference in peoples' personal lives, it is crucial to understand the structure of these convictions. Evidence suggests that both patients and their relatives have attitudes towards living kidney donation that are often open to change and, accordingly, can be influenced. We show how ethical theories can account for this reality and can help us to discern between justified and unjustified interference. We refer to Stephen Toulmin's model of the structure of logical argument, the Rawlsian model of reflective equilibrium, and Thomas Nagel's representation of the particularistic position.

INTRODUCTION

In most Western countries the waiting time for cadaveric kidney transplantation has increased dramatically. In the Netherlands this is 4.5 years on average, with approximately 1,100 patients on the waiting list and an alarming mortality-rate among kidney patients (20% a year). This pressing situation is similar in many other countries (1, 2). Health care professionals and health care policy makers have good medical and ethical reasons to promote the many options of living kidney donation (3, 4). This donation has important advantages over cadaveric donation and donor risks are low. Living kidney donation helps patients to circumvent the waiting list and relieves them of the burden of dialysis. Furthermore, the kidney survival rates for living kidneys are significantly better (50% still functioning after 20 years; for post-mortem organs this is only 10 years). Indeed many patients seem to prefer living to cadaveric donation (5). Facilitating any transplantation program also has important societal implications, as the end stage renal disease program consumes a considerable amount of the health care resources, e.g. in the Netherlands 1% of the health care-budget (6). Both policymakers and health care professionals may therefore feel an obligation to bring these facts to the attention of patients and their relatives.

How actively, we ask, can or should this be done in the clinic? What kind of professional interventions in personal relationships is justifiable? In Norway, for instance, where the option of kidney dialysis is not widely available, doctors often take the initiative in contacting the families of kidney patients to ask them explicitly to consider living donation. Lennerling et al. (7) have stated that “Recruitment of the donor represents a medical and moral responsibility.” But at what point is such interference viewed as unjustified pressure? Living transplantation programs are increasingly taking place or being proposed, e.g. cross-over and list exchange programs (8, 9), altruistic (anonymous and non-anonymous) donations between strangers (3, 10), and payment arrangements accompanied by ethical constraints (11, 12). These developments make it even more necessary to evaluate the counselling process and to ensure that the information provided is clear and helpful and does not deteriorate into propaganda. Moreover, greater insight is needed into the attitudes and beliefs of recipients and donors with respect to living donation.

As part of several psychological investigations (5), we have contacted, among others, patients in the process of living kidney donation as well as patients on the waiting list for kidney transplantation at our centre. We studied the views of both patients and their relatives (family members, partners, friends) with respect to living kidney donation. We used structured, semi-structured and in-depth interview techniques to explore their knowledge of the topic and the information they received (i.e. risk perception, attitude, communication, family system, mutuality of personal relationships and views on the effect of a transplantation on these relationships). We tried to have them elicit the obstacles to transplantation as they perceived them, and possible measures that could be taken to remove those obstacles. Do these patients and/or relatives disapprove of the transplantation option? Are they positive but unable to find a donor? Do they have difficulties communicating with relatives about transplantation? Do they anticipate changes in their relationship with their loved ones? Do they need additional information? Are their fears or anxieties specific enough to describe? Why do they postpone making a decision, etc.? The results of this investigation, which in itself was already experienced by some as a far-reaching interference, will be published elsewhere.

In this article, we focus on the justification of intervention in light of the needs and views of patients and their relatives, as expressed with regard to living donation and transplantation. The article itself is structured as follows: given the various obstacles that people encounter (par. 2), and given the aim of professional interference (par. 3), we describe the shortcomings of prevailing professional ideals – non-directivity in counselling and value neutrality of information – and suggest another approach (par. 4). Then we go on to discuss the justification of interventions in personal convictions and fundamental beliefs (par. 5), and to portray the consequences for the counselling process and conclude that counsellors should be open to the particularities of a situation and sensitive enough to appreciate the moral weight of those particularities; moral language appears to be necessarily ambivalent, and general ethical concepts are inadequate (par. 6).

Obstacles: practical, fundamental and complex

Patients and their relatives initially encounter many obstacles that keep them from offering or receiving a kidney. Some of those obstacles are purely practical and health care professionals can often diminish or eliminate them. This might be achieved by providing more information, or a better explanation of the benefits or risks of transplantation, or a clearer view of the alternatives, etc. Crucial, however, is the way in which this information is presented (13).

Obstacles may also have a fundamental character. Some objections or doubts refer to fundamental beliefs; when, for instance, a potential donor says: “I would not easily donate an organ myself, because I believe that the human body should remain a whole.” (NB: this and the following citations, though based on our research, are constructed depictions, for the sake of argument). Views on man and the human body are frequently reflected in terms of integrity or a telos (an ultimate goal), such as “organs do belong – and are bound – to this body, and are not meant for another”, or the view that living organs are not just a commodity: “We should not treat organs as merely a product that has value independent of its natural locus.” (14, 15). Other obstacles have a more complex nature, for instance when a potential recipient makes the observation that “I would never ever accept a kidney from a relative, because I am afraid that I will feel guilty when something goes wrong with my donor after the transplantation.” Note that medical, psychological and ethical considerations here are intertwined in a complex way.

The crucial question is whether and under what conditions it is acceptable to interfere in these practical objections, fundamental beliefs and complex convictions. We shall argue that fundamental beliefs are open to change and that showing respect for these beliefs does not necessarily imply that we should not intervene.

THE AIM OF INTERFERENCE

In health care, it is quite common to interfere in the lives of individuals. Health care professionals make decisions in patients' best interests in situations where they are not able to decide for themselves. In general, however, kidney patients and their relatives do not fall within this category. Justification of interventions is based on 'patient empowerment': health care professionals seek to support patients and their relatives in making autonomous decisions (16). The aim of interference is to strengthen or restore the autonomy of patients and their relatives, and therefore to enable them to make well-informed judgments and be in control (17). Interference is therefore justified in the sense that it provides support and gives help. Later we will take a look at what it means to interfere in counselling, and more in particular, in fundamental beliefs.

In addition, it could even be argued that it would be unjust if some individuals took more advantage of the living transplantation program than others, simply because health care providers were not helping to remove the obstacles that prevent more reluctant patients and relatives from participating.

One particular feature of the situation, however, complicates this picture. We should note that concepts such as 'support' and 'help' may have a very different meaning for patients than for potential donors. What benefits do donors have when we turn them into patients? Is not the best advice we could give them that of staying away entirely from the donation process in the first place? We must find a way to deal with this double challenge.

INTERFERENCE IN COUNSELLING

Crucial issues in counselling concern the question of what information is appropriate, and how this information should be (re)presented. Prevailing concepts of non-directivity and value neutrality have shortcomings that make them unfit for supplying adequate guidance. We will show why, and suggest another approach.

Appropriate information is contextual and personal

Legislation requires that health care professionals fully inform patients about all relevant facts with respect to treatment and alternatives. The many treatment options on offer include: dialysis, cadaveric transplantation, transplantation within and outside families, and cross-over transplantation. Each alternative has its own benefits, disadvantages and risks. The professional and moral obligation to provide adequate and relevant information is not limited to providing medical facts. The obligation also includes the counselling process as a whole. It is a health care worker's duty to help patients understand the information, and to enable them to act accordingly. His/her concern should be not only to simply provide the information, but also to ensure that the patient has understood properly. Intervention should try not only to determine whether patients and their relatives require any additional information, but should also strive to correct misperceived information. The aim is to provide support for the making of well-considered judgements (13). In the context of genetic counselling, it is acknowledged that a right-not-to-know exists. Individuals may have their own (good) reasons for not seeking further information (or asking for it at a later date). Their wishes should, of course, be respected. This consideration places a clear moral and professional constraint on all counselling. This constraint can only be established through open communication, free from coercion, if patients are willing to share their reasons, which is obviously up to them.

A number of concepts are used to describe both the threats and ideals implicit in the counselling process. These include determining the point at which free decisions become forced, deciding when to apply less or more pressure, and differentiating between inducement and persuasion. Other factors that can harmfully affect behaviour may also include, for instance, money (18) or gender (19). 'Value neutrality' is often put forward as the guiding criterion with regard to the appropriate representation of information. But what exactly is meant by this concept, and can it be a guiding principle?

First of all, professionals should understand that medical information in the context of a health care relationship cannot be value neutral. Even so-called 'pure' facts will be understood within a certain context, and may, in this setting, comprise a moral appeal. For example, someone who calls out "She is bleeding to death", might also mean "We must do something about this and prevent it". The word 'must' is understood against the background of a conviction, i.e. the view that lives should be protected and saved, if possible, and that – as a rule – we prefer life over death. A statement such as "Each year you wait for a kidney increases your chances of dying", implies that "You'd better come up with a living donor". These examples demonstrate a second feature of providing information. Since each piece of information is interpreted and experienced within the context of a person's views and earlier experiences, information is always person-relative. Questions such as "What represents a great risk?", "How great a burden is it to be on a waiting list?", or "Should dying always be prevented?", do not allow for objective answers (i.e. scientific, quantitative, separated from person or situation) but ultimately require a personal, non-value-free response. Health care workers can only help to find this response when they accept that the information they give is not neutral. Value neutrality therefore seems not only impossible to achieve, but is not even desirable.

Pitfalls in (re)presenting information

With regard to the counselling process, 'nondirectiveness' is generally cited as the ideal. But what does it mean? We can explore the meaning by pointing out some main pitfalls in counselling. The above-mentioned observations about the contextrelative and person-relative character of information provide the basis for what follows.

First of all, health care professionals are not justified in providing directive counselling if it means presenting facts in a one-sided, selective way, and therefore (intentionally or otherwise) underexposing some options while favouring others. The issue is not that counsellors should be nondirective, or that information should be presented impartially or in a value neutral way. Presenting all options as equally good alternatives ignores the fact that, often, some options are simply better than others, and there is no good reason not to say so. Information should be truthful, not distorted by personal prejudice or professional preference. The option, for instance, of early, pre-emptive transplantation (i.e. before a patient starts dialysis) has many advantages over transplantation later on. Counsellors who do not inform their patients about this fact are providing biased information and are making a serious mistake. But, at the same time, they should acknowledge that all information contains values. Professionals should try to deal transparently and communicate these values openly. Counsellors, if they endeavour to provide truthful information, are more likely to be viewed as trustworthy.

Secondly, health care professionals are not justified in providing directive counselling if they focus predominantly on the medical perspective, consider this perspective to be the 'most reasonable' and are blind to other perspectives. From the patient's perspective, considerations other than purely medical ones may be highly relevant as well; for example his/her relationship to the donor, his/her social network, etc. Living transplantation may, for instance, be 'better' than cadaveric transplantation for a number of medical reasons, but it is not self-evident that this medical perspective should be given more weight than other, i.e. ethical, social, psychological, perspectives. Conversely, it would be equally mistaken to suggest that a donor who is overweight does not represent a greater risk. Again, the issues here are not nondirectiveness and value neutrality, but rather the fair portrayal and explanation of the different ways of evaluating and weighing these options.

We suggest that no one single objective description of 'reality' will suffice. The presentation of 'the facts' should provide patients and their relatives with the tools to decide for themselves what they think is best. It should be acknowledged that the assessment of all information is ultimately a personal one, in which the perspective of the donor or recipient is decisive.

Thirdly, it would not be justified to provide directive counselling by approaching potential donors as merely a means to an end, instead of showing them the respect they deserve. It would be mistaken to argue that saving the life of a patient (or relative) outweighs the relatively small risks and disadvantages for the donor, because this view overlooks alternative options and does not take account of other viewpoints and considerations. Respect for patients and their relatives implies that relatives will be contacted if, and only if, patients give their consent. Moreover, if health care professionals are viewed as the advocates of their patients, other advocates should also be appointed to defend and to protect the interests of the (potential) donors. In general, people can have reasons of their own, by referring to the particularities of their situation (20). Potential donors as well may have their own good reasons for not donating an organ. Professionals should help donors to express their perspectives, considerations and convictions. It should not be forgotten that donors also have families and lives of their own. For example, they may have doubts about the health risks involved in donation, uncertainty about their social situation, anxiety concerning the implications for personal relationships, duties towards others such as a partner or children, loyalties with regard to their occupation, or other commitments. Many of these concerns will be valid and should be taken seriously.

Justified interference: issues to be solved

Within those constraints noted in sections 4a and 4b, however, there is room for justified intervention. We have found, quite surprisingly, that, when asked, more than 50% of the patients and their relatives waiting for a kidney are open to the idea that doctors, (with the patient's consent) should address relatives directly. Some patients feel confused and threatened by the situation in which they find themselves. It is hard to imagine how these patients are able to ask a relative to donate a kidney. Many patients are afraid their relatives will refuse, but mask their fear and find reasons not to ask them to donate ("Given her situation, my friend should not donate") or not to accept any possible future offer ("I am not prepared to live at the expense of others"). Psychological and ethical issues are intertwined. This situation may be an appropriate opportunity to interfere, as health care professionals may be able to help the patient find a way out of this predicament. They can help patients to distinguish reality from imagination, and to disentwine their psychological defence mechanisms from their true personal needs and moral considerations. The counsellor, for example, might ask the patient: "How can you be so sure that he doesn't want to donate if you haven't discussed it?", or "Why don't you give your friends the opportunity to decide for themselves whether they wish to become your donor?", or even "Why don't you give your son the opportunity to help you?". Given the apparent scope for justified intervention, however, some important issues remain to be solved.

First of all, should the patient's doctor (or any doctor) take the initiative to contact relatives, or are other professionals, such as psychologists or social workers, in a better position to do so? And should we find these experts within or outside the transplantation centres? Much depends on the emphasis one wants to put on the medical perspective, and the faith one has in doctors. And what role can patient organizations have in empowering patients and their relatives?

Secondly, what exactly should be the role of experts or support groups: to mediate between patient and potential donors, or to represent either the patient or the potential donor? To provide basic information, to offer counselling in a particular situation, or to refer to other experts for decision-making (through mediation, pastoral counselling, etc.)?

Thirdly, a health care professional must provide support for patients and their potential donors in light of their distinct needs. The interests of patients and their donor-relatives do not necessarily coincide, and may even be at odds. In a transplantation program it is important to decide at what point in the counselling process we should consider a patient and his/her relative(s) as a single unit, and at what point we should treat them as individuals with their own personal needs and wishes. If we assume that each relationship has its own unique characteristics, and that interests can overlap, it is far from self-evident where the interests of one individual end and the interests of the other begin. It seems that this not only requires clear and formal safeguards (e.g. by assigning potential donors their own personal health advocate), but also sensitivity to the fundamental needs of both parties on the part of health care professionals.

This is not just a practical issue. We believe that the impact of transplantation on close relationships requires more conceptual clarification. Patient and donor may, as we have said before, have strong common interests. There are disadvantages (health risks) for the donor, but also benefits from the transplantation. For example, transplantation may relieve donors of the burden of caring for the patient, they may regain a healthy partner, have better prospects of a future with their relative, or it may give them the feeling that they are being altruistic, etc. Yet this raises questions to which there are no easy answers. Should donors feel a duty to donate? Should donors also have benefits, and if no such benefits are present, should their offer to donate be refused? Or should donors accept at least some form of payment? Should a donation be based on altruism, or does the principle of reciprocity offer more solid moral ground? Or is a motivation based on the donor's self-interest the better option? Should one say that, in general, the overall benefits for a patient outweigh the harm to the donor and his/her family, as is claimed for cadaveric donation? Another pitfall of counselling assumes that one simple unequivocal answer can be appropriate for these complex questions – that there is a monolithic view available concerning morality and personal relations. As we will show, unique relationships and particular situations require their own answers. In explaining this, we will refer in what follows to the structure of fundamental beliefs and personal convictions, and conclude that general ethical concepts cannot fully account for the richness of moral experience.

INTERFERENCE IN FUNDAMENTAL BELIEFS

The structure of fundamental beliefs and personal convictions can be pictured in accordance with a number of models. Here we describe three such models, referring to well-known theories by Stephen Toulmin, John Rawls and Thomas Nagel, and ask whether interference in fundamental beliefs and personal convictions can be justified. We use these models in an heuristic way. All three represent ways of moral reasoning that exist alongside each other in everyday life, and can help counsellors to be sensitive to the strengths and weaknesses of these beliefs and convictions.

A deductive model

In a deductive model, as described by Stephen Toulmin, a conviction can be represented by a general principle or axiom that is applied in a particular situation. We may expect the logic of reason also to be valid for ethics (21, 22). For example:

Principle: "One should not cut in a healthy body"

Fact: "In transplantation surgery – as well as in cosmetic surgery – one has to cut in a body that is healthy"

Inference: "Therefore, I reject this surgery"

This logical conclusion is not as strong and stable as it seems, and this belief (axiom) less deep and fundamental than one might think at first sight. Often people will be prepared to adjust their views, for various reasons, and in a number of ways:

- by qualifying the fact, e.g. “Kidney transplantation is a ncessity, cosmetic surgery is merely a luxury, and sterilization is sometimes a good option.”
- by limiting the principle, or its sphere of influence “One should never cut in a healthy body, unless something good can be accomplished by it.”
- by specifying the conclusion “If the benefits outweigh the disadvantages, I can accept organ transplantation.”
- by introducing or referring to another fundamental principle: “the principle of beneficence for me has priority over the principle of bodily integrity; this principle of charity should be ultimately decisive.”

The insight which this model gives provides us with a justification for intervention: beliefs are not fixed, but dynamic, and should not be taken at face value. Interferences can contribute by helping patients and their relatives to refine the argument and give their views a more strong and stable character.

A network model

The network theory, borrowed from John Rawls, holds the view that the basis of our moral beliefs is not founded on fixed and solid ground. Instead of searching for ultimate principles or fundamental axioms, we should look at moral justification in a different way. The concept of coherence can explain how a moral point of view is comprised of various parts. Each view consists of a great number of ingredients: innumerable and very diverse facts, ethical principles, moral intuitions, experiences, values, considerations, etc. When we try to take a stand, what we usually do in everyday life is look for sufficient (internal) coherence (23, 24). For example, a patient says “I would happily accept a kidney from my partner (unfortunately he does not match), but not from my daughter. I could live with the small risk for my spouse, as with other risks in life, like his mountaineering, but not with the risks for my daughter. At this moment we are happy with my dialysis and my nephrologist is content with how things are going.”

In everyday life, we try to bring the various considerations together and obtain a more or less coherent picture of our situation. Considerations back each other up and strengthen one another mutually. This coherence is shaped in a dynamic, reflective process, in which facts are qualified, principles are limited and positioned vis-a’ -vis each other, moral intuitions are reconsidered, and provisional conclusions are specified. The aim is to give fair consideration to as many elements as possible. One can refer here to a “reflective equilibrium”. An initial preference may be replaced after reflection by a more stable, well-considered judgement. In this process, (even) fundamental convictions are open to change. The example above may continue as follows:

- initial preference: “We appreciate dialysis at home (because my partner’s kidney does not match).”

- new fact: "Our doctor has told us that we can take part in a cross-over programme."
- moral intuition: "I find it hard to accept the idea of receiving a kidney from a stranger, with its potential, unknown risk."
- basic value: "My partner, who is a doctor, is prepared to donate cross-over; he wants me to have confidence in this programme."
- experience: "I am, however, afraid of disappointment and do not want to cross this barrier; moreover, I have heard that blood group 0-patients, like myself, do not match very well and have little chance of successfully receiving a kidney transplantation."
- new fact: "My sister-in-law said at a birthday party that she was willing to donate a kidney to me. However, I'm not sure how serious she was in saying this; she had already had a few drinks."
- moral intuition: "I think that I would prefer a kidney from my sister-in-law."
- new fact: "My son has found a reliable address abroad where one can get a kidney from a stranger in exchange for money; we have the money, and this would at least eliminate the risk for my partner."
- moral intuition: "If I accept a kidney from a stranger, I would prefer this to cross-over."
- well-considered judgement: "So far, my experience with dialysis is fine and I consider cross-over to be taking things one step too far. I will wait to see what the future brings. My daughter has two young children who need their mother, my son has his own small business to run, and my relationship with my daughter-in-law has never been perfect. I'm reluctant to talk to my sister-in-law about her offer, maybe it's better to wait and see whether she brings it up again. My son is probably right that the better option can be found abroad. At the moment, all is going well, we should leave it as it is."

This personal judgement is provisional, but wellconsidered. It is the temporal close of a reflective process that never ends, as it is open to new facts and circumstances. For now it has balanced the various options.

This second model also provides a justification for intervention. Counsellors can see it as their role to keep the communication with patients and their relatives open. They can look for elements that can be reconsidered and take the initiative to open the discussion about these elements. They can try to give their support, if requested, in instances where facts are biased, views distorted, certain perspectives underestimated, and where room exists for new considerations. The network model can account for the dynamics of moral beliefs and the process character of moral reflection. It may help to understand the counselling process as a truly reflective process.

An agent-relative model

In the third model it is emphasized, for instance by Nagel (25), that particularistic values also play a part in everyday morality, in addition to general ethical premises and principles. Individuals often have (good) reasons of their own, reasons that are highly personal in nature. These reasons reflect unique situations and personal commitments. They are by definition partial, in the sense that not every perspective is given impartial weight. Partial considerations can make up the core argument in moral judgements (26). They can bear significant weight. Take expressions such as "I choose to donate just because ...":

- "I love her."
- "he is my mate."
- "her life is the only thing that matters to me."
- "I would never forgive myself if I didn't donate to my sister".

Or, "I choose not to donate because" ...:

- "I have responsibilities towards my little son, who is totally dependent on me"
- "I have duties towards the people I have employed in my new business."
- "I live for my professional career (Olympic synchronic swimming)."
- "I think my niece is in a much better position to donate."

These arguments can be called 'person-relative', because they are in a unique way connected to the person who utters them. Various websites recall these unique stories (27). They do not express general moral truths, applicable to all others in the same situation, but a reality that is only true for the person concerned. Interestingly, particular features of the situation turn out to be morally significant. Significant for this person (actor, 'agent') are loyalties to particular individuals, commitments to certain personal projects or ideals, or coincidental circumstances, like the existence of a vulnerable niece.

This 'agent'-relative model seems to govern the morality of personal relationships and is highly relevant in the context of kidney disease. The strong appeal to potential donors who live in a patients' surroundings induces unique personal responses. Agent-relative considerations, more than all others, seem particularly decisive. A general rule like "One should not let one's soul mate die" or "Partners have caring duties towards each other, as part of their marital bond" is not the leading principle, but personal commitments and loyalties such as "As far as I am concerned, I will not let my partner down". Thus a general principle of beneficence (doing well) or maleficence (doing harm) is not applied, but a particular moral point of view is expressed, based on a highly personal ideal about what constitutes the particular good. Donors may refer either to what is perceived as good for a sick relative, or to the donor's own moral self-image, or to the unique relationship with the recipient.

To be able to understand someone's choice, health care professionals need to understand these ideals and the commitments and loyalties they represent. It may seem that these agent-relative views are less open to change and that counsellors can do nothing but simply comply with them. Does this imply that interventions are not justified within this model? To draw such a conclusion would be to misunderstand the agent-relative perspective. Agent-relative reasons are embedded in views about personal and moral identity (20, 26) and therefore have their own justification. This identity is not something fixed and closed to all consideration. The justification of a position commonly takes the form of a narrative, a personal story that can be more or less coherent and constant over time. Counsellors can take part in the shaping of this story, and in the identity formation of a patient or donor struggling with living transplantation (if, of course, the patient or donor wants such help and is open to it). An open discussion pays in fact tribute to the autonomy of agents. Agents, capable to consider reasonable arguments and willing to reconsider their views, will emerge stronger than before.

Counselling: inadequate concepts, but open minds

The agent-relative model can explain why many general ethical concepts – commonly used without much thought – are inadequate. In the context of personal relations, these concepts seem to lose their unambiguous, self-evident, ordinary meaning. This is true even for core concepts. What precisely is meant by a “free choice for living donation”, a “voluntary decision”, “an option worth considering”, a “moral duty”, an “altruistic gift”, a “natural and self-evident act”, a “reciprocal transaction”, a “motivation based on self-interest”, etc? In this context, it seems, a very different moral logic applies. Take a mother who can save her child’s life by donating part of her liver. What do we mean when we stipulate that hers must be a free, voluntary gift? However ambiguous it may be, this is something health care professionals should ascertain. Interestingly, in everyday life we find a moral language that is necessarily ambivalent. The sense that neither of the characterizations mentioned above (free choice, self-evident act, moral duty, reciprocity, etc.) is entirely adequate is due to the fact that our minds and moral experience are open to the many particularities of a situation. Our prevailing general concepts cannot fully account for this. In people’s utterances we can detect moral intuitions that are authentic and double-edged at the same time:

- A parent: “I felt I had no choice, but it gave me a good feeling that I could donate and help my child; I took responsibility; I didn’t feel like a victim of the situation; I took an active part in the process.”
- A friend: “Of course, one has the choice, whether or not to donate; but I would not have forgiven myself if I had not done it; it was an inevitable duty.”
- A sister: “It is only natural to help; this is simply what you do. I did not give it much thought. It has nothing to do with duties.”
- A child: “It’s both free and not free; she would have done it – reciprocally – for me.”
- A partner: “Is it altruism? I don’t know; I do it for him, and I do it for myself. It’s easier to live with a healthy spouse than with a sick one; it’s good for us both.”
- A doctor: “We should do this for each other, when risks are low. I believe that ethics demands that we consider it as a deadly serious option.”
- A son: “I would help my father. Fortunately, I have never had to consider donating a kidney seriously, because he doesn’t want to talk about it.”

These views suggest that there are many ways to refer to what is morally at stake. It would be a mistake to think that ethics can and should be combined in one unambiguous language. This would reduce the richness of moral life (28).

The third model not only opens our eyes to this richness, (the second model does this, too), but also distinguishes between an internal and external moral perspective. Whereas the external perspective applies to general concepts, the internal perspective is more sensitive to the particular morally significant features of a situation. Both can differ considerably, and cannot easily be reconciled. Without going into the precise relationship that both perspectives should have with each other, we can reasonably conclude that general principles or social norms cannot give a full and adequate description, but should at least be augmented by more particularistic, personal pictures of the moral reality. Counsellors should therefore be open to these particularities of a situation, and sensitive enough to appreciate their moral weight.

CONCLUSION

We have argued that interference in peoples' personal lives is justified – if not obligatory. This interference, however, can easily become unjustified pressure. We have shown, first of all, that prevailing concepts in counselling, i.e. value neutrality and non-directiveness – given the pitfalls they imply – cannot account for the complex reality of living donation and transplantation and have only limited value as guiding principles in living organ donation. What is required instead is truthful information and counsellors people can trust. In addition, adequate information and effective counselling should be context- and person relative, in order to respect the particularities of each case.

Secondly, we have shown that interference with personal belief systems can be justified. Views are open to change and can, accordingly, be influenced. Ethical theories account for this dynamic reality in different ways. They can help to discern between justified and unjustified interference. We recommend a heuristic use of the models offered. A patient's personal view or belief may be better represented by one model than by another. A sensitive counsellor can make use of this insight and look for the model's potential openness for change (Toulmin), and for deliberation (Rawls). It might seem that Nagel's model is less open to external consideration, but this does not mean that counsellors have no role in the matter. They can support patients, if they wish, in their shaping of a personal story and in their (dynamic) identity formation. Nagel's representation of the particularistic position takes into account the richness of moral reality, and suggests that health care professionals should not reduce moral language to the general ethical concepts that often prevail but be sensitive to the particularities of a situation and appreciate their moral weight.

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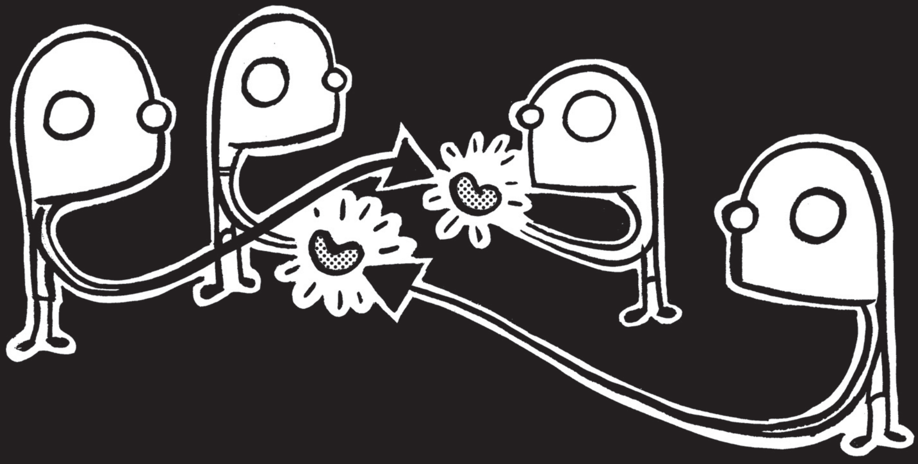
PART II: INDIRECT DONATION

The previous part of this thesis describes studies about donors donating their kidneys directly to their recipients. This part concerns donors who have the same intention, namely to directly donate their kidneys to their recipients, but are unable because of blood type incompatibility or a positive crossmatch. Fortunately for those donor-recipient combinations, there is the possibility of exchange donation. In exchange donation, incompatible donor-recipient couples exchange donors in such a way that two compatible donor-recipient combinations become possible. The donor donates his kidney to someone else (someone other than his intended recipient), on the condition the person for whom the kidney was initially intended receives a kidney from another living kidney donor. Exchange donation is donation 'via someone else', and therefore referred to as indirect donation.



Chapter 6

Starting a Crossover Kidney Transplantation Program in the Netherlands: Ethical and Psychological Considerations

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Transplantation 2004 27; 78(2): 194-7.

SUMMARY

On April 15th, 2003, the first crossover kidney transplantation took place in The Netherlands. In September of the same year, a national database was established to facilitate kidney exchange between two donor–recipient couples. During 2004, kidneys from living donors will be exchanged between the seven university medical centers in The Netherlands. One of the conditions for successfully implementing this program was the need to address the ethical and psychologic implications involved. In this article we will discuss the ethical and psychologic considerations that are accompanying the practical preparations for the first Dutch crossover transplantation program. We identified five topics of interest: the influence of "donation by strangers" on the motivation and willingness of donor–patient couples, the issue of anonymity, the loss of the possibility of "medical excuses" for unwilling donors, the view that crossover is a first step to commercial organ trade, and the interference with existing organ donation programs. We concluded that whether viewed separately or in combination, these issues do not impede the efficient organization of a crossover program or raise worrying ethical issues.

INTRODUCTION

The Netherlands has a population of 16 million. Approximately 375 to 425 kidneys per year are transplanted from cadaver donors. In addition to cadaver transplants, approximately 200 kidneys from living donors were transplanted during 2003. Although the growing number of available living donors helps prevent the waiting lists from growing further, there are not enough kidneys available to help the 1,300 patients already on the waiting list. After starting dialysis, kidney patients have an average waiting time of 4 years before a kidney becomes available. In the meantime, their health status declines. Currently, the mortality rate of patients on dialysis is approximately 20% per year (1).

Living organ donation by family or friends offers an opportunity to reduce the long waiting lists. However, in a third of these cases, the transplantation cannot take place because of ABO incompatibility or donor-specific sensitization (2). A crossover transplantation program offers new hope. The program provides a lifesaving opportunity when a donor cannot give his or her kidney to his or her recipient. If another donor–recipient couple experiences the same problem, the kidneys can be exchanged.

In South Korea, such a crossover kidney exchange program has been operating successfully for more than 10 years (3). The United States also has experience with “kidney swapping” (4). In Europe, however, crossover transplantations have been attempted only once in Switzerland, in Romania, and in Rotterdam. This conservative European attitude is in part explained by concerns surrounding the ethical and psychologic implications of crossover transplantation. When a crossover program was initiated in The Netherlands, it was agreed that these concerns should be addressed. A multidisciplinary research effort was conducted to determine the most prominent psychologic and ethical issues that surround crossover kidney exchange and to propose practical solutions. We identified five topics of interest: (1) the influence of “donation by strangers” on the motivation and willingness of donor–patient couples; (2) the issue of anonymity; (3) the loss of the possibility of “medical excuses” for unwilling donors; (4) the view that crossover might be the first step to commercial organ trade; and (5) the interference with existing organ donation programs.

Next we describe these five topics in detail and suggest practical solutions.

LIVING ORGAN DONATION BY STRANGERS

When discussing the ethical and psychologic issues of a crossover transplantation program, a prominent issue is the possibility of a difference in motivation and willingness of kidney donors and recipients compared with the attitudes of those involved in a direct living donation program. At first glance, crossover donation between two couples is not significantly different from direct living kidney donation. The motivation of the donor is the same: helping a friend or a family member by giving a kidney. The result for the patient is equivalent as well: He or she receives the much needed organ. Furthermore, the medical impact for the four people involved is the same as for the two direct living kidney donors. Psychologically, however, it might matter for those involved whether the donation comes from a stranger. It is known from literature that some recipients are affected cognitively and emotionally in regard to the origin of the organ that is being donated (5, 6). Sanner quotes a patient as saying "What if it comes from a sinful man? Then God has to clean my new heart." When the donor is a family member or a friend, patients are often more reassured because their kidney originates from someone who is known to them, a feeling of trust that it is from a "good" person. This could be described as an application of the "magical law of contagion," a traditional belief that describes the transfer of properties (moral, physical, harmful, or beneficial) through contact (7). The possibility of meeting or knowing the donor distinguishes crossover and direct donation from cadaver donation. Crossover differs from direct donation in that there is no prior emotional closeness or familiarity between donor and recipient. Crossover donation can be viewed as being more abstract and detached compared with direct donation. Donor– recipient couples could perceive the crossover program as being less intimate, more formal, and abstract. This might be helpful to recipients who are struggling with the idea of "eternal gratefulness" toward the donor. The idea of eternal gratefulness comprises worries that the recipient forever owes something unrepayable to the donor (8). In addition, some living related donor recipients and living unrelated donor recipients might feel pressured to keep up an optimally healthy life style (9). The fact that the relative of the recipient does not donate directly might relieve this kind of pressure or perceived obligation. It also might be the case that even if direct donation were possible, a couple might still be willing to participate in a crossover exchange anyway because they would be helping another couple

We conclude that currently it is not possible to assess the impact of the involvement of an unknown donor on the decision about whether to participate in crossover donation. We do not know whether people prefer one option over another, and moreover we do not know the motivation for their preferences. Nevertheless, we were also not able to determine any insuperable moral obstacles resulting from the involvement of an unknown donor. This issue will be explored further during the program.

THE ISSUE OF ANONYMITY

Before crossover transplantation can take place, a practical decision has to be made about whether the couples should be introduced to each other. We investigated attitudes toward this issue of anonymity in 14 potential participating couples in the crossover transplantation program. It emerged that, without exception, all preferred anonymity (10). A frequently cited reason was the desire to focus on a "normal healthy" life, instead of being confronted by, and perhaps becoming emotionally involved with, others who have comparable health problems. People also expressed other reasons for desiring anonymity. For instance, anonymity prevented psychologic pressure that might result from acquaintance. A further reason for preserving anonymity was to avoid any pressure or conflict between the two couples in instances in which there were different transplantation outcomes (11). The involved donors and recipients might be inclined to compare the functioning of both donated kidneys, for example. If outcomes are different, this can cause anger and feelings of resent toward the other couple with a better functioning graft. Another reason in favor of anonymity was the possibility that couples might view each other negatively before the procedure, which might eventually result in the cancellation of both transplants.

After taking all arguments into account, we decided that the anonymity between the couples should be safeguarded. Our main reason for this view was the unanimous preference for anonymity expressed by our panel of potential couples and the belief that there would be less emotional distress for the couples involved if they were not acquainted with each other.

No more possibilities of virtual excuse

In the case of direct donation, the donor might perceive pressure to donate his or her kidney. This pressure might emanate, for example, from the medical world (including patient organizations), government, the recipient or other family members, or the donor's own conscience (12). Some donors have been reported as having a strong but unspoken preference not to donate and are often relieved to learn, for example, that they are ineligible because of ABO incompatibility (13). In this case of direct living donation, the true motivation of an unwilling donor can be covert by introducing fake medical reasons. It is known that in this way doctors protect the unwilling donor from precarious interpersonal situations. The greater possibilities of crossover transplantation increase the chance that one is a suitable donor. In the mean time, a helpful lie (as sometimes used in direct donation) becomes much more difficult, if not impossible. The blockade of this emotional emergency exit might enhance the pressure to donate. Care should be taken not to pressurize potential donors in any way, for instance, by presenting living organ donation as a citizen duty.

We think that the disappearance of the "medical lie" as escape route does not countervail the solution that the crossover transplantation program might bring for the participants of this program. We advocate developing a protocol that focuses particularly on the attitude and willingness of the potential donor. This can be achieved by providing the potential donor with a confidant and, in case of doubt, psychologic screening.

IS CROSSOVER A FIRST STEP TO COMMERCIAL TRADE OF DONOR ORGANS?

According to Dutch law (supported by public opinion), the commercial trade in donor organs is not allowed. Although crossover transplantation cannot be defined as commercial, a transaction is involved, which could be defined as a process of exchange or barter. The donor's kidney goes to a stranger, but not for free. It is exchanged for something valuable, namely, another organ for a loved one. There are concerns that this might lead to a monetary trade in organs. We will argue that crossover transplantation can be considered separately from any development in commercial donor trade.

To participate in the crossover transplantation program, we consider the donor's motivation to be the same as for direct living donation. The only aim for the donor is to give his or her kidney to provide a loved one with a needed organ. Compared with direct donation, the "net gain" is the same: The donor receives nothing, and the couple gains nothing more than they would have gained through direct donation. There is gain for the donor, namely, the joy of helping a loved one, a new shared future, financial benefits (in that the recipient will be able to return to work), and feelings of (and increase in) self-esteem (14). However, this gain does not differ from the gain from direct exchange. Because direct donation is allowed, this cannot be the kind of (financial) gain that is forbidden by the Dutch law and in most other countries. Moreover, the Dutch crossover transplantation program takes place within a system in which various elements of the kidney exchange are taken into account, such as donor age and likelihood of a successful transplantation. This implies that the weighting of the different determinants of the exchange is not undertaken by the donor or the recipient, but by an independent agency, an arbiter. In this way, market forces are eliminated and the crossover transplantation program remains complementary to the existing living kidney donation program, with no attendant danger of becoming commercial.

INTERFERENCE WITH EXISTING ORGAN DONATION PROGRAMS

It could be argued that the introduction of a new kidney distribution program could interfere with existing programs that might introduce unfair overall allocation of resources. The proposal to mix the cadaver pool and direct living donations has been dismissed in the literature (15). The reason given for this is the vulnerability of blood group O recipients who would have to wait longer because of the extraction of blood group O kidneys from the cadaver pool for the benefit of blood group O recipients with a living (non-blood group O) donor. This problem is not likely in the Dutch situation, because the pool for crossover transplantation will consist of couples that have registered for, but could not be helped by, direct living donation. In this way, the crossover pool does not interfere with the pool of patients waiting for a transplantation of a cadaver donor kidney. However, we might query whether the arguments for a strict separation of the pools in all circumstances are strong enough. What if because of an unforeseen problem with the donor organ one of the patients in a crossover program cannot obtain the promised organ? Would it be fair to offer the first available organ from the cadaver pool to this patient? The separation of the pools for living donation from the cadaver pool is based on the idea that people who (with the help of a partner, friend, or family member) can bring in a kidney have the right to get one in return. This implies that others have to wait longer for a cadaver kidney. It is not clear what is equitable and just in these situations. On the one hand, it is considered unethical to ask a donor who is able to donate directly to a loved one to donate to a larger pool (16). On the other hand, by strictly separating organ donation programs, the situation will probably arise in which the crossover pool stagnates because it consists of A/B donors and O recipients. One large crossover pool (including all living related donor and living unrelated donor couples) seems to be wise if the number of transplantations is to be optimized. A condition of such a system could be that every recipient receives the best matching kidney because there is one large living donor pool.

Clearly the introduction of a new distribution system raises issues about whether and in what situations the various organ distribution programs might interact. Any interaction will introduce new discussions on which theory of justice is appropriate. Because the discussion is still ongoing, we have tried to prevent as far as possible any interaction occurring between the pools. For this reason, the Dutch program has decided to perform both crossover transplantations simultaneously. This implies that if one transplantation has to be canceled because of unforeseen reasons, the other transplantation will also be canceled, avoiding the problem of an appeal to the cadaver pool. This will be discussed beforehand with the donor–recipient couples as part of the informed consent procedure. In cases in which cancellation of the transplantation is impossible, new judgments about fairness and equity in regard to allocation will have to be made. For this reason, interactions between systems will be recorded and discussed during the evaluation of the crossover program.

CONCLUSION

Although the “net results” of crossover transplantation are in many respects similar to direct living donation, crossover transplantation raises a range of additional issues. We have identified five important topics: the influence of “donation by strangers” on the motivation and willingness of donor–patient couples, the issue of anonymity, the loss of the possibility of “medical excuses” for unwilling donors, the view that crossover is a first step to commercial organ donation, and the interference with existing organ donation programs. None of these issues, either separately or combined, seem to impede the efficient organization of a crossover program or raise worrying ethical issues. This has provided reassurance that when the program is accompanied by careful evaluation at each stage, there is no reason why the program should not be successful in The Netherlands.

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Chapter 7

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 percent 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

Table 1. Donor and recipients characteristics.

	Exchange		Comparison		
General	Donors	Recipients	Donors	Recipients	Total
N	24	24	24	24	96
Male/female	10/14	11/13	4/20	14/10	
Median age	54	49	52	45	
Median waiting time in years		1.0		2.0	
Idem: SD and range		1.2; 0 – 4		1.7; 0 – 7	
Relation					
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

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' for unwilling donors, the influence of anonymity on the well-being of participants, the

Table 2. The questions and answers about 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 (0%)	6 (27%)
	4. Very difficult	0 (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.	1. I prefer anonymity	17 (71%)	16 (67%)
How do you feel about that?	2. Indifferent	2 (8%)	4 (17%)
	3. I would have preferred to get acquainted	5 (21%)	4 (17%)
Questions after 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?	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 add up to 20 because we lost one recipient due to nontransplantation-related complications.

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 traditional 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. 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 differ-

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

ence 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 k 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 k 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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Chapter 8

One Donor, Two Transplants: Willingness to Participate in Altruistically Unbalanced Exchange Donation

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SUMMARY

Kidney exchange donation programs offer a good solution to help patients with a willing, but incompatible living kidney donor. Literature shows that blood type O patients are less likely to be selected for transplantation within a living exchange donation program. 'Altruistically unbalanced donation' could help these blood type O patients: one donor-recipient pair is incompatible (e.g. A-donor > O-recipient) and the other pair is compatible, but not identical (e.g. O-donor > A-recipient). Exchanging these kidneys would result in two compatible living donor kidney transplants. We studied whether compatible pairs would be willing to participate in such procedure. We included 96 living kidney donors and recipients in our study. These donors and recipients could be divided into two groups: (i) donors and their direct recipients (n = 48), and (ii) paired exchange donors and their intended recipients (n = 48). All were asked whether they would be willing to participate in altruistically unbalanced exchange donation, as long as direct donation was also an option. We found no group differences. We found that one third of the donors and recipients are willing to participate in altruistically unbalanced kidney exchanges. Therefore this form of donation may be a feasible addition to already existing living kidney exchange programs.

INTRODUCTION

The shortage of kidneys for transplantation is widely considered to be a problem for patients with end-stage renal disease. In the Netherlands, the waiting list for deceased donor kidney transplantation has increased to a median waiting time of 4.1 years and even 5 years for patients with blood type O (1). Living kidney donation has prevented the waiting list from growing further, and has proven to be a good solution for many donors and recipients. In the recent past, patients with a willing but incompatible donor would be put on the deceased donor kidney waiting list after all. Nowadays, kidney exchange programs offer an alternative to prevent patients from having to endure this unfortunate situation and to increase the amount of kidneys for transplantation (2–6). As the idea of kidney exchange donation was proposed in the literature, the vulnerability of blood type O recipients in kidney exchange programs has been the subject of intense debate (7–10). Results from de Klerk et al. (4) show that couples with a positive crossmatch have better chances of finding a matching donor than couples with ABO incompatibility. This is especially true for those recipients with blood type O. O recipients have a 24% chance of finding a match within the Dutch kidney exchange program. In comparison, all B-donor > A-recipient combinations and all O-donor > B-recipient combinations entering the program could be matched successfully.

A possible solution to help blood type O recipients in a living donor exchange program is 'altruistically unbalanced exchange donation' (3 7,11–12). In this case, one donor-recipient pair is incompatible (e.g. A-donor > O-recipient) and the other pair is compatible, but not identical (e.g. O-donor > A-recipient). Exchanging these kidneys results in two ABO compatible living donor kidney transplants. Thus, altruistically unbalanced exchanges could be beneficial to optimize the number of transplants (3,11). However, without the support of the potential altruistically unbalanced exchange donors (and their recipients), this type of exchange donation is likely to remain a 'paper solution'. At the time this solution was first discussed in the literature, it was named 'altruistically unbalanced' because of 'differences in the degree of altruism required by the two donor-recipient pairs' (7). Ross and Woodle (7) noted in their article that there was a need for empirical data about donor attitudes on altruistically unbalanced exchange donations. Until then, they indicated that they would not be supportive of altruistically unbalanced exchanges, because they feared that under the current circumstances of kidney shortages the request for an altruistically unbalanced exchange donation risks donor coercion: i.e. the donor might consent to donate only in order to benefit his paired recipient so he might feel coerced to participate although he had no interest in doing so. On the other hand, it could be argued that an O-donor might be willing to participate in an altruistically unbalanced exchange, because in doing so he has an opportunity to help two recipients instead of one; the O-donor has already decided to donate his kidney anyway. It is very likely that he knows of, or has experiences with the unfortunate situation of kidney patients on dialysis. Knowing this, he might feel that it would be worthwhile to help another person in the same situation at the same time.

As far as we know, there are no empirical data on attitudes of living kidney donors and their intended recipients towards altruistically unbalanced kidney exchanges. In our study, we included 96 living kidney donors and recipients. All were asked whether they would be willing to participate in altruistically unbalanced exchange donation, as long as direct donation was also an option.

MATERIALS AND METHODS

Participants

We included 96 living kidney donors and recipients. These donors and recipients could be divided into two groups: (i) donors and their direct recipients, and (ii) paired exchange donors and their intended recipients. We included 48 living kidney donors (24 direct donors, M/F: 4/20 median age: 52; 24 paired exchange donors, M/F: 10/14, median age: 54) and 48 living kidney recipients (24 direct living kidney recipients, M/F: 14/10, median age: 45; 24 paired exchange recipients, M/F: 11/13, median age: 49). Recipients in the direct recipient group had a median waiting time on the deceased donor waiting list of 1 year and recipients in the exchange recipient group had a median waiting time of 2 years. All participants were included before donation/transplantation. They had undergone all the pretransplant medical treatment necessary before undergoing the donation/transplantation procedure. The average time between the interview and the planned transplantation date was 6 weeks. Participants were seen in the context of a broader study on psychosocial support for participants in living kidney donation programs. In this article, we will focus on the attitudes of living kidney donors and their intended recipients towards altruistically unbalanced kidney exchanges.

Materials

We used a structured interview for all participants. Participants were interviewed at the hospital or at home. We left it up to the preferences of the participants whether they would be interviewed in the hospital or at home; almost all participants considered it more convenient to be interviewed at home. Donors and recipients were interviewed separately. All donors and recipients participating in the living kidney exchange program were asked whether they would be prepared to participate in the living kidney exchange program, given that a direct donation would have been possible for them. All donors and recipients participating in the regular, direct donation program were asked whether they would be prepared to participate in the living kidney exchange program in their current situation (thus, although a direct donation is possible). To both groups, it was explained that the purpose of the proposed type of donation was to help another couple for whom a direct donation was not feasible because of blood type incompatibility. For both the ‘exchange donation group’ and the ‘regular donation group’, the interviewer took as much time as needed to explain what the proposed form of donation comprised. If constructive, the information was further concretized by drawing the exchange procedure on a paper. After full comprehension was established, all participants were asked to choose one of the five response categories: (i) no; (ii) no, probably not; (iii) yes, probably; (iv) yes; (v) I do not know. All participants were asked to explain their answers. Once the participant had provided an explanation, the interviewer 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. There were two interviewers involved in the administration of interviews. There was no statistically significant difference in data obtained by the one or the other interviewer ($p = 0.45$).

Statistics

To compare donors and recipients, the exchange donation group and the direct donation group, land of birth (native or nonnative) and male-female differences we used the Mann–Whitney U-test, exact testing; a was set at 0.05. We discerned four types of donor-recipient relationship [(i) partners ($n = 48$); (ii) parent-child relationship ($n = 24$); (iii) siblings ($n = 11$); (iv) other ($n = 13$)]. We used the Kruskal–Wallis test to investigate whether donor–recipient relationship influenced willingness to participate in altruistically unbalanced exchange donation. We also used this test to investigate whether the sex of donors and recipients within a couple influenced willingness to participate in altruistically unbalanced exchange donation, there were four subgroups: (i) male donating to male ($n = 4$); (ii) male to female ($n = 24$); (iii) female to male ($n = 46$); and (iv) female to female ($n = 22$). To investigate the strength of the relationship between time on the waiting list and willingness we used Spearman's correlation. We used the method of Cohen's kappa for correspondence to take into account the pairedness within the structure of the dataset: each individual is part of a donor–recipient dyad (for instance, spouses), and therefore a dependency between responses could be expected.

RESULTS

Thirty-one percent of all 96 participants in our study were probably or definitely willing to participate in a living donor kidney exchange program, even if direct donation was also a feasible option. Fifty-one percent of the participants were probably or definitely not willing to participate in an exchange program if direct donation was also possible. A relatively large proportion (18%) of participants were not sure what they would do in such a situation. Table 1 provides a more detailed overview of these findings (Table 1).

The explanation that was most often given for a reported willingness to participate in the exchange program, given that direct donation was also possible, was the wish to help another couple. A typical comment in this respect was 'by doing that you also help someone else. It would not be fair to withhold someone else a kidney'. The second most often named reason in favor of participating was the possible gain in quality of the kidney, in that the kidney received via the exchange procedure would provide a better match. This argument was also reversed in that some

Table 1. Willingness to participate in altruistically unbalanced exchange donation, given that a direct donation would also be possible

	Yes	Yes, probably	?	No, probably not	No	Total
Donors exchange (n=24) (%)	5 (21)	2 (8)	5 (21)	7 (29)	5 (21)	24 (100)
Donors direct (n=24) (%)	4 (17)	2 (8)	6 (25)	7 (29)	5 (21)	24 (100)
Recipients exchange (n=24) (%)	4 (17)	4 (17)	3 (12)	9 (37)	4 (17)	24 (100)
Recipients direct (n=24) (%)	4 (17)	5 (21)	3 (12)	4 (17)	8 (33)	24 (100)
Total (n=96) (%)	17 (18)	13 (13)	17 (18)	27 (28)	22 (23)	96 (100)

participants feared a worse match if they participated in an exchange program. The most often named reasons not to participate in an exchange program however were emotional reasons, for instance one recipient commented ‘I know he does it for me, and for himself, and not for someone else. Emotionally it makes a difference whether the kidney is donated directly or indirectly’; or from a donor, ‘[if direct donation were possible] then there was no need for an exchange. I’ll do this for her, not for someone else’. Other reasons not to participate in the program were practical objections, for instance if the donor had to travel to another hospital. Participants who were undecided stated that they had never thought about this option. In most cases, they added that they found the question puzzling thereby recognizing the advantages and disadvantages of the proposal. They felt that they would need more time to consider their view.

We found no statistically significant difference in willingness between participants in the regular living kidney donation program and participants in the exchange donation program ($p = 0.58$). We also found no statistically significant difference between donors and recipients ($p = 0.71$). More specifically, we found no statistically significant differences between the direct donors and the exchange donors, and also no difference between the direct recipients and the exchange recipients (respectively $p = 0.83$; $p = 0.35$). Furthermore, we found no statistically significant differences between men and women ($p = 0.90$), and the sex of donors and recipients within a couple was not of influence on willingness to participate in altruistically unbalanced exchange donation ($p = 0.79$). Donor–recipient relationship was not related to willingness to participate in altruistically unbalanced exchange donation ($p = 0.35$). There seems to be a trend that nonnatives (compared with natives) are less willing to participate in this type of donation ($p = 0.052$), but it should be noted that there were only six nonnative participants in our sample. Time on the waiting list seemed not to relate to willingness to participate in the exchange program solely to help another couple ($p = 0.38$). We found a statistically significant correspondence between donors and recipients belonging to the same couple (Cohen’s $k = 0.55$; $p < 0.001$).

DISCUSSION

The use of the term 'altruistically unbalanced exchange donation'

The term 'altruistically unbalanced exchange donation' refers to the situation wherein one ABO incompatible donor–recipient pair exchanges kidneys with another pair that is ABO compatible, but not identical. The term 'altruistically unbalanced' was used when this situation was described in the literature earlier (7). To maintain continuity, we have chosen to use the same terminology for this paper. However, 'altruistically unbalanced' is quite a complicated term in that it is not clear what exactly is meant by altruism. Altruism can be defined in many ways. According to one definition, something is altruistic only when it costs you; if it is no bother for you, it's not really altruism (13). Within this definition of altruism, it is possible to speak of degrees of altruism (more/less; low/high). As Ross and Woodle (7) define altruistically unbalanced exchange donation as a donation where 'more', or a higher degree of altruism is asked from one donor–recipient couple, it is likely that they conceive of the concept of 'altruism' as defined above. Looking at altruism in this way, the question is: are the costs attached to donating to a stranger (under the condition that your loved one will also receive a kidney) higher than donating directly to your loved one (so no stranger receives a kidney)? If we adhere to the definition of altruism as discussed above, the answer probably is yes. Our results show that at least half of our participants feel that donating indirectly in order to help more patients (taking into account that direct donation is also a possible option), indeed requires a 'higher degree of altruism'.

Discussion of the results found

Willingness to participate in altruistically unbalanced exchange donation was not related to group (either exchange donation or direct donation), being a donor or a recipient, sex, donor-recipient relationship, or time spent on the waiting list. The questions then rises what is a determinant for willingness to participate in altruistically unbalanced exchange donation? From our results, it seems that a factor like empathy, or 'altruism' in it's common sense meaning might be predictive for willingness. In this respect it might be helpful to refer to studies on altruistic (or anonymous, Samaritan, nondirected) donation. Especially a study by Landolt et al. seems of relevance here (14). They found that persons who were likely to act as altruistic donors tended to score high on the 'Agreeableness' scale of the NEO-PI-R, a widely used and validated psychometric instrument for measuring stable personality characteristics (15). Persons scoring high on 'Agreeableness' are moved by others' needs and show an active concern for others' welfare. Further research could investigate whether there indeed is a relationship between the personality characteristic 'Agreeableness' and the willingness to participate in altruistically unbalanced exchange donation.

Furthermore, our results showed that the quality of the exchanged kidney was an important factor in decision making about altruistically unbalanced donation. For instance, there were participants who choose against altruistically unbalanced donation, but were willing to switch if the exchanged kidney provided a better match. One person said for example, 'My first reaction is "no", but I would if it proved to be a better match, or if a child was involved'. Apparently the idea of better and worse matches are still common amongst donors and recipients, although nowadays it is known that the number of human leukocyte antigen (HLA) mismatches no longer accounts for a significant difference in successful living kidney transplantation (16).

Practical implications

The main ethical objection to altruistically unbalanced exchange donation was raised by Ross and Woodle (7): they were cautious to support altruistically unbalanced donation (mainly) because of the potential of donor coercion given the current organ shortages. However, we wish to emphasize the word potential, as in clinical practice coercion can be anticipated, for example by a protocol that describes how to prevent feelings of coercion and by giving the donor an independent confidant.

Next to the issue of potential coercion, altruistically unbalanced exchange donation has several other implications for potential participants, to cite Spital (12) 'giving up the comfort of knowing the donor intimately, jeopardize family visits after surgery and risk compromising the outcome by adding complexity and unknowns to the process'. As we explained in the results section of this article, all of these issues were recognized in the explanations of the 50% unwilling to participate in altruistically unbalanced exchange donation. The other half was either in doubt, or expressing a certain willingness to help two recipients rather than one at the same time. However, it should be noted that attitudes may be subject to social desirability bias and may not be a good predictor for actual behavior. This is a limitation inherent to this type of research and only testing the idea in clinical practice will provide more insight into whether the attitudes found were accurate predictors of behavior.

Finally, it may be of relevance to refer to altruistic living kidney donation once more (14,17–20). Although altruistic donation of course differs fundamentally from altruistically unbalanced exchange donation, there may be similarities with respect to the fulfillment of 'altruistic wishes', a desire to help another in meaningful way without receiving anything in return (17). This motivation is recognized as 'valid', and nowadays altruistic donors are welcomed as a valuable 'source' of donor kidneys; yielding positive results both for the altruistic donors and the recipients (17–19). Given our results and the positive experiences with altruistic kidney donation, perhaps the time has come to consider the altruistically unbalanced exchange donation more seriously as an addition to already existing living kidney exchange programs.

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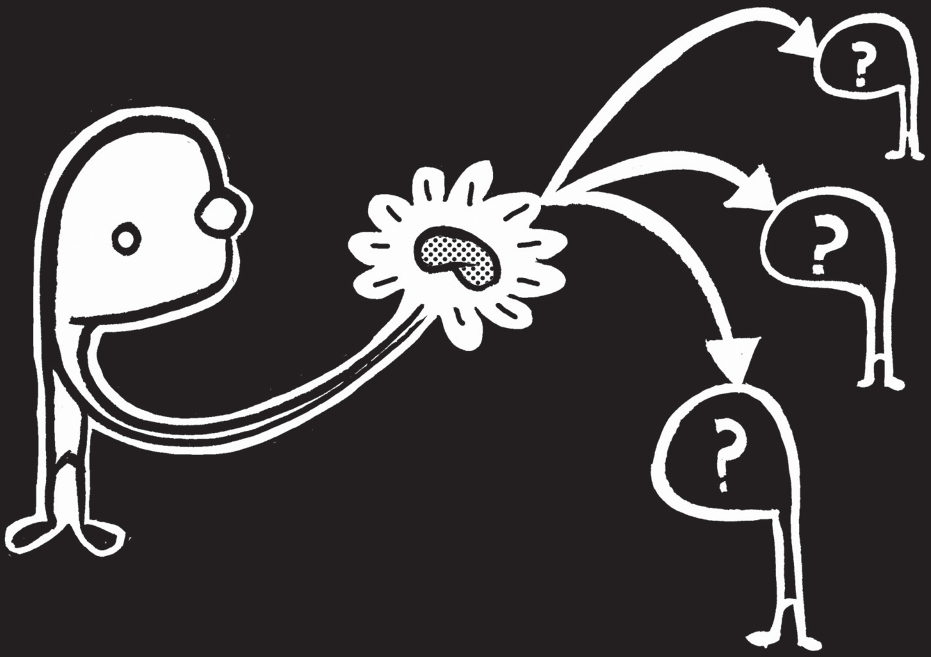
PART III: NON-DIRECTED DONATION

Non-directed donation is different from directed donation. Directed donation refers to the situation where the donor directs his kidney to a specified person, for instance to his father. In non-directed donation, the donor usually wishes to donate his kidney to “someone in need of a kidney”, with no further specifications. The donor leaves it up to the medical professionals to further direct his gift. In clinical practice this implies that the kidney is given to the first suitable recipient on the waiting list for a deceased donor transplant. In some situations the kidney is directed to the recipient of an incompatible donor-recipient pair with the incompatible donor in turn donating his kidney to the first suitable recipient on the waiting list for a deceased donor transplant.



Chapter 9

Altruistic Living Kidney Donation Challenges Psychosocial Research and Policy: a Response to Previous Articles

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SUMMARY

Background. Policies with respect to altruistic living kidney donation to strangers (both non-directed and directed donation) should, in addition to medical criteria, preferably be based on valid attitude research data. However, deciding on what data are relevant is a normative issue. The challenge for both research and policy making is to bring together empirical and normative issues. Methods. By comparing two recent surveys, the authors shed light on the complex methodologic and ethical questions surrounding altruistic living kidney donation. Results. The authors found that the main methodologic issues were the distinction between the willingness to donate and the acceptability of the offer, the difference between public attitudes observed in surveys ("facts") and wellconsidered moral judgments ("norms"), and biases caused by a misperception of central moral concepts (e.g., discrimination and injustice). The authors argue that transplantation centers have a good case for applying or initiating altruistic living donation programs. Centers should seek to influence public attitudes if these attitudes are shown to be biased by prejudice and misunderstanding. Conclusions. The authors advocate an interaction between research and policy making. Social research can best influence transplantation policies in altruistic living donation by in-depth interviews into the complicated background beliefs underlying personal preferences. In addition, the public should be encouraged to judge the immanent issues in a morally responsible way. In the end, a fair balance should be established between the impartial requirements of social justice and the partial motivations of individuals involved in altruistic living donation. Although discriminatory acts should be rejected categorically, donation policies should be willing to consider, support, and accept motivations based on personal loyalties.

INTRODUCTION

Research into the acceptability of altruistic living kidney donation to strangers is receiving growing attention. In this Journal, both Spital (1) and Landolt et al. (2) have pointed out that a significant proportion of individuals are willing to donate to a stranger or are prepared to consider it. Actual numbers of transplantations between strangers, however, fall short of what is needed. Moreover, most local and national policies are conservative and give preference to a close relationship—family or emotional—between donor and recipient. Policies that do approve of altruistic living donation to strangers usually accept anonymous, nondirected donation but are reluctant to allow donation in instances where a donor expresses a wish to donate to a particular person or a member of a particular group of persons. Current policy issues are concerned with the motives of altruistic donors, the nonanonymity in relation to (covert) payment and the question of social justice (in directed donation), and restraints on recruiting altruistic donors. The enduring scarcity of available organs puts policy makers under pressure to find solutions.

Social and psychosocial research is increasingly (and rightly) being incorporated into medical practice. However, two methodologic key problems persistently return. First, policy should be based on reliable data. There is an issue of what data are considered to be relevant. Second, good policy should be supported by empirical information, but ultimately it remains a normative question. The methodologic challenge for both research and policy is to bring together empirical and normative elements (3). In this article, our aim is to engage in this challenge, with regard to both nondirected and directed altruistic kidney donation.

METHODS

Two survey studies in this Journal, mentioned above, were taken to represent the empirical element. Their methods and results serve as the input for our ethical reflections. We realize that the authors have made valuable published contributions to research in the field of living altruistic kidney donation and put forward additional arguments elsewhere. However, by comparing both studies, we have the opportunity to observe some remarkable differences between them, not just in terms of the empirical outcomes but also in terms of the normative methodologic choices made in the study design and interpretations of the outcomes. Our method is based on the tools of moral analytical philosophy and reflects our own experience with this type of research into organ donation (4). In this article, we point to the distinction between the willingness to donate and the acceptability of the offer, the difference between public attitudes found in surveys (“facts”) and well-considered moral judgments (“norms”), and biases caused by a misperception of central moral concepts (e.g., discrimination and injustice).

The Difference between Willingness and Acceptability

Landolt et al. take the motivation of potential altruistic donors as crucial factors. Beginning with a telephone survey of a large number of randomly selected individuals, they showed in a follow-up subsample (using a questionnaire and in-depth interviews) that it is possible to find a significant number of committed individuals who are prepared to donate to a stranger in a nondirected way. Interestingly, most individuals were not aware of the possibility of donating to a stranger. The authors concluded that “more provocative measures to engage the public” in living anonymous donor programs are justified and should be advocated by patient groups and professional bodies. They considered public awareness to be a first step (2). We sympathize with this approach.

At one point, however, their conclusion seems flawed. They do not argue for it but take it for granted that there is “ethical latitude in allowing the promotion of living altruistic donation.” This could be a reference to the less conservative transplantation practices of some local centers (e.g., Saint Barnabas, NJ, and the University of Minnesota). However, philosophy teaches a clear distinction between facts and values. The fact of willingness, demonstrated convincingly in the study, can contribute to public acceptance but cannot in itself be a reason for its acceptance. Acceptation is a normative issue and should be assessed in its own terms. The authors’ conclusion therefore that we should accept altruistic donations to strangers, and the even stronger conclusion that we should publicly and actively promote these donations, is not supported by the data presented. The normative argument is necessary to justify the policy conclusions made by the authors. For instance, a normative argument could be that one and only one fact counts morally—the outcome in terms of actual donated organs—and that for this reason amore active recruitment policy can be justified. If that is the case, then it is important to convince people of the superiority of this ethical position above other views that take a more conservative stance. In short, the authors have shown convincingly that many of the potential altruistic donors interviewed are sincere in their motivation and judgment. However, willingness does not in itself justify a much more provocative policy.

Fact or Norm: Should We Accept the World?

The study of Spital addresses a related issue: the willingness and also the acceptability of living altruistic donation to strangers that is directed to a particular person or a member of a specific group of persons. Whereas transplantation centers, although still conservative in their recruitment policies, increasingly accept nondirected donations to strangers, both local and national policies are much more conservative in their approach to directed donation. Spital has explored the attitudes of the general public regarding directed donation in two large national telephone surveys. He concludes that the general public has more objections to, than support for, directed donation and that present policies that exclude directed donation should therefore stay in place (1). This is remarkable, because in many earlier publications, Spital has drawn attention to “unrelated” and “unconventional” donations, directed donations included (5, 6). On the basis of this recent survey, however, he seems bound to conclude that the general norm should be nondirectedness, although he permits an exception for directed donation toward children, in accordance with respondents' views. He is well aware that these findings may change over time and discusses them in the context of an ongoing argument for and against directed donation.

If we contrast Spital's study with that of Landolt et al., a number of considerations arise. Landolt et al. conclude that public attitudes can and should be changed, including those of professional bodies and patient advocacy groups, given the sincere motivations of potential altruistic donors found in their study. Spital takes the public views he finds, although perhaps variable over time, as a given and normative basis for policy making. But why?Why should we accept the world as it is and not try to change it? As discussed above, in ethics, facts do not speak a moral language. Moreover, which facts should inform our judgment? The attitudes of the general public or the attitudes of a special, selected group of potential altruistic donors? Data frequently do not provide us with a unanimous message; facts cannot be evaluated without interpretation and without taking the methodologic issues (e.g., psychometrics) into account. How facts and figures should be used and how social research can contribute to developments in transplantation are methodologic and normative questions. We should take the public's attitudes seriously, without allowing them to determine policy. This requires a balance between our concern to base policies on the preferences of the general public, on the one hand, and encouraging the public to make judgments in a responsible way, on the other hand.

Facts and Well-Considered Moral Judgments

Landolt et al. present a sophisticated understanding of the motivations and commitments of potential donors, their receptiveness to the suffering of others, and humanitarian values. The study gives us good insight into altruistic behavior toward strangers and is therefore interesting for policy makers. In contrast with the study by Landolt et al., it is less easy to interpret Spital's data. He has confronted his public with a complex question—as he indicates himself—about the acceptability and the willingness to choose one's own recipient. He uses fixed questions and response categories, which makes it difficult to allow for changing views. Moreover, respondents may have been tempted to give socially desirable and politically correct responses as a result of the complexity of the question.

So how do we know that the public understands the hypothetical, heterogeneous question and the associated range of complicated issues? The public's response is difficult to interpret, as no reasons are given. Therefore, it is difficult to assess the data: how should we understand the responses and weigh them? As Spital concedes at the end of his article: "the question of directed donation is a complex one for which one size does not fit all." Nevertheless, he does draw some firm conclusions. He abandons, for instance, the option of directed donation to patients advertising for a kidney through the media, although almost half of the public questioned would accept this practice. This is similar to the issue of the half-full or half-empty glass of water. Should we positively conclude that directed donation through advertising is indeed a feasible option for many or negatively that it is not an option for the majority? This clearly illustrates that in cases of diverse attitudes among the public, the interpretation of the public's views requires an additional ethical argument. The norms of equity or fairness are probably used by Spital for filling the gap between the empirical data and his normative conclusion ("do not give people advertising priority over others"), but he does not clarify this. Note that for Landolt et al., the view of a minority of individuals who express willingness to consider altruistic anonymous donation to a stranger is taken as a positive sign. Another fact that Spital presents concerns children. A clear majority (74%) would accept directed donation to an unknown child. (Note: what if the media would advertise for a child?) Spital endorses this outcome, but why does he not give more weight to the 26% who clearly oppose this option? It is important to grasp the moral significance of this figure, as it could refer to issues associated with unfairness, illegal payment, and dubious motivation.

Spital, of course, is well aware of the many prevailing arguments about directed donations. Our observations do not concern this discussion; rather, our criticism focuses on a methodologic aspect, as follows. Spital's research shows how difficult it is to connect survey data with the arguments for and against acceptability, as found in the literature and in public debate. It is equally difficult to relate the data to the conclusions obviously based on it. The presented data may give a realistic and true insight into the feelings of the public and their moral intuitions with respect to various but diverse forms of directed donation. However, we can and should not take them at face value as well-considered moral judgments. Perceptions may be based on imperfect information and feelings may flow from incorrect premises. All kinds of biases may unjustly influence sound judgment. The data call for understanding, interpretation, and possibly also correction.

Bias: Discrimination As Exclusion

One possible cause for misperception is an obvious link with racial discrimination. Spital mentions a Ku Klux Klan incident, in which parents only wanted to donate to a white recipient. This condition is clearly inspired by a form of racism and as such is forbidden by law. It reflects the racist belief that white people are of more value than black people, and this belief contradicts the fundamental ethical norms of human dignity and respect (7, 8). It excludes and humiliates entire groups and their individual members. Society and medical practice should, of course, not support or tacitly endorse this belief, even if there are good reasons otherwise to accept the donor's offer (9).

With this discriminatory type of case in mind, the public may have judged the desirability of directed donations. Spital has explicitly specified certain groups in his questionnaire (i.e., children, the media, race, and religion) in relation to directed donation. This could have shaped people's responses.

In societies where both race and religion have created deep conflicts, the fear of discrimination can be real indeed. Many countries have to deal with racism and other forms of discrimination, such as sexism or ageism. Some cases, for example, refer to the refusal to grant liver transplants to exalcoholics (7, 9). However, many preferences in directed donation are not based on discrimination (e.g., the wish to donate to a member of one's sports or fan club, medical school, local church community, or women's network). These preferences reflect, in general, not exclusion, but often deeply felt personal bonds and commitments, similar to family donation. The wish to donate to an AIDS patient, as mentioned by Henderson and Landolt et al., may be equally sincere. If it springs from a "spirit of benevolence," we can hardly classify this wish, as they do, as "a restriction" (10). Their conclusion that donations to strangers should always be strictly anonymous and nondirected, does not follow from the data they present. Not all preferences regarding donation are based on dubious beliefs that exclude and humiliate. They can reflect a sincere and altruistic wish to help particular others. These specific wishes may flow from very basic feelings and particular loyalties. They are essentially personal in nature and express who we are and who we want to be. They are closely tied to our moral identity and the relationships we value and find ourselves in. It is therefore not obvious why we should require that altruism is only respectable if it is expressed in impersonal, anonymous terms (11, 12). At the basis of the focus of Landolt et al. and Henderson et al. on anonymity and nondirectedness, however, seems to be the noteworthy, contestable view that "Altruism receives its highest expression in the absence of personal relationships" and represents altruism of a "supreme kind" (13).

Understandably, Spital's questionnaire cannot be expected to tap into the whole range of relationships between people that might influence their decision for directed donation. However, it does appear that people's commitments and loyalties go far beyond genetic and emotionally related bonds. Research into the various motivations to help particular others requires more specific in-depth interviews than Spital has undertaken. To quote David Pence: "in view of the heterogeneity of classes of unrelated donors it will be impossible to detect a homogeneous attitude towards them even within a single culture" (14). Although it is important to acknowledge the risks and dangers inherent in donors' personal preferences (e.g., exclusion and humiliation), it is not wise to overreact.

The study of Landolt et al. has given a good in-depth insight into motivations based on general humanitarian values in relation to the question of nondirected donation ("How do we feel connected to strangers in need?"). However, the issue of directed donation requires research that looks at our particular values that are embedded in our relationships, motivations, and commitments. The Foster Parents Plan projects explicitly link our particular motivations to particular others in need. We suggest that particular motivations and their background beliefs, not only with respect to children, should be at the center of our research.

In short, we are concerned with the question of how research can inform and direct policy in cases of altruistic donation. We suggest that the fear for racial and religious discrimination, misunderstood as this is, can be detected in the general public's response toward directed donation and that this probably would not have appeared if the topic had been presented in a more positive, less biased way.

Bias: Injustice and the Claim of Impartiality

Another possible bias is connected to the idea of “distributed justice” as a universal ethical concept. In measuring the attitudes of the general public, the public’s views might be influenced negatively by a misunderstanding of this concept. Probably, the public is most familiar with cadaveric organ transplantation, which is governed by sound ethical allocation principles of impartiality and equality that are anonymous and nondirected. It is therefore understandable that people’s first response toward directed living donation may be negative. This appears unjust, because personal preferences favor some people at the cost of others. Henderson et al. and Landolt et al. clearly hold this view: “The transplant center should be prepared to lose a donor rather than sacrifice the ethic of equal access for all those on the waiting list” (10).

Spital also takes the dismissive response for granted. He found that those who were already rather hesitant and conservative in their approach to donating to a stranger were more strongly motivated to donate (27%) given the additional (hypothetical) option of directed donation; however, others (17%) did not view this as a positive incentive at all. Spital draws the unreserved conclusion that nondirected donation should be the norm and that an additional option of directed donation would not add a great deal to a transplantation program. Although we may think that these figures are too weak to provide firm conclusions, the negative response may partly be explained by feelings of injustice. However, if this is the case, are these feelings justified?

In cadaveric organ donation, undirected donations are the norm, but living donation to family members and friends is, by definition, directed and therefore not based on impartiality and equality. This living donation is “unfortunate” in that it favors some people over others and gives some individuals advantages over others. It is not clear whether the respondents of Spital’s investigation are aware of this. Because no in-depth interviews have taken place, we can only guess at the motives and background beliefs that led to their negative responses. Furthermore, it seems inappropriate to use moral terms such as “unjust” or “unfair,” or despise the choice as immoral, if someone expresses a preference to help a family member or friend. In fact, these preferences, based on personal bonds and loyalties, are valued highly and so cannot simultaneously be considered immoral. If we simply consider directed preferences in terms of injustice or unfairness, as Spital also seems to do, we denigrate such personal bonds and loyalties. The assertion that personal preferences are always made at the expense of others and are contrary to fundamental principles of justice and equality can only be true if we endorse the view that persons unknown to us hold the same rights to our kidneys as our partners, friends, or anybody else to whom we feel deeply connected. This position is hard to defend. In living donation scenarios, donations are partial, not impartial: we make a personal choice to donate to certain people and not others. Family donation is a morally accepted practice, and existing policies endorse this for good reason. Our particular ties motivate us to donate, and without these bonds, loyalties, and commitments, there would be hardly any donation at all. Mostly, we feel connected to particular others and not to others “in general” or humanity as a whole. Moral particularism is in this context generally considered to be a good thing, not something to be rejected. A considerable growing body of literature has brought this to the heart of the current philosophical debate (15). Personal relations are an essential part of the moral realm, and only further research can shed more light on the implications for the acceptance of directed donation. How wide the range of partiality in personal preferences that society should be willing to permit is open for discussion. If in our societies organs are freely available and at our disposal, we should, of course, allocate them according to the norms of fairness (impartiality, equity, and medical need). However, organs only become available if individuals are willing to donate them. That they wish to do so according to their loyalties and commitments is only human and ethically justifiable. The crucial issue then is not simply the fair allocation of organs, but the more complex concern that includes appropriate acquisition. This implies that policy makers should find a fair balance (not necessarily a utilitarian one) between partial and impartial considerations (8, 16). We are therefore concerned that misconceptions regarding the issues of fairness and justice may be obscured by research.

Implications

The implications can be summarized as follows. First, the willingness to donate to strangers—both directed and nondirected—should be distinguished from the acceptability of the offer. Normative questions (e.g., policy considerations to reject or actively support this) should be assessed in their own terms.

Second, survey data call for understanding and interpretation, but also correction. Psychosocial research can best influence transplantation policies if it includes research into complicated background considerations and fundamental beliefs. Personal preferences often hide strong moral convictions. They can be well founded but can also be driven by fear, prejudice, and misunderstanding. In-depth interviews can shed light on this and further aid ethical and philosophical arguments and provide the basis for future policy decisions. Preferences, attitudes, feelings, motivations, and moral intuitions form a starting point in ethics. If, for instance, the public is shown to accept directed donation to children (despite media attention), it may be consistent to also accept donations to other vulnerable groups of individuals who are dependent on the help of others—for example, blood type O patients waiting for a blood type O donor for a long time. Directed donation (anonymous or not) may be for them a welcome and feasible option and acceptable to a well-informed public. Landolt et al. are right in their conclusion that there can be good reasons to educate the public and actively change attitudes. We should, however, be aware of the fact that surveys of public attitudes can easily be used politically to support the ethical preferences of the transplantation profession and “not just to assess, but to sway, public opinion” (17).

Third, although some (directed and nondirected) preferences to donate originate from dubious motives or objectionable beliefs, many others are sincere, understandable, and ethically justifiable. Directed donation is neither discriminatory nor unjust in itself. It is part of our personal morality that we give preference to those to whom we feel connected. The importance and value of this “moral particularism” can be revealed by social research. It is up to policy makers to make the normative decision as to what degree society can accept this. Sincere individual motivations and good intentions do not necessarily lead to fair and socially acceptable outcomes (8). To find a balance between partial and impartial considerations is a delicate matter, and research may endorse and influence policy (e.g., by mapping the various personal relationships we find ourselves in and their importance to us). We have shown that the concept of equality, considered as an impartial norm and used to judge and reject partial wishes, is unfounded or at least highly questionable in the context of living donation. It is a misunderstanding to think that the concept of equality is not consistent with directed donations. Note that this observation may even have implications for cadaveric donations. What reasons do we have to reject the wish of someone who is going to die to offer his or her kidney to a sick relative after his or her death?

Finally, we think therefore that transplantation centers have a good case to apply or initiate altruistic living donation programs, given their societal mission to help the sick wherever they can. Reliable empirical evidence suggests that motivated, altruistic donors can be found in significant numbers. Moreover, reliable normative evidence gives reason to consider the option of directed altruistic donation alongside nondirected donation, given the moral importance of partial wishes and personal bonds. Centers should not just follow but should influence public attitudes and personal views if these are shown to be biased by prejudice and misunderstanding.

CONCLUSION

We advocate an interaction between research and policy making. Social research can best influence transplantation policies in altruistic living donation by in-depth interviews into the complicated background beliefs underlying personal preferences. In addition, the public should be encouraged to judge the immanent issues in a morally responsible way. In the end, a fair balance should be established between the impartial requirements of social justice and the partial motivations of individuals involved in altruistic living donation. Although discriminatory acts should be rejected categorically, donation policies should be willing to consider, support, and accept motivations based on personal loyalties.

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Chapter 10

Systematic Review of the Psychological Screening of Samaritan Kidney Donors

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Submitted.

SUMMARY

Background: Living kidney donation to a loved one has become common practice these days. Another type of living donation that is becoming more acceptable to the transplant community is ‘ Samaritan donation’. Samaritan kidney donors are willing to donate to patients they do not know. Until recently there has been great reluctance to accept the offers of Samaritan donors, because one feared that these donors would be mentally instable.
Methods: The purpose of this article is to review the literature about the psychological evaluation of potential Samaritan kidney donors on donor suitability. We have performed a systematic literature search in Pubmed, ISI Web of Science and PsycINFO. We compare and discuss how each study approaches the question about Samaritan donor selection. In addition, we have also screened the studies found for reports of rejections of Samaritan donors on psychological grounds.
Results: We have found five articles that at least in some detail describe the evaluation of potential Samaritan donors. For all five articles found, a consultation with either a psychiatrist or a psychologist is standard part of the donor evaluation procedure. This evaluation consists of an interview, and in most instances of additional psychometric testing. Basically, according to the articles found, the two major criteria for donor rejection are psychopathology / psychological instability and motivational issues. Three studies reported on the actual rejecting of potential donors on psychological grounds.
Conclusion: The evaluation of Samaritan kidney donors is a developing field in clinical medicine. Given the scarcity of follow-up data on this type of donation, we recommend the exchange of experience between centers that run a Samaritan donor program, in order to improve the evaluation criteria and care for this type of donors.

INTRODUCTION

Living kidney donation to a family member or your partner has become common practice these days. However, donating one of your kidneys to an unknown patient on the waiting list for transplantation is one step beyond. A thirty-year old man decided to do so: "It is about the feeling you get if you are able to do something for someone else in a meaningful way" (from: Daily Newspaper: "De Limburger", Wednesday November 16, 2005).

An important clinical question is the validity of such motivation: is the motivation a well thought of aspiration, or is it a sign of mental instability. A careful psychological evaluation to distinguish between the two is warranted if society wishes to proceed in the case of 'Samaritan donation' This article describes a review of the literature on how such evaluation is best constructed.

The shortage of kidneys for transplantation is widely considered to be a problem for patients with end stage renal disease. In the Netherlands, the waiting list for deceased donor kidney transplantation has increased to average waiting times ranging from 2 years for patients with blood type AB to 5 years for patients with blood type 0 (1). In the meantime patients are dependent on dialysis treatment, which is associated with severely lowered quality of life, morbidity and mortality (2): approximately 25% of all Dutch patients die while waiting for a transplant (3).

Living kidney donation saves these patients from waiting this long. In the past, only the patients' close relatives were considered as living donors. However, since non-related living donors kidneys' proved to have similar good outcomes, the proportion of non-related donors such as spouses and friends has increased significantly over the past years (4, 5). Another type of living donation that, only very recently, is becoming more acceptable to the transplant community is the so-called 'Samaritan donation'. Samaritan donors are people that are willing to donate to patients they do not know at all. The idea and use of Samaritan donors goes back as early as 1971, when Sadler was the first to describe a sample of Samaritan donors (6). Despite this early report, up until recently there has been great reluctance to accept the offers of Samaritan donors. The most important reason for this reluctance is the feeling that these donors would be mentally instable (7). Although a case is known wherein the donor saw giving away all his body parts as an inevitable necessity (8), feelings and fears of donor insanity often proved not to be true (6; 9-12). Over the last years, the reluctance towards Samaritan donors seems to be decreasing: recently some transplant centers have started to publish their first results with Samaritan donation, whereas other centers have started to develop protocols for their planned Samaritan donation programs (13). A recent survey has shown that so far every center seems to be developing its own protocol separately, in absence of a common 'Samaritan donor protocol' (13). It seems that many local protocols share the basis of the existing 'regular' living kidney donation protocols, with a special attention to the psychological and / or psychiatric evaluation of the Samaritan donor. At present however, information about how this specific psychological / psychiatric evaluation is best constructed is scarce. The purpose of this article is to systematically review the existing literature about the psychological / psychiatric evaluation of Samaritan donors, and to come to a proposal for the contents of the psychological / psychiatric evaluation of Samaritan kidney donors. The rational for a well-defined psychodiagnostic tool to screen Samaritan donors is to rule out cases where the psychological risks of donation are bigger than the benefits. This especially is important since psychological benefits are generally seen as a major moral justification for the surgical practice of living donor nephrectomies (14).

METHODS

As 'Samaritan donation' is a specific form or subcategory of 'living kidney donation', we first studied the commonly used current guidelines and consensus reports for the psychological evaluation of directed living kidney donors (such as parents or spouses). By including these guidelines, we can examine into what extent protocols for the psychological evaluation of Samaritan donation can or should differ from the psychological evaluation of the more traditional living kidney donors. Next, in April 2007, we performed a systematic literature search in Pubmed, ISI Web of Science and PsycINFO. We used the search terms: 'Samaritan' OR 'anonymous' OR 'nondirected' OR 'non-directed' OR 'altruistic' AND 'kidney donation'. We did not make time restrictions with respect to publication dates. We screened all articles found for a detailed description of the contents of the psychological / psychiatric evaluation of Samaritan kidney donors; and checked whether psychological exclusion criteria for donation were reported. We also screened the studies found for reports of rejections of Samaritan donors on psychological grounds. In case we figured that the articles found referred to articles on Samaritan donation that we had missed as a result of our initial choice of search terms, we included these articles as well (i.e. the snowball method). In all these articles, we studied how each clinical group actually approaches the question about eliminating psychopathology or eliminating patients with poor motivation.

RESULTS

Guidelines and consensus reports for psychological evaluation for 'conventional' living kidney donation

Before presenting the results for the Samaritan kidney donor evaluation, we will first present the results for conventional living kidney donation. The best descriptions or guidelines of the psychological evaluation for 'conventional' living kidney donation were found in three types of documents: 1. Consensus statements, 2. Guidelines and 3. Scientific reports. For each type, we included two documents: the consensus statement on the live organ donor and the Amsterdam Forum reports (14-16); the current US and UK guidelines (17, 18); and in the studies of Leo and

Olbrisch (19, 20). There was considerable agreement about the headlines of the contents of such evaluation. We identified five common elements: 1. the purpose of the evaluation is to uncover clinical psychiatric disorders that would preclude donation, 2. the assessment of psychosocial stability, 3. to asses if the donor comprehends all risks and benefits involved, and is capable of making an informed decision. Both the morbidity/mortality risks for the donor and the chance of succes for the recipient should be discussed, 4. the absence of pressure or coercion to donate, and, in most instances 5. the donor's relationship with the recipient and within the context of the wider family. Some documents explicitly included the motivation to donate as a topic for the evaluation (19, 20), whereas for others motivational issues fell under the exploration of the voluntary nature of the decision. There were differences between the documents with respect to the inclusion of third parties in the evaluation procedure. Two documents mention the inclusion of third parties: Olbrisch et al. (2001) have included a collateral spousal interview in their evaluation procedure, and Abecassis et al. (2000) describe that for potential donors undergoing mental health treatment, the mental health professional caring for this patient should contribute to the evaluative process. Another difference between the documents concerns the informing of the potential donor of the psychological risks and benefits assosciated with kidney donation. Although all documents state that a well informed decision should be made (thereby implicitly including the psychological risks and benefits of a donation procedure), Kasiske et al. are the only one to explicitly describe these psychological risks: "A small minority of patients may, at some time, become depressed as a result of kidney donation", "rare cases in which the donor committed suicide after the kidney they had donated failed" and possible adverse effects on marriage. Benefits, that are much more common, include superior psychological health compared to the rest of the population, increase in self-esteem, and improvement of the relationship with the donor (17). Furthermore, there exists considerable difference into what extent the different documents describe what kind of psychopathology could be a contra-indication for living kidney donation. In this respect, the study of Leo et al. (2003) provides the most concrete descriptions. This study includes a table of poor prognostic factors that may be identified in presurgical psychological evaluation of prospective living kidney donors. These factors are: psychotic disorders, major mood disorders, major depression, bipolar disorder, substance abuse / dependence, severe personality disorders, risks for suicide, issues influencing the decision to donate (coercion, monetary gain, economic factors, desire to enlist the organ recipient in a reciprocal relationship, desire to create indebtness in the organ recipient). The study of Olbrisch et al. (2001) does not work from diagnoses, but rather from questions such as "Is the donor sufficiently emotionally stable to cope with stresses which may come up before, during and after the donation?, Is there overt or indirect evidence that the wish to be a donor reflects self-destructive or suicidal feelings? What is the potential that the donor will develop somatisation symptoms that could result in high medical resource utilization, prolonged disability, chronic pain, attention seeking, or other secondary gain as a result of undergoing an elective surgery? Is the donor prepared to handle medical complications that either the donor or the recipient might experience?". Despite the differences, what is commonly described in these documents is that decisions on rejecting or accepting living kidney donors on psychological grounds should be made on a case-by-case basis, and that there is not a ‘diagnose based recipe’ for these decisions.

Literature review: psychological evaluation for Samaritan kidney donation

By using our search terms, we found 84 articles on Samaritan donation by using Pubmed, 75 in ISI Web of Science and 3 in PsycINFO. After controlling for overlap between the results found, there were 111 articles left. Only five of them included detailed descriptions of the contents of the psychological / psychiatric evaluation of the donors (9, 10, 12, 21, 22). Typically, this evaluation starts as soon as the interested potential Samaritan donor telephones the transplant center. During this telephone conversation, the transplant coordinator or transplant nurse performs an initial evaluation to rule out those with obvious medical or psychosocial contra-indications. Following this evaluation, if candidates seem eligible for donation, they receive an information packet of donor educational information. Next, if after reading the information the donor candidate is still interested in donation, he or she has to contact the transplant center again to make arrangements for further donor evaluation. For all five articles found, a consultation with either a psychiatrist (10, 21) or a psychologist (9, 12) is standard part of the donor evaluation procedure. This evaluation consists of an interview, and in most instances of additional psychometric testing. The interview consists of a variety of topics. The articles found differ into what extent they describe the topics of the interview. The shortest description of interview topics is provided by Jendrisak et al. (2006): “a standard psychiatric interview using DSM IV criteria for major psychiatric disorders such as depression, anxiety, mania, schizophrenia, substance abuse, and other disorders along with a MMSE. Donor motivation is also addressed in depth during the interview”. Gilbert et al. (2005) also provide a compact description of the interview contents: “motivation, decision-making process, health concerns during and after donation, expectations of the relationship with the recipient, family members’ viewpoint on the donation and health expectations for the recipient. An axis -I, -II or -III impression is given and also a recommendation whether or not to proceed with the donation.” Jacobs et al. (2004) and Dew et al. (2007) provide the most detailed description of the topics asessed during the interview. In addition to the interview topics already named above, they also include: ‘history and current status’ (22), including f.e. employment, cultural background, religious beliefs and practices, history of volunteerism, and charitable deeds. Furthermore, they include the financial situation of the donor in their evaluation interview (9, 22) . Morrisey et al. (2005) refer to Jacobs et al. (2004) in their description of interview contents. Only Jendrisak et al. (2006) descibe to use a standard DSM-IV interview for the evaluation of psychiatric disorders. Gilbert et al. (2005) describe that an axis I, II or III impression is given, but do not state how this impression was accomplished. Next to the interview, psychometric testing forms an important part of the psychological evaluation of Samaritan donors. Both Jacobs et al. (2004) and Jendrisak et al. (2006) make use of the Minnesota Multiphasic Personality Inventory-2 (MMPI-2; 23). In addition, Jendrisak et al. (2006)

also apply the Temperament and Character Inventory (TCI) and the Mini Mental State Examination (MMSE). Gilbert et al. (2005) state that the psychiatrist used standard psychiatric tools to assess competence of the donor in making an informed judgement, the presence of social or medical concerns that would place on undue burden on the individual or their family during the post donation period and for the presence of psychiatric illness. It is however not described what these "psychiatric tools" were. In the study of Morrisey et al. (2005), the use of psychometric testing is not mentioned. Furthermore, four out of the five studies recommend including a family member of the potential donor to take part in the evaluation procedure (9, 12, 21, 22).

The five articles vary in their description of contra-indications or exclusion criteria for Samaritan donation. These contra-indiations are summarised in Table 1, except for Morrisey et al (2005), who follow Jacobs et al (2004) in their description of contra-indication on psychological grounds, (although they do not mention the age restriction) and Jendrisak et al. (2006) do not explicitly describe contra-indications for Samaritan donation. Next to the five articles discussed above, our literature review resulted in the finding of the article The nondirected live-kidney donor: ethical

Table 1. Contra-indications for Samaritan donation

Article	Contra-indications
Adams et al. (2002)	1. An unrealistic expectation or demand that the transplant would be free from rejection and failure; 2. The misperception by the donor that if the transplant is not successful, it is because a personal failure as a donor; 3. Monetary compensation; 4. A desire for media attention (that could not be supported by the transplant center); 5. A response or remedy for a psychological malady, such as severe depression, low self-esteem, or other underlying mental illness; 6. A desired selection of the recipient by gender, race or ethnicity; 7. A desired involvement in the recipient's life after donation, possibly unwanted by the recipient, that could not be supported by the transplant center
Jacobs et al. (2004)	1. an impulsive decision making process, 2. unrealistic or ulterior motives to donate (e.g. individual or societal approval, compensation, atonement, redemption, media attention), 3. severe forms of depression, active grief, low self-esteem, or other underlying or untreated mental illness. Candidates are ruled out if psychosocial issues are present that could increase their vulnerability to withstand potential donor-related stresses or that could exacerbate any psychological morbidity, and 4. an age under 21.
Gilbert et al. (2005)	"evidence of significant psychiatric illness", in that case "offers are rejected as lacking the mental health necessary for an authentically voluntary offer".
Dew et at. (2007)	Dew et al. Describe risk factors for poor psychosocial outcomes in living kidney donors, factors of heightened importance of unrelated donors (such as Samaritan donors) are in italics. They also describe a number of protective factors (see Dew et al., 2007): Significant past or ongoing psychiatric symptoms or disorders; Substance abuse or dependence; Limited financial capacity to manage donation (lost wages, travel, job concerns); Lack of health insurance; Limited capacity to understand donor risks/recipient benefits and alternatives; Increased medical risks (e.g. chronic pain conditions); Marked ambivalence about donating, or unrealistic expectations about the donation experience and potential recipient outcomes; Motives reflecting desire for recognition, or a desire to use the donation to develop personal relationships (e.g. desire for publicity, desire for a relationship with an individual or with treatment providers); Multiple family stressors/obligations/concerns; Subordinate relationship (e.g. employee/employer) or other evidence of coercion; Evidence of, or expectation of, secondary gain (e.g. avoidance of military duty, financial support from recipient); Poor relationship with family; poor family support for donation.

Table 2. Donor exclusion on psychological grounds

Article	Included donors	Excluded donors
Jacobs et al. (2004)	5 had received counselling at some point in their lifetime, 5 were taking psychotropic medication, and 3 were in active therapy for some type of intervention.	4/51 had been rejected for "psychosocial reasons", but these reasons were not further specified
Gilbert et. al. (2005)		13/51: 7 for active substance abuse, 3 for depression, and 3 for bipolar disorder.
Morrissey et al (2005)	4 donors were taking medication for depression	None (0/16)
Jendriskak et al (2006)	2 individuals had remote episodes of anxiety/panic disorder and depression and one had dysthemia, treated in the past for a 3 month period with antidepressiva.	None (0/19)
Mark et al.(2006)		9/76: anxiety, schizophrenia, body issues, pain history and fear

considerations and practice guidelines: A National Conference Report (24). According to this report contra-indications to Samaritan donation are the same as for directed donation. In addition, they list a number of reasons for donor exclusion, which are also summarised in table 1. Given these contra-indications, we studied how many Samaritan donors candidates have been reorted to be rejected for donation on psychological / psychiatric grounds so far. Our literature survey yielded five reports on te outcomes of Samaritan kidney donation programmes. These results are summarised in Table 2. This table also includes the results for those donors who were receiving counselling or psychotropic medication, but nevertheless were accepted for donation. There were no adverse psychological consequences after donation reported for these donors.

In addition to the studies described above, we found three more studies that not in particular described the clinical evaluation procedure of Samaritan donor candidates, but rather could be described as research into the personality characeristics of (possible) Samaritan donors (7, 11, 26). Landolt et al. found that people likely to volunteer as Samaritan donors were more likely to ascribe humanitarian values and less likely to be influenced by the external costs of donation. Furthermore, they filled out the NEO-PI-R, a self report instrument measuring five major personality domains (27, 28). Results showed that they were more likely to score high on the NEO-PI-R subscales "openness to experience", indicating a certain willingness to question authority and to entertain new ethical, social and political ideas, and were more likely to score high on and "agreeableness", indicating qualities such as kind-heartedness, friendliness, benevolence, empathy and a believe in the fundamental good of others (11). The study of Jendrisak et al. (2006) also included a validated questionnaire on personality traits, namely the TCI (29). They found that Samaritan donors were not thrill seekers, and were less harm-avoidant than the general population. Furthermore, they scored lower on self-transcendence than the general population, suggesting that as a group they were not especially tied to organized religion or spirituality. Boulware et al. (2005), found that potential stranger donors were willing to undergo greater risks associated with donation (compared to the general population), but that there were no differences with respect to prevalence of depression and anxiety symptoms, and no differences with respect to altruistic or religious attitudes. Regarding religious motives, the results of the various studies are not in agreement. Opposed to the studies of Jendrisak et al. (2006) and Boulware et al. (2005), the study of Henderson (2003) suggests that people likely to volunteer as Samaritan donors are more likely to have a spiritual belief system. In addition, the study of Jacobs et al (2004) provides evidence that at least part of the Samaritan donor are motivated by religion, as nearly a third of the 49 assessed candidates in their study had a strong religious and/or Christian conviction and believed that donating was an act of living out their faith and their dedication to serving others.

Discussion

The evaluation of Samaritan donors should at a minimum include the same issues as the evaluation of conventional living donors (22, 24). In addition, a consultation with a psychologist or psychiatrist is a standard procedure in many transplant centres. Compared to the procedures for conventional living kidney donors, we found that motivational issues played an more prominent role in the evaluation of Samaritan donors. In conventional donation, the donor motivation is evaluated more in terms of absence of pressure (and good reasons for donation are more or less taken for granted), whereas the evaluation of the motivation of Samaritan donors is more extensive. Thus, in case of Samaritan donation, the psychologist / psychiatrist is called in to evaluate psychopathology, the motivation for donation, and the possible relationship between psychopathology and motivation. As described above in the results section, we found no uniform description of what type(s) of psychopathology should preclude either a conventional living kidney donation or a Samaritan donation. Possibly due to this indistinctness, it turned out that in one study 3 people were rejected on grounds of depression (21), whereas in another study 4 people with depression on medication were accepted for donation (10). There we no psychological complaints reported for these 4 donors after donation (10). With respect to the methods used to uncover mental illness, for one study we found that a standard DSM-IV interview for the evaluation of psychiatric disorders is used (12), or that at least an axis I, II or III impression is given by the psychiatrist (21). For obvious reasons we prefer a standardized interview (for example the Mini-International Neuropsychiatric Interview; 30), but we think that in clinical practice the experience and preference of the treating psychologist / psychiatrist will be decisive. In addtition, psychometric testing is used for the evaluation of Samaritan donors.The MMPI-2 is part of the evaluation protocol in the studies of Jacobs et al. (2004) and Jendrisak et al. (2006) (see also, 31). An important reason for including this instrument is that the instrument is hard to ‘look through’ or fake, because it is almost impossible for the patient to know what the right or wrong answers are. We think such feature is helpful as in cases the Samaritan donor might try to conceal something he or she thinks would be a contra-indication for donation (20). It is also known from other studies that the way people fill out questionnaires is influenced by the specific context and, consciously or unconsciously, may bias the results (32). Furthermore, the TCI is used in the psychological evaluation of Samaritan donors (12). Although the TCI adds to the evaluation of Samaritan donors, we wonder whether it is necessary to include this instrument as a standard in the clinical psychological evaluation of Samaritan donors. This instrument may be better suited for research into personality or other characteristics of Samaritan donors. We found that for the psychometric instruments described above, cut-off scores were lacking. Although Jendrisak et al. (2006) describe that the scores of the evaluated donors were within normal ranges, we are not sure whether this implies that donors would have been rejected if scores were significantly lowered or elevated. This can be compared to the situation of conventional living kidney donation evaluations, where decisions are also made on a case-by-case basis. To cite Dew et al. “The safety and well-being of each donor will be maximimised only by considering (a) the unique circumstances that led the individual to come forward for donation and (b) the unique set of psychosocial risk and protective factors that the individual brings” (2007).

Opposed to the open descriptions of unacceptable psychopathology, rules or criteria for evaluating the motivation of Samaritan donors appear much stricter. Adams et al. (2002) name seven categories of “unacceptable donor expectancies” (table 1). We think that several of these “unacceptable expectancies” also apply to conventional, directed donation, such as expectancies of “monetary compensation…”. Unacceptable donor expectations that apply exclusively to Samaritan donation are: “a desire for media attention (that could not be supported by the transplant center), “a response or remedy for a psychological malady […]”, and “a desired selection of the recipient by gender, race or ethnicity”. With respect to the latter issue, we think that a full discussion of this issue is beyond the scope of this manuscript. In this respect we would like to refer to the study of Hilhorst, that provides a detailed discussion of the pro’s and con’s of Samaritan donors directing their gifts (33). Regarding media attention, this motivation is also defined as unacceptable by Jacobs et al. (2004) and Morrissey et al. (2005). Furthermore, they name as untolerable motivations: individual or societal approval, compensation, atonement and redemption. They explicitly state that in such instances the offer would be declined (9, 10). We think that one of the most important “unacceptable expectancies” Adams et al. (2002) describe is a response to, or a motive stemming from a psychological malady. In addition to the psychological maladies that are already named above, we think that the possibility of borderline personality disorder deserves careful attention. Typical for persons suffering from borderline personality disorder is a very weak sense of self-existence and self-boundary, resulting in feelings of inner emptiness and difficulty in relating to other people. Patterns of self-mutilation and suicide are common in this group. Hypothetically, someone suffering from this condition could wish to donate a kidney to fill this inner emptiness with meaningful behavior, or to cross physical body borders as an extreme attempt to get connected to some other person. Other conditions that could possibly influence the motivation to donate a kidney are psychosomatic disorders, especially Factitious Disorder and Body Integration Identity Disorder (34-37).

Finally, we wish to comment on the inclusion of third parties in the psychological evaluation of Samaritan donors. Jacobs et al. (2004), Gilbert et al. (2005), Jendrisak et al. (2006) and Dew et al. (2007) are positive about including a spouse or significant other of the donor in the evaluation process. We are supportive of this idea, and we think that it should be up to the psychologist / psychiatrist to decide for each specific situation apart whether he thinks it is necessary to include 'a significant other' of the potential donor. Furthermore, although the articles described in the Results section "Literature review: psychological evaluation for Samaritan kidney donation" do not mention this procedure, just like Abecassis et al. (2002), we would encourage the psychologist/psychiatrist to contact the former/present mental health professionals of the Samaritan donor, if applicable. This information should be seen and weighed in the broader context of the whole evaluation procedure.

Why do we subject potential Samaritan kidney donors to a stricter psychological evaluation procedure than conventional living kidney donors? The underlying thought is that we have insufficient data available yet that describe the differences between the conventional and the Samaritan donation experience. At present, data seems accumulating that Samaritan donation leads to satisfactory outcomes in terms of psychological health of these donors (9, 10, 12, 21, 38). Nevertheless data are still limited, and numbers are not large enough to be fully convinced of the absence of adverse psychological outcomes for Samaritan donors. Furthermore, most experience in this field is from the USA. Professionals from Europe seem more conservative about this type of donation, and consequently fewer results have been published (39-41). Whatever our decisions are whether or not to accept somebody as a Samaritan kidney donor, and whatever the consequences of these decisions, we would like to encourage the exchange of information so we can learn from each other's experiences in this developing clinical field about the evaluation process and care for Samaritan donors.

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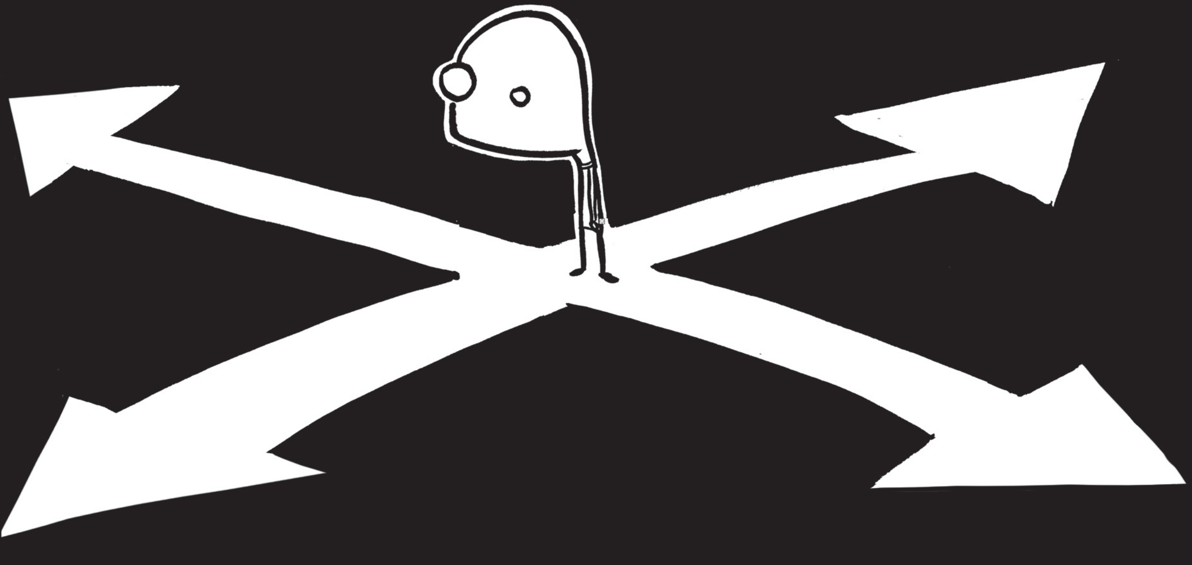
PART IV: FUTURE DIRECTIONS?

The previous parts of this thesis have discussed the various types of living donation: direct(ed) donation, indirect donation and non-directed donation. Living kidney donation has helped to prevent the waiting list for a deceased donor kidney transplant from becoming even longer. Nevertheless, the waiting time is still several years, and a substantial number of patients still die while waiting for a transplant. Therefore, novel strategies to increase the number of kidneys for transplantation are explored. Two of these strategies are paid kidney donation and xenotransplantation. In both cases, the term 'donation' is no longer valid, as it difficult to argue that pigs would purposely decide to 'donate' their kidneys to humans. Further, instead of paid 'donation' it is more appropriate to refer to it in terms of rewarded gifting, kidney vending or kidney selling (depending on the system of paid 'donation' that is used).



Chapter 11

Public Survey on Financial Incentives for Living Kidney Donation

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Submitted.

SUMMARY

Background: One of the most fiercely debated strategies to increase the number of kidneys for transplantation is the introduction of financial incentives. As the success of such strategy largely depends on public support, we performed a public survey on this topic.

Methods: We developed a questionnaire on financial incentives for living kidney donation. We investigated the public opinion on two different fixed compensations: either life long health insurance compensation or € 25.000. Furthermore, we investigated public preferences on the practical implementation: either the patient seeks a donor or the donor registers for donation at an independent institute. For all examples, health insurance companies would cover costs of treatment. TNS NIPO, a professional organisation for market research sent the survey to a response panel that is made representative for the general population.

Results: 550 respondents (M/F: 60/40; median age: 46) filled out the questionnaire. 46% considered the situation wherein health insurance companies would introduce financial incentives to increase the number of living kidney donors undesirable (26% undesirable; 20% very undesirable), compared to 25% who perceive this as desirable (20%desirable; 5% very desirable). The option wherein the donor registers at an independent institute to donate to a patient on the list and in turn receives life-long health insurance compensation was chosen as most favourable. Of all respondents, 5.5% stated that there was a (very) great chance that they would donate a kidney in order to get compensation if such system were to be reality.

Conclusion: Although almost half of the respondents (46%) were reluctant towards introducing a system with fixed compensation to increase the number of living kidney donors, still 25% of the general public reacted positively.

INTRODUCTION

The idea of introducing financial incentives to increase the number of living kidney donors is subject of impassioned debate. Some authors seem willing to consider a regulated system of paid living kidney donation, provided that certain conditions are met. Conditions that have been stressed repeatedly by various authors are: 1.) The condition of a fixed price, equal for all donors (1, 2). The premise of a fixed price model is the egalitarian principle that equal contributions merit equal remuneration (3). This equal remuneration can be expressed in money, but some authors have argued that remunerations should be expressed in other valuables than money, for instance in health insurance benefits (4, 5). 2.) The condition of a single mediating institute that would be the only legalised body responsible for the reimbursement of the donor. This “would prevent the rich using their purchasing power to exploit the market at the expense of the poor” (6, see also 7-8). 3.) The condition of more empirical studies on the public acceptance and potential impact of the introduction of an incentive system for living kidney donation (3, 9-11). The present study addresses all three conditions mentioned above.

SUBJECTS AND METHODS

Materials

We developed a questionnaire to investigate the public opinion on introducing incentives to increase the numbers of kidneys for transplantation (Table 1; for the original Dutch version of the questionnaire, see (12)). This questionnaire was based on a questionnaire on the same topic that had been tested in a pilot-study at an earlier stage (13). The questionnaire aimed to investigate public opinion for two different types of fixed compensation: either life long health insurance compensation or € 25.000 ($32.396; £16.930). In addition, we investigated public preferences for two different types of practice: either the patient seeks a donor (as is current practice) or the donor registers for donation at an independent institute. The questionnaire consisted of eight items with multiple choice response categories. Six of the eight items had multiple response categories on an ordinal level (items 1, 2, 3, 4, 6, 8) and two items had multiple choice response categories on a nominal level (items 5 and 7). The questionnaire was administered via the Internet to a response panel. All items of the questionnaire appeared one-by-one, each on separate computer screens. Respondents could click backwards and forwards to change or check their responses during filling out the questionnaire. This was not true for item eight; respondents had to fill out this item without checking or comparing their answers to previous items. The questionnaire was preceded by a short text acquainting the response panel with living kidney donation. This information described the context of organ shortage on the one hand, and on the other hand the risks for living kidney donors.

Subjects

TNS NIPO, a professional organisation for market research, commands a large database of people that represent a cross-section of the general population. These people regularly fill out questionnaires on a variety of topics for TNS NIPO and in return receive a small compensation. 550 respondents filled out the questionnaire. Minimum age for filling out the questionnaire was 16. Respondent characteristics were: Gender M/F: 60%/40%; Age: mean age was 47 (range 16 – 82, SD = 17); Education level: low - 33.8%, average - 39.1%, and high - 27.1%; Religion: 54.9% religious (of which 45.3% Christian), 45.1% non-religious. These respondent characteristics are comparable to the characteristics of the general Dutch population, where gender distribution is M/F: 49%/51%; mean age (above 20) = 49; education level = low – 33.4%, average – 41%, high – 25.6%; and 59% is religious (of which 51% Christian) (14).

Statistics

We analysed our data with SPSS 11. For investigating male-female differences and differences between religious and non-religious subjects we used the Mann-Whitney U test (α was set at 0.05). For investigating the strength of the relationship between age and the responses for single items, and the relationship between education level and the responses for single items we used Spearman’s correlation. For investigating the relationship between items with response categories on a nominal level (items 5 and 7) and respondent characteristics we used X^2 testing for binary variables, and ANOVA testing for continuous variables.

RESULTS

We found that 46.6% of the respondents considered the situation wherein health insurance companies would introduce financial incentives to increase the number of living kidney donors undesirable (27.1% undesirable; 19.5% very undesirable), 21.6% of the respondents was ambivalent, and perceived this as desirable (19.5% desirable; 4.5% very desirable) (question 4, table 1). The option wherein the donor registers at an independent institute to donate to a patient on the list and receives life long health insurance compensation was chosen as most favourable. Response distributions for all eight items are presented in Table 1.

Gender: For all items, there was no statistically significant difference between male and female subjects. Only for item 1, there was a tendency for females to be more likely to donate to a ‘family member or good friend’ awaiting transplantation (p=0.06).

Religion: For all items, there was no statistically significant difference between religious and non-religious subjects.

Level of education: There was a small but statistically significant negative correlation between level of education and the willingness to donate to ‘someone you do not know’ (item 2; r = -.118;

Table 1: questionnaire items and results

ITEM DESCRIPTION	RESPONSE OPTIONS	RESULTS (%)
1. [..] How do you estimate the chance that you would donate one of your kidneys to help someone you know, who is on the waiting list for transplantation (for instance a family member or a friend)?	1. I would never do that	1.6
	2. Very small	8.2
	3. Small	8.9
	4. Intermediate(ipv not small, not large)	28.7
	5. Large	31.5
	6. Very large	19.3
	7. I will not answer the question	1.8
2. [..] How do you estimate the chance that you would donate one of your kidneys to help someone you do not know, who is on the waiting list for transplantation?	1. I would never do that	14.2
	2. Very small	32.5
	3. Small	23.8
	4. Intermediate	22.0
	5. Large	3.3
	6. Very large	1.7
	7. I will not answer the question	2.4
	8. I have donated one of my kidneys	0.0
3. Would the chance that you would donate one of your kidneys to a patient on the waiting list increase, if in turn you would receive an attractive financial compensation? This chance would …	1. …not increase.	81.9
	2. …possibly increase.	15.0
	3. …definitely increase.	3.1
4. [..] Would you consider it a preferable or a rejectable development if health insurance companies would decide to offer living kidney donors quite some financial compensation to increase the number of kidneys for transplantation?	1. A very adverse development	19.5
	2. An adverse development	27.1
	3. Not an adverse, not a preferable development	21.6
	4. A preferable development	19.5
	5. A very preferable development	4.5
	6. I really do not know / cannot say	7.8
5. Imagine that health insurance companies would indeed decide to start offering compensations to living kidney donors. Which of the following types of compensations would you consider most preferable?	1. The donor receives €25.000	3.5
	2. The donor receives a life long free health insurance	12.7
	3. Equal, the donor should be able to choose the preferred compensation	27.3
	4. Neither, I am against a system based on compensations	38.4
	5. I really do not know / cannot say	18.2
6. Imagine that there would be such compensation-based system that causes more persons to donate. In that case it is possible for kidney patients to go out to find themselves a donor (someone they may not have met before). Do you consider it acceptable that kidney patients try to find themselves such donor in order to get transplanted as soon as possible?	1. Definitely not acceptable	19.6
	2. Not acceptable	28.5
	3. Intermediate	17.3
	4. Acceptable	22.4
	5. Definitely acceptable	4.5
	6. I really do not know / cannot say	7.6

ITEM DESCRIPTION	RESPONSE OPTIONS	RESULTS (%)
7. If you had to choose between the following, which option do you consider best (or the least bad)?	1. A kidney patient finds himself a donor, the donor receives €25.000	4.7
	2. A kidney patient finds himself a donor, the donor receives a life long free health insurance	13.3
	3. A donor donates to the first patient on the waiting list, and receives €25.000	29.1
	4. A donor donates to the first patient on the waiting list, and receives a life long free health insurance	52.9
8. There is a lot you can do with €25.000, and a life time free health insurance also saves you a lot. Both compensations are attractive. At some point in your life this may be very welcome. If a compensation system were reality, how do you estimate the chance that you would donate one of your kidneys to receive such compensation?	1. I would never do that for that reason	37.1
	2. Very small	24.0
	3. Small	13.3
	4. Intermediate	20.2
	5. Large	4.9
	6. Very large	0.5

p = 0.009). In answering item 7, people with a higher level of education were more likely to choose response option 3 as most favourable (”a donor donates to the first patient on the waiting list, and receives € 25.000”; p= 0.042).

Age: A younger age was positively correlated with: the willingness to donate to a ‘family member or good friend’ awaiting transplantation (item 1; r = -0.255; p < 0.001); a higher chance of donating to receive financial compensation in return (item 3; r = -0.330; p < 0.001); acceptance of health insurance companies paying donors (item 4; r = -0.183; p < 0.001); acceptance of kidney patients trying to find themselves a paid living kidney donor (item 6; r = -0.163; p < 0.001); and likeliness to donate for a compensation (item 8; r = -.241; p < 0.001). Furthermore, in answering item 5, younger people were less likely to choose against a system based on financial compensations (response option 4; p = 0.01). In answering item 7, younger people were more likely to choose response option 3 as most favourable (“a donor donates to the first patient on the waiting list, and receives € 25.000”; p = 0.07).

Of all respondents, 5.5% stated that there was a great or very great chance that they would donate a kidney in order to get compensation if such system were to become reality (n = 30; M/F = 19/11; median age = 31.5 (range 17-82; SD = 13.7); education level low/average/high/(missing): 6/14/7/(3); religious/non-religious/(missing): 17/10/(3)). Two of these 30 explicitly preferred the € 25.000 as compensation; 4/30 preferred the health insurance, 6/30 could not answer the question, and 18/30 felt that the donor should be able to choose the preferred compensation himself.

DISCUSSION

We found that 46.6% of the respondents opposed the situation wherein health insurance companies would introduce financial incentives to increase the number of living kidney donors. If we compare the outcomes of questions 4 and 5, then it seems that although 46.6% of the respondents considers the situation wherein health insurance companies would introduce financial incentives to increase the number of living kidney donors undesirable, only 38.4% seems truly opposed to this situation. This suggest that there exists a small group of 46.6- 38.4 = 8.2 % who considers introducing financial incentives undesirable, but apparently not so undesirable as to choose response option 4 for question 5 (see Table 1). Twenty-five percent of the respondents considered the situation wherein health insurance companies would introduce financial incentives to increase the number of living kidney donors desirable (20% desirable; 5% very desirable). These results are comparable with results from the study of Boulware et al. who found that 28% of their respondents approved direct payment to living donors by the government (15). Strikingly, respondents with lower education levels (and consequently, lower incomes) were not more likely to be acceptant about the idea of introducing financial incentives; and they were not more likely to donate for money themselves, as may be expected. Furthermore, younger people were more supportive of ideas on introducing incentives to increase the number of living kidney donors. This may be caused by the liberal attitude of the younger, but could also be interpreted as a sign of changing societal values. In the latter case, the idea of introducing financial incentives for living kidney donation may count on larger support in the future.

We investigated the public opinion with regard to two types of incentive: either life long health insurance compensation or € 25.000. Although at first glance a life-long free health insurance may sound less attractive than instantaneous payment of € 25.000, a life-long free health insurance can mount up to over €70.000 ($90.710; £47.409) in the end, assuming 60 years of benefit of saving € 1200 premium per year. In our study, the majority preferred a life long reimbursement of health insurance costs to remuneration in money. A possible explanation is that this is because the monetary value of the health insurance option is higher in the end (at least, for people under 60, the elderly will of course profit less from a life-long free health insurance). Although this sounds like a reasonable explanation, we think that something else it stake here. An alternative explanation would be that the public's reluctance towards remuneration in cash stems from a likeliness to associate the concept of 'money for organs' with the negative reports of exploitation of the poorest and the repellant activities of "organ harvesting" (16-17). These associations may induce fears that introducing money as incentive, even in a legalized, well-organized system, will lead to comparable practices. Taking these fears too lightly could harm the "extraordinary degree of trust" between the public and kidney transplant teams that has developed over the past decades (18).

CONCLUSION

Although almost half of the respondents (47%) were reluctant towards introducing a system with fixed compensation to increase the number of living kidney donors, still 25% of the respondents reacted positively. A younger age was positively related with approval of ideas on introducing incentives to increase the number of living kidney donors. Most respondents preferred a system wherein the donor would register at an independent institute to donate to a patient on the list and in turn receives life long health insurance compensation.

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Chapter 12

Reluctant Acceptance of Xenotransplantation in Kidney Patients on the Waiting list for Transplantation

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SUMMARY

Previous research has shown contradictory results regarding the acceptance of xenotransplantation (XT) by kidney patients. This variance in attitude towards XT could be explained by differences in knowledge of XT, the availability of alternative treatment options, specific beliefs and cognitions of the patient, and differences in the health status of the patients. We studied 61 patients in this contention in the Netherlands waiting for a kidney transplant. All took part in in-depth interviews and filled out questionnaires on two occasions, once before and once after an information brochure on XT had been read. We found that a better health status is correlated with a greater acceptance of XT, but only before information was given. After information had been given, the acceptance of XT decreased significantly. However, if XT is the onlypossibility in a life-threatening situation, almost all patients are willing to accept XT, except for a small group (approximately10–15%) with fundamental religious and/or spiritual objections against such treatment. When alternative treatment options such as a human cadaver donor, a living related donor or commercial donors are offered, the majorityof patients would prefer those to XT. The main reason for reluctance is uncertainty about the risks of XT to personal health. Because alternatives are currently available, we expect that XT will become more popular only if future results of this procedure have proved to be comparable to transplantation with a human donor kidney.

BACKGROUND

In the Netherlands, the average waiting time for a cadaver kidney transplant has increased to approximately four years. A future alternative that could shorten the waiting list is xenotransplantation (XT). However, XT is a controversial topic for medical (e.g., infection with porcine retroviruses), ethical (e.g., individual versus collective risk-problems) and psychological reasons (e.g., adjusting to lifelong lifestyle prescriptions). Studies investigating attitudes towards XT research and accepting xenografts have emerged in many countries over the past ten years (see the reviews of 1-6). However, research has shown ambiguous numbers regarding the acceptance of XT by kidney patients. Outcomes range from 78% that would accept a pig organ in a British study (7), while results from Australia were much more modest (42%: see 8). It is difficult to see why these results differ so much, as in both studies written questionnaires were used that allowed for simple responses only without a clarification or motivation for the response. In the present study, we used both written questionnaires and a semi structured face-to-face interview to investigate these controversial findings. In particular, we investigated whether the attitude towards XT could be explained in terms of differences in knowledge of XT, the availability of alternative treatment-options, different belief systems and differences in the health status of patients.

METHODS

Patients

We studied 61 patients on the waiting list for a kidney transplant (57% male). The mean age was 50. Thirty-eight patients (62%) were undergoing hemodialysis, 20 (33%) of the patients were treated with continuous ambulatory peritoneal dialysis and 3 (5%) were about to start dialysis. All patients treated with hemodialysis or continuous ambulatory peritoneal dialysis were on the waiting list for a kidney transplant, and the patients that were about to start dialysis were to be put on the waiting list in the near future (at starting dialysis). Of these 61 patients, 15 patients (25%) came to the transplantation unit of our University Hospital for the very first time, and 18 patients (30%) of these 61 had been transplanted before. Included were patients on the waiting list for a kidney transplant, or those to be put on the waiting list in the near future and those with sufficient mastery of the Dutch language. New patients were enrolled consecutively, and patients already treated with continuous ambulatory peritoneal dialysis or hemodialysis were randomly selected from the registry. Despite the inclusion criterion with regard to the Dutch language, only 34 patients (56%) were born in the Netherlands. The interviews took place at the faculty or the University Hospital, and occasionally at the patient's home. The University Medical Ethical Review board has approved this study and informed consent was obtained from all patients. Notably, this study was conducted in 2002 and 2003, when the Dutch public became more aware of virally transmitted diseases. At this time, the epidemics of classical swine fever and mad cow disease were at their height and receiving a lot of media attention. A possible increase in awareness of viral risks might have influenced the responses of the patients.

Materials

All patients were seen twice: both meetings consisted of written questionnaires and an in-depth face-to-face interview. During the interview, participants had to fill out four exercises on their willingness to undergo XT. We aimed to address an effect of knowledge on attitudes by giving patients an information brochure after the first meeting. This brochure contained general information on kidney transplantation, and specific information on living kidney donation, cadaver kidney donation, commercial donation and XT. In this brochure it was clearly stated that law forbids commercial donation and that XT was not yet possible. The specific information focused in particular on (presumed) waiting time, (presumed) quality of the kidney and the risks for the persons involved. This brochure also contained information on lifestyle prescriptions for patients after XT (FDA guidelines on infectious disease issues in Xenotransplantation, 2001). Two weeks elapsed between the first and second meeting (M1 and M2, respectively). The anticipated increase in knowledge was measured by closed interview questions (e.g., Do you know which animal would be used for XT of the kidney?) and open interview questions (e.g., Why would they use that kind of animal?). A correct answer was scored as 1 (max = 8).

Health status was assessed using medical status data (i.e. kind of treatment, being transplanted before, and time on waiting list) and the EuroQol. The EuroQol consists of the EQ-5D (EuroQol 5 dimensions), a five question health-related quality of life questionnaire, and the EQ-VAS, a visual analog scale (VAS) that indicates the subjective valuation of one’s health (9).

To investigate the willingness to undergo XT, we used four methods that differed in whether or not alternative treatment options were offered. We used a (waiting) time trade-off method, a VAS, statements (8) and a ranking task. The purpose of the waiting time trade-off method is to find out how many years on the waiting list one is willing to trade for the immediate acceptance of XT. Our starting point was the question: “What would you choose; to undergo XT now, or to wait for four years for a kidney from a human cadaver donor?” Depending on the answer, we added to or subtracted years from these four years. The period of four years was chosen as the starting point because it is the current average waiting time for a human cadaver donor (CAD) kidney in the Netherlands. In addition to this trade-off, we also asked patients if they would accept XT if it were the only option in a life-threatening situation. The VAS consisted of a 10 cm vertical line on which patients indicated their personal willingness to undergo XT (willing vs. not willing on either scale end). For the ranking task, patients ranked the following options: CAD, living related donor (LRD), XT and commercial donor (CD). The alternative “CD” was explained in its broadest sense as “someone who gets paid for his or her kidney”. We asked them: “Suppose that all four forms of transplantation were available, what would you in that case prefer first (second, etc.)?”

The semi-structured interviews started with the questions on knowledge, followed by the exercises on willingness to undergo XT. Special attention was given to the thoughts and motives underlying individual choices. Finally, the interview also included questions about the need for additional information about XT and anticipated support if it were to become an actual treatment option.

Statistics

To compare scores of the patients between measurements 1 and 2 (M1 and M2), we used the paired samples t-test, Wilcoxon signed ranks test and McNemar test. To compare variables or scores of sub samples within M1 and M2, t-tests for independent samples were used; a was set at 0.05.

RESULTS

Knowledge and information

We observed a significant increase in knowledge about XT when the mean knowledge-scores on the first and second interviews were compared (M1 vs. M2, $p < 0.001$, paired samples t-test).

Health status

At the time of the first measurement, we found that high scores on the five individual dimensions of the EQ- 5D, which indicates a poor health-related quality of life, were negatively related with the acceptance of XT as measured with the yes/no statements (independent samples t-test, $p = 0.03$). Furthermore, we found that a shorter time spent on renal replacement therapy was related to the acceptance of XT (independent samples t-test, $p = 0.03$). However, after information was given the relation between the acceptance of XT and health status disappeared.

Willingness to undergo XT

Given the current state of affairs, most patients (67%) would prefer to wait four years in order to receive a human cadaver kidney than to undergo XT. After information was given, significantly more patients preferred waiting for a human cadaver kidney (Wilcoxon signed ranks test, $p = 0.02$). When XT would be offered as the only treatment option in a life-threatening situation, 80% of the patients were willing to undergo XT at the time of the first interview, a percentage that hardly changed upon the second interview. Willingness was also measured by a VAS and by statements. These methods also indicated a more negative attitude towards XT after information was given (resp. paired samples t-test and McNemar test, $p = 0.03$ and 0.02) (Table 1). Fig. 1 shows the results for the ranking task, and illustrates that a LRD is, in general, the most popular alternative for patients at present. After that, patients prefer, respectively, a CAD, a CD and finally XT. A similar distribution of preferences was seen during the first and the second interviews.

Table 1 Acceptance of xenotransplantation before and after information was given

Statement	Percentage in agreement		
	Before information n = 61 (%)	After information n = 61 (%)	Previous research (Mohacsi 97; n=113 (%))
I would accept xenotransplantation myself	67	54*	n.a.
I would accept an organ from an animal closely related to man (e.g. baboon)	59	44*	42
I would accept an organ from an species distant to man (e.g. pig)	64	52	42
I would accept an organ from a living relative	80	90	61
I would accept an organ from someone genetically unrelated but living (e.g. spouse)	82	89	61
*Statistical significant; Mc Nemar test $p < 0.05$	67	54*	n.a.

Motives for change of preference and reluctance to XT

Relevant in this respect is the group of patients that changed preference in favor of waiting for a human kidney after information had been given (13 patients, 21%). The explanations that accompanied their answers upon interview tell us that the change in preference does not necessarily reflect an attitude opposing XT, but rather reflects a cautious attitude to ‘choose the safest option’, having read and thought about XT in the period between interviews. Another group (over half) of patients ranked XT last in both the first and second interview (Fig. 1). This group feared most the unknowns of XT and the possible risks, most often described as personal health risks. Beside this motive, these patients often reported feeling uncomfortable with the notion of having an animal organ.

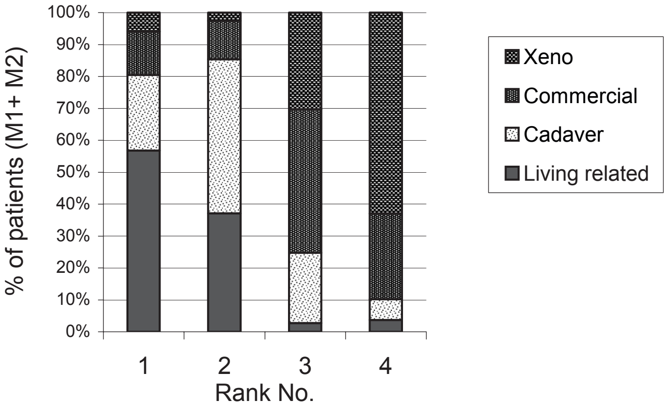

Figure 1: Ranking of donation options. Bars represent the first preference, the second and so fort. The percentages are calculated from patients’ preferences at M1 and M2.

Extreme motives

What were the main reasons for seven patients to say that they would never ever accept a pig's kidney, both before and after information had been given? These patients had religious and other spiritual objections. They contended, for example, "If you take animal stuff you'll become like that animal yourself". And: "God created man and animal and there's a border that cannot be crossed". In explaining these objections, some patients referred to the Jewish or Islamic religions, which hold that pigs are impure animals. However, not all Muslim participants were unwilling to accept XT if it were a life-saving treatment option. There were five Muslim and no Jewish participants in our study. By contrast, a group of 11 patients (18%) preferred XT instead of waiting 4 years for a human cadaver kidney on both measurement occasions. These patients found it emotionally less disturbing that the kidney would be from an animal rather than a human donor, or wished to be transplanted as soon as possible regardless of the source of the donor organ.

Identity

Nine patients (15%) felt that XT might change their personal identity, while seven (11%) were sure it would. Five of these seven patients stated they would rather die than to accept a pig's organ.

Need for information and support

A large proportion of patients (85%) were interested in extra information about XT and/or support if XT were to become an actual treatment option. In particular, they would be interested in general information and what to expect in terms of medicine-use, survival rates of the porcine kidney and the results in terms of health status of previous patients who had undergone XT. Thirty-seven patients (61%) stated that they would like to have extra support if XT would become a treatment option. They especially would appreciate having the opportunity to talk to someone about what to expect after transplantation, and to receive emotional support (Fig. 2).

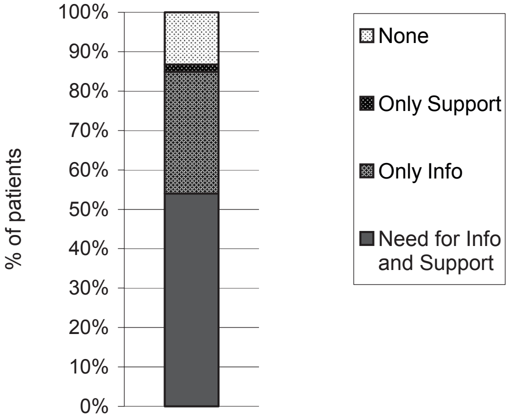

Figure 2: Need for additional Information and support on Xenotransplantation

DISCUSSION

The large increase in knowledge about XT after information was given maybe explained by the fact that most patients knew little about XT when first interviewed. Therefore, an improvement in knowledge was relatively easy to attain. The results, which were obtained by various measurement methods, consistently showed an increased reluctance to accept XT after information had been provided. At that point, health status no longer related to the acceptance of XT. These findings foremost indicate that knowledge of the subject matter, in this case XT, is an important determinant of reluctance toward experimental treatments. In the absence of such knowledge (e.g., M1), other factors such as health status may affect reluctance. Before turning to a discussion of those factors, we wish to consider why health status no longer related to XT acceptance after information was given.

The finding that patients' health status lost predictive value to XT acceptance at M2 could partially be explained by perceptions of possible gain. Typically, the perception of possible gain results from weighing the anticipated personal risks and benefits. This weighing becomes difficult in medical frontline research, such as XT, since it is unclear what exactly is to be weighed (10). In this study, the main reasons for changing preference in favor of waiting for a human cadaver kidney after having read XT treatment information were the unknowns of XT, or more specifically 'being unable to make or have an evidence based judgment of the number and types of risks associated with XT'. We believe that an increased awareness of the risks associated with XT (i.e., perceptions of little/no gain) made patients apprehensive of XT treatment. As such, the explanation of possible gain underlines the impact that information may have on treatment decisions or acceptance. In explaining why both seriously ill and less ill kidney patients did not necessarily consider XT treatment beneficial after reading the information, we must assume that all perceived the risks to be considerable (or the gains to be marginal). If not, the perception of possible gain cannot satisfactorily explain why health status lost predictive value.

We also believe that an increased awareness of any risk, not just viral risks, will make a person more apprehensive of experimental treatments. It would be interesting and important in this respect for future studies in transplantation to address individual characteristics of patients, such as the willingness to take risks. Such characteristics may bear relevance to the acceptance of new, experimental treatments like XT.

Before information was given, we found that both better health status and shorter time spent on renal replacement therapy were related to acceptance of XT. Beside the fact that health status and time spent on replacement therapy are likely to be related, both findings could be interpreted in terms of weighing risks and gains, as suggested above. Patients who spent a shorter time on replacement therapy, on the one hand, gained a large reduction in waiting time if they were to undergo XT, compared to patients who have been on replacement therapy a few years already. Relatively healthy patients, on the other hand, arguably make decisions that promote becoming even healthier while relatively ill patients are more inclined to prevent their health from becoming worse. They are, in other words, more conservative in their perceptions of possible gain and hence preferred treatment options. A helpful framework in this respect is coping theory, in particular assimilative and accommodative coping strategies. Whereas the former evolves around previously set personal goals (such as working, having children, going abroad on vacation), the latter is all about accepting the current situation (dialysis) and adjusting old goals. It is well known from other illnesses, for instance chronic pain, that the assimilative strategy often precedes the accommodative strategy (11). Knowing this, it could be argued that relatively healthy patients employ an assimilative rather than accommodative coping strategy, and consequently are more willing to take risks and make unconventional decisions. Once more, it would be interesting and relevant in this respect to address a willingness to take risks in future studies of experimental treatment options. Besides being an individual characteristic that may explain differences between patients in similar circumstances, the willingness to make risky decisions could be an important confound of observed findings. We suggest, for example, that it is not necessarily health status per se that predicted XT acceptance in this study but rather an emotional state of mind. Such nuances may have large consequences for health professionals and the issues they target.

The one group that would not accept XT, under any circumstance, were patients with fundamental religious or other spiritual objections against XT. Although previous research indicated that religion is not a predictor of XT reluctance (4), our findings suggest that religion is a relevant factor. It is not necessarily the kind of religion someone adheres to, but rather the way religion is experienced. Some religious or spiritual beliefs were so strong that they seemed to relate directly to the contention that XT affects personal identity. Most patients, however, did not think that XT would influence their identity. In general, the attitude we observed was consistent with the 'spare part view' (12), the idea that the body consists of several parts and that replacing one (in this case the kidney) for another does not change the person on the whole.

Despite the viewpoint taken by the monotheistic religions that donor organs are being viewed as purely functional and not affecting the recipients' personal identity (13), we found that this might not be experienced as such by individual adherents of a certain religion. A similar topic concerns the impureness of the pig for Islam and Judaism. Daar and Phil (14) points out that despite there being a leeway to accept a pig's organ for Jews and Muslims (since "need and necessity can allow that what is forbidden"), a minority opinion exists that pigs, because they are ritually unclean, cannot be used as source animals for organ transplantation. Indeed, this is what we found in our study. Two of the patients who stated that they would never accept XT did so on grounds of their Muslim religion.

We found that the percentage of patients that would accept XT varies with the availability of alternatives: 80–90% would accept XT if it were the last option in a life-threatening situation; 54–67% said 'yes' to the question 'I would accept XT myself' (presented amongst statements on other options); about 30% when it was offered as an alternative to waiting four years for a CAD; and finally o10% preferred XT to a CAD when it was offered amongst alternatives in a ranking task (forced choice method). The finding that a higher percentage of patients are willing to accept XT in a life-threatening situation is consistent with the conclusion of Persson et al. (5). These findings suggest that attitude towards XT depends on the available treatment options presented to the patients. This helps to explain the differences found in previous research: the study in which alternative treatment-options were presented (8) resulted in a lower percentage of patients that would accept XT compared with the study that focused on XT alone (7).

Two critical comments can be made at this point. The first is a general comment on the need to invest into alternatives to cadaver transplantation. The ‘four years on the waiting list’ that we have used in our study is the average waiting time. Many patients will have to wait longer, while in the meantime their health status declines, and sometimes to the point where transplantation is not a feasible option anymore. The second comment refers to the interpretation of the results of the ranking task. In this exercise, the term “CD” was used. This term was explained in its broadest sense as “someone who gets paid for donating his or her kidney”. We found that the majority did not need further explanation of the term, since they dismissed the hypothetical option of a “CD” as unethical. However, further research could investigate whether a more refined distinction in various kinds of commercial donation influences the results of a similar ranking-task.

Conclusion

Providing information about a new, experimental medical treatment may inversely affect the acceptance of the treatment. In this study, information supported reluctance towards, rather than acceptance of, XT. Beside knowledge, patients’ health status can inversely affect acceptance of experimental treatments like XT. This maybe related to individual characteristics and coping strategies rather than actual health status, however. The reluctance was unapparent when XT was offered as the only option in a life-threatening situation. In that case, most patients were willing to accept XT, except for a relatively small group with strong religious and/or spiritual objections. Since alternatives are currentlypresent, the majority of patients are likelyto prefer waiting for a human cadaver kidneythan to accept XT treatment. Reluctance mainlystems from the unknown risks that are yet associated with XT, especiallyto patients’ personal health. If XT is ever to become of comparable risk to human donor kidney transplantation, its acceptance bykidneypatients is likelyto increase.

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Chapter 13

Discussion

PATIENT EMPOWERMENT IN END STAGE RENAL FAILURE PATIENTS

Part one of this thesis comprises studies on donations from living kidney donors to someone they know, with whom they have a genetic and/or emotional relationship. The conclusions of the chapters in part one all point in the same direction. The conclusion of Chapter 2 is positive about stimulating further development of the living kidney donation program and emphasizes the need for routinely offering patients psychosocial support. The conclusions of chapters 3 and 4 even go one step further, and state that patients eligible for transplantation may profit from professional support to find a way to deal with their situation that best suits their personal needs. Professional support could be offered, for instance, in assisting patients in finding a living donor. Chapter 5 goes even further and concludes that in the case of living kidney donation, active intervention in peoples' personal lives is justified - if not obligatory. Chapter 5 outlines the justification for such interventions, and addresses the pitfalls that can occur in designing or applying interventions. Interventions in cases of living kidney donation are justified as long as they are motivated by patient empowerment, supporting patients in such a way that they are able to make well-informed and autonomous judgements and decisions (1). Health care professionals should not only provide information, but should also strive to ensure that patients have understood properly and should endeavour to correct misperceived information (2). It could even be argued that it would be unjust if some individuals took more advantage of the living transplantation program than others, simply because health care providers were not helping to remove the misunderstandings that prevented more reluctant patients and relatives from participating. In providing information, the health care provider should always acknowledge that information is person and context dependent. Information is understood within a certain context and may, within that specific context, comprise a moral appeal. Information is also person dependent. Different persons may interpret the same facts quite differently. In providing health care information, professionals should avoid the following three pitfalls: 1) a one-sided, selective or biased presentation of the facts, whereby other options receive insufficient attention; 2) a predominant focus on the medical perspective, a tendency to consider this perspective to be the 'most reasonable' perspective, overruling psychological, social, religious, or other perspectives; and 3) the assumption that one simple unequivocal answer is appropriate for a variety of situations, that there is only one monolithic view concerning morality and personal relations. General ethical concepts, such as the importance of 'a free choice' or 'altruism' cannot sufficiently take account of the complex moral reality of living kidney donation. This is, because our minds and moral experience are open to the many particularities of a situation (3). For instance, imagine the case where a mother can save her child's life by donating part of her liver. What do we mean when we stipulate that hers must be a free, voluntary gift? General principles or social norms cannot give a full and adequate description, but should at least be augmented by more particularistic, personal pictures of the moral reality. Counsellors should therefore be open to the particularities of a situation, and sensitive enough to appreciate their moral weight. From the summary above it is apparent that Chapter

5 outlines the conditions for intervention in the situation of living kidney donation. Working from this background, questions arise about the practical implementation of these interventions. Below I will address these issues.

POSSIBILITIES FOR PATIENT - AND DONOR - EMPOWERMENT

Patients who visit the transplant physician for the first time can be divided approximately into four 'types' (Chapter 4): patients with a living kidney donor; patients without a living donor, but who are willing to accept a donation from anyone; patients without a living donor who are willing to accept a donation, but exclude some persons; and patients who are not willing to accept the offer of a living kidney donor. So should all these different types of patients receive the same treatment? In the first instance, the answer is yes. All should be fully and adequately informed about all possible treatment options: haemodialysis, home-dialysis, deceased donor transplantation, and living kidney donation, inclusive of living kidney exchange donation. Afterwards, differing courses can be set for different types of patients. Patients who already have been offered a living kidney - and are willing to accept this offer, can enter the program for living kidney donation. Donors will have to undergo several medical tests to investigate whether they are suitable for donation. Next to these medical tests, patients and donors are seeing both a transplant coordinator and a social worker. An important issue here is that patient and donor counselling should be separated at some point. According to the guidelines for living kidney donation / transplantation, the donor should always have the opportunity to change his/her mind right up to the moment before the operation (4, 5). If this were not possible, donor-coercion could occur (Introduction, Chapters 6-7). Therefore, it is important for the donor to have a professional to whom he/she can speak freely about possible hesitations, without the patient being present. It would of course be optimal if one counsellor could take care of the interests of one party, either the donor or the recipient (5, 6). Even if a counsellor is perfectly able to separate the interests of both parties, it is still not the most ideal situation because the donor knows that the counsellor is also representing the interests of the patient (and therefore may be reluctant to speak freely). Up to here is about the course for patients and their living donors.

But what about the patients who do not have, or do not want a donation from a living donor? Patients without a living donor will be placed on the waiting list for deceased donor kidney transplantation. In addition, they are encouraged to reconsider a living donation procedure. They are, for instance, invited to attend patient information meetings on living kidney donation. Family members and friends of the patients are also welcome at these meetings. However, our experience shows that these meetings are mainly attended by patients and donors who have already decided to pursue living kidney donation. Patients, who are unwilling to accept the offer of a living kidney donor, are unlikely to attend these meetings. It is important to understand why these patients are unwilling to accept a living kidney donor. If their reluctance is based on misperceptions, efforts should be made to explain the issues better otherwise these patients will fail to benefit from the living donation program (for the wrong reasons). Those patients can be referred for an extra consultation with a counsellor about their treatment options. The counsellor can be either a nurse practitioner, transplant coordinator, psychologist, or the physician him/herself; as long as this person is willing to address openly the patient's reluctance towards living kidney donation, is sensitive and respectful towards the patient's personal values and situation on the one hand, and is able to address possible misunderstandings on the other.

A more difficult situation occurs if it is not the patients who are reluctant about living kidney donation, but the potential donors. Whereas patients fall under the medical responsibility of the physician, potential donors do not and consequently they cannot be contacted directly (at least not without permission of the patient). Patients, willing to pursue living kidney donation are encouraged to bring their family members and friends to the patient information meetings described above, but this may have no effect. It is possible that the same situation occurs here as in the study described in Chapter 3. In this study we asked patients whether they would allow us (the researchers) to approach their family members / friends to participate in the study. Even though it was explained that this would be for research purpose only, several patients were reluctant to give permission. For these patients, asking others to participate felt like they were begging for a kidney (albeit indirectly) and evoked their fears about compromising the relationship. So what alternatives are there to assist those patients in reaching their potential donors? We know of two strategies that are applied elsewhere with good results. Below we describe these strategies.

STRATEGIES TO REACH POTENTIAL DONORS

The first strategy we describe is the "Norwegian approach": the physician asks the patient about the presence of potential donors (7). Afterwards, if the patient agrees, the physician telephones the potential donors, to invite them for a consultation about living kidney donation. Results from Chapter 4 show that slightly over half of the patients on the waiting list and their relatives are supportive of this strategy. On the other hand, patients and donors who decided to pursue living kidney donation, were generally negative about this option. Our findings do not support an unconditional adoption of the "Norwegian approach". A conditional approach can be considered. Two issues are important here. First, the historical context of the Norwegian approach. Due to geographical characteristics, dialysis treatment in Norway is hard to obtain, patients often live too far from dialysis centres and there were few places available. Therefore, they had to rely on living kidney donation. To facilitate this process, physicians took on the role of patient advocate. Norwegian patients and donors generally consider this to be a common and non-threatening approach (8). In the Netherlands, there has always been sufficient dialysis treatment, and consequently there were few acute reasons to rely on living kidney donation. If physicians suddenly were seen to be taking on an active role in approaching potential donors, it is not automatic that this would be appreciated in the same way by the Dutch as by the Norwegians. Another issue is the role of the physician. If the physician is not fully supportive of this method, or hesitates, a satisfactory outcome is unlikely. Patients are sensitive to nonverbal signals in the patient-doctor communication (9). If they sense that the doctor is not sure about this method, they are unlikely to trust the procedure or give consent for their family to be approached.

A second option may be health counsellors visiting patients and their potential donors in their private homes (10). In this way various aspects of living kidney donation can be discussed in a confidential setting. The study of Rodrigue shows that a home-based educational program is effective in increasing the number of living kidney donations. The home-based educational program was carried out in a study-design. This means that participation was on a voluntary basis, and that therefore outcomes may not be as promising as they seem. For example, the study sample might be biased in that those people who consented to participate in the study were already open to living kidney donation. We do not know what the effectiveness of this approach would be if it was carried out in a real life situation.

A third option that, as far as we are aware, has not been explicitly tested elsewhere, is an intervention in the pre-dialysis phase. The advantage of this is first that pre-emptive dialysis offers patients a better prognosis (11). Furthermore, patients (and potential donors) still have open minds to choose from the various treatment options that are offered (12). Once patients choose an option, for instance home-dialysis, it may be harder for them to change their minds. Once a person makes a choice from several alternatives, he/she automatically starts to appreciate the chosen option more than the alternatives, because admitting to having made a wrong choice causes distress. A difficulty with the ‘pre-dialysis approach’ may be that because patients do not feel ill (yet), they are not willing to think of and make decisions about future treatment. They may not have fully accepted their illness and may consequently try to repress thoughts about being ill and requiring future treatment (13). On the other hand it may not necessarily be that patients have to be ill before they are willing to consider future treatment perspectives. Data from Chapter 2 and 12 show, that patients with a better health status were more open to the consideration of alternative treatments.

THE COUNSELLING OF POTENTIAL DONORS

If potential donors are willing to attend or participate in a conversation about living kidney donation, they should never be approached as a means to an end. They should be shown the respect they deserve (Chapter 5). They may have their own good reasons for donating, but they may also have their own good reasons for not donating. Health care professionals should help donors to express their views, considerations and convictions. In doing so, health care professionals may make use of the models described in Chapter 5: Toulmin’s model of logical reasoning, Rawls’ reflective equilibrium and Nagel’s agent relative model. A potential donor’s personal view on living kidney donation may be better represented by one model than by another. Using the best-suited model, it may turn out that, in theory, some arguments used by potential donors may be easy to counter. In some situations, the countering of these arguments may reveal new insights or perspectives that may cause potential donors to change their minds. However, one major pitfall in counselling occurs if arguments are always taken at face value. The counsellor should keep in mind that arguments can also be used as justifications. It may not be the contents of a specific objection against living kidney donation that is important, but rather that there exists an objection that is acknowledged and accepted by the recipient. In other words, the argument or objection not necessarily needs to be true, as long as it fulfils a certain function. This function is the maintenance of the relationship between patient and potential donor. The specific reason for objecting to living kidney donation may be camouflaged by a deeper underlying reason not to donate, a reason the potential donor is not necessarily aware of him/herself. The psychological defence mechanism of rationalisation may play a role here. Rationalisation is described as dealing with an emotion intellectually, in order to avoid emotional concern. It implies faulty reasoning, since the problem remains unsolved at the emotional level (14). In reasoning for -or against- living kidney donation, there is also a relationship between the narrative identity briefly mentioned in Chapter 4 and the agent relative model (Chapter 5). In chapter 4, the term “narrative identity” is mentioned with respect to the situation of patients, but this term can also be applied to the situation of the potential donors. The point is, that in order to be able to continue to live with oneself as oneself, one needs a certain consistency through the time (15). To have no consistent life story may cause restlessness and unpleasant feelings, often translated in phrases such as “I do not know who I am” and “I am looking for my self” (16). Thus, any story of donation or non-donation needs not only to be accepted by the patient, but should also be credible for the (non-) donor him/herself. This may be best explained by an example of an objection of the ‘agent-relative type’: ” I choose not to donate, because I have to take care of my little children”. By saying this, the non-donor is not necessarily consciously shaping his/her own life story - as if he/she were continuously reflecting on his/her life so far “Considering my story so far, this should be the logical or consistent way to act”. But still, the reasons for donating, or for not donating should fit into his/her story. A specific reasoning for non-donating (” I choose not to donate, because I have to take care of my little children”) may fit someone’s story; in such a way that others would say “Oh that was exactly how I expected him to react”. The same reasoning would, in someone else’s story completely not suit, it would not be credible - as if he/she was assigned the wrong text. This does not necessarily imply that all is pre-determined in scripts and texts. Identity formation is a dynamic process. Counsellors can support potential donors, if they wish, in their (dynamic) identity formation and in their shaping of a personal story (17). Personal stories differ. There may be many shared features, just as love stories all have their common themes and characteristics. Nevertheless Phyramus and Thisbe are not exchangeable with Romeo and Juliet. In the same way, counsellors may start to recognise patterns and similarities: ”Oh this is a typical mother-who-does-not-want-to-receive-from-her-daughter situation", but they should realise that each situation, although very similar to another situation is unique.

PSYCHOLOGICAL SUPPORT IN LIVING KIDNEY DONATION

Chapter 6 describes the results of a literature search on psychosocial and ethical issues related to kidney exchange donation. We identified and discussed five issues: 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. Chapter 6 concludes that in theory none of these issues, or the combination of them, seems to provide 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, to evaluate, and if necessary, adjust our existing protocol for psychosocial support. Chapter 7 describes the empirical study of the psychosocial implications for participants in a living kidney exchange donation program. In this study, participants in an exchange donation program are compared to participants in the regular 'direct' living kidney donation program. We found that ten percent of the participants in our study appreciated additional emotional support, and that in this respect there were no differences between participants in the exchange donation program and participants in the direct donation program. On the one hand, this is reassuring news. Even though patients and donors undergo major surgery and go through a highly emotional period, the great majority is able to cope with this. The type of counselling that is currently offered, the consultations with the transplant coordinator and the social worker, seems sufficient. Most patients and donors do not need additional psychological support. These data show that even in turbulent situations, namely a living kidney donation procedure and even a living kidney exchange procedure, patients and donors are able to cope in these situations. This could be compared to the situation of people who are involved in disasters. The occurrence of completely normal emotions after a shocking event is sometimes equated with the need for and thus necessity of psychosocial support. It is argued that this may lead to a self-fulfilling prophecy, i.e. that people think that after a shocking event they should search for professional support, that subsequently they seek this support, and that seeking support is considered to be evidence that they indeed are in need of support. This completely ignores the self-coping mechanisms, resilience and social support of victims (18). However, on the other hand, we found that the existing psychosocial support is not enough for 10% of the participants in a living kidney (exchange) donation procedure. The stress-coping theory may be helpful in explaining this. Stress-coping theory focuses on the interaction of people and their external environment. The occurrence of stress is dependent on how the stressor is appraised initially and how the individual appraises his/her resources to cope with the potential stressor (19). The 10% of people who require additional psychological support are those people who are unable to cope with the stress they experience. This may be due either to personal predispositions, 'personality', or to their personal circumstances, the occurrence of other stressful events in the same time period as the donation procedure (for instance, the death of a family member), or the occurrence of complications during the donation procedure. A previous study has shown that the occurrence of complications in a living kidney donation procedure indeed causes an increased need for psychosocial support (20).

Apart from these situations, another subgroup of patients and donors who are in need of additional psychological support are donors (and/or patients) who utilise the donation procedure as an explanation of their (psychological) problems. In reality, these problems often date back to a period prior to the donation, but they are often painfully brought to light by the donation procedure. For example, the donor may hope and expect that the donation will improve the relationship with the recipient in a specific way. If the relationship remains unchanged after donation, this will lead to disappointment and frustration (21). For the situations described above, the 10% who need additional psychosocial support and the patients and/or donors with pre-existing psychological problems, psychological support is indicated and should be offered by the transplant centre.

Motivation for living kidney donation

As stated in Chapter 6, exchange donation is sometimes perceived as a first step to commercial organ trade. This is because a transaction is involved, that could be defined as a process of exchange or barter. The donor's kidney goes to a stranger, but not for free. It is exchanged for something valuable, namely, another organ for a loved one. There are concerns that this might lead to a monetary trade in organs. It is tempting to see a progression from direct donation - 'a kidney for free' (Chapters 2-4), to exchange donation - 'a kidney for a kidney' (Chapter 7), to paid living kidney donation 'a kidney for money' (Chapter 11). This reasoning however is not valid, because the motivation to donate in the first two situations differs from the motivation in the third situation. In the first two situations, one donates so that a loved one, someone the donor feels connected to, receives a kidney (22, 23). Living kidney donation for financial reasons implies that the donor would not donate if there were no financial incentive. These donors are motivated by financial reward and even if money is not the only part of the motivation, at least it is the decisive part. A common objection to paid living kidney donation is that this would "erode altruism" (24). The "eroding of altruism" occurs in a situation (caused by paid living kidney donation) whereby people no longer do things for each other for no reward (at least not for some material repayment). If we follow the latest scientific developments, this reasoning at least holds a degree of truth. A recent study in Science "The psychological consequences of money" has shown that people who were primed by money were less likely to interact with others and were less helpful to others (25). If we wanted to link various types of donation described in this thesis, it may be more defendable to link exchange donation ‘a kidney for a kidney’ (Chapter 7) to ‘a kidney for a kidney plus satisfaction of altruistic ideals’ (Chapter 8) to ‘ a kidney for satisfaction of altruistic ideals (only)’ (Chapters 9-10). It seems that the people in Chapter 8 who are willing to participate in “altruistically unbalanced exchange donation” are those donors (and patients) who feel invoked by the needs of others. They may have a personal system of values wherein helping others in need is a core value. Those people described in Chapter 8 may display similarities with the people in Chapters 9 and 10. These similarities may be explained, as “altruism”. The term altruism however, can be interpreted in different ways (26). As it is beyond the scope of this thesis to explore the term “altruism” in detail, I will comment on it only very briefly. A common way to perceive altruism is as the direct opposite of self-interest – as if it were a form of self-sacrifice. Opposed to this view is the idea that self-sacrifice does not necessarily involve conflict of morality and self-interest, and that when making sacrifices we do not necessarily harm our self-interest or well-being (27). According to this view, reasons for action are value-based. We choose to act in a certain way because that action appears to posses some characteristics that makes it worthwhile, or better than the alternatives. Being able, being in the position to live according to the values you consider important, will contribute to your well-being. This may exactly be what is at stake for (at least some of) the altruistic or Samaritan donors: by donating one of their kidneys they are able to live life according to their personal values. Therefore the remark of an altruistic donor “I am so grateful that I can do this”, may seem odd or even contradictory at first sight may not be so strange after second thoughts.

Concluding comments

The last chapter, Chapter 12, is about patients’ willingness to undergo xenotransplantation. The study population of Chapter 12 is the same population as described in Chapter 2. The preferences of these patients are clear. The treatment option described in Chapter 2, living kidney donation, is far more popular than the possible future treatment option of xenotranplantation. However, these preferences also appear to be context dependent. In a situation where the waiting time for a deceased donor kidney is long, living kidney donation has become “a” or maybe even “the” standard treatment option, having superior results compared to deceased donor transplantation, it is not surprising then that patients are choosing living kidney donation as the preferred treatment option. But as soon as circumstances change, people’s preferences may change as well: “If xenotransplantation was proved to have similar good results as a human transplant, I would opt for xenotransplantation”. In this respect Rawls may offer the best explanatory model. New information will lead to new considerations and perhaps to new preferences and decisions. Maybe this would even be true for paid living kidney donation: “if it is legal, and kidneys that have been paid for are available anyway, I am not bothered”. This is similar to the kind of argument put forward for eating goose liver: ”Actually I am against it, but since it is on the menu anyway I might as well have it". From a patient perspective, this is completely understandable. Our data show a strong will to survive, to get transplanted and to continue life. Whatever type of transplantation is supplied "even from my worst enemy" (Chapter 4); or "from a canary" (Chapter 12), the demand for transplantation is evident. As long as there is no significant change in the supply of deceased donor kidneys, these new options will remain. An ongoing discussion about the moral implications and psychological consequences of new strategies aimed at increasing the number of kidneys for transplantation is essential for decisions about if and how to implement new strategies to increase the number of kidneys for transplantation.

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Summary

INTRODUCTION

The number of living kidney donations has increased rapidly over the past decade in the Netherlands. Three major changes have contributed to this increase and are described in Chapter 1, ‘Introduction’: 1) an increase in donations from genetically non-related donors such as spouses and friends; 2) the start of a kidney exchange donation program; and 3) the acceptance of so called ‘Samaritan kidney donors’; people that are willing to donate a kidney to a patient they do not know at all. This thesis focuses on the ethical and psychological implications of these recent developments in the field of living kidney donation. Each of the three developments named above are addressed in a separate part of the thesis. The first part of the thesis refers to the first recent development in the field of living kidney donation that is named above, the enlargement of the pool of potential living donors. The second part addresses ethical and psychological questions raised by the start of a kidney exchange donation program; and the third part of this thesis comprises moral and psychological dilemmas as a consequence of the acceptance of Samaritan kidney donors. This thesis also comprises a fourth part that describes psychological barriers and moral implications of possible future developments in the field of living kidney donation.

PART I: DIRECT(ED) DONATION

The first part is titled “direct(ed) donation”, and focuses on donations from living kidney donors to someone they know; with whom they have a genetic and/or emotional relationship. There are four studies included in this first part. The aim of the first study ‘Post mortal or living related donor: preferences of kidney patients’ (Chapter 2) is to investigate how kidney patients appreciate their treatment options. We studied the willingness and motives for accepting a living kidney donation in 61 kidney patients on the waiting list on two occasions. Between both moments of measurement patients received general information on transplant options. We tested whether demographic data, medical status data or quality of life correlated with treatment choice. Our results showed that 61% of the patients preferred living kidney donation to post mortal donation. Their main motivation for this choice was the better quality of the living kidney. The most often named reasons to choose post mortal donation were unwillingness to burden a loved one and fear of psychological problems in relation to the donor after transplantation. There was no statistical significant change of preference between both moments of measurement; however there seemed to be a tendency in favour of living kidney donation. Fewer years spent on renal replacement therapy correlated statistically significant with the choice for living kidney donation. These findings encourage the development of new strategies to facilitate the living kidney donation program, and confirm the need for the standard option of psychosocial support for patients. After this study had been published, we received a reaction from Spanish authors that the high preference for living kidney donation found in our study was not in line with their findings. We responded them by means of a letter, which is also part of Chapter 2. Given that we found such high preferences for living kidney donation in the patients we studied, we wondered why then, still, so many patients do not pursue living kidney donation. This is the research question of Chapter 3 'Psychological barriers in expanding the living kidney donation program'. This study focuses on the knowledge and acceptance of living kidney donation in the group that actually is eligible for living kidney donation and transplantation; the patients on the transplant waiting list and the persons in their close environment, the potential donors. Investigating these groups is the strategy to explore if barriers for living kidney donation can be overcome. We interviewed 91 patients on the waiting list for a kidney transplant who seemed unwilling or unable to pursue living kidney donation, and their potential donors (n = 53). We also included a comparison group of 53 patients and 51 donors who had planned to undergo living kidney donation/transplantation in the near future. All respondents underwent an in-depth interview by a psychologist about topics that could influence their willingness to pursue living kidney donation: sociodemographical and medical variables, knowledge and information, attitude towards living kidney donation, communication, expectancies about the future relationship with the donor (or: recipient) and risk perception. We found, again, that many patients were willing to pursue living kidney donation: 78% of the patients on the waiting list were willing to accept the offer of a living donor. The main reason that was given for not pursuing living kidney donation was reluctance to discuss the issue with the potential donors. If the potential donor does not offer spontaneously, patients are likely to interpret this silence as a refusal to donate. We found evidence that this interpretation not always holds: over one third (19/53) of the potential donors were in a pre-contemplation phase, open to consider themselves as a potential donor. On the other hand, an in size comparable group of potential donors (21/53), was reluctant about donation. Main reasons for donor reluctance were 1) Fear for their own health, 2) The specific relationship with the intended recipient, and 3) A lack of information about living kidney donation. Chapter 4, 'Avoiding the issue: patients (non)communication with potential living kidney donors' builds upon Chapter 3. This Chapter brings into focus what we think are important findings of the previous chapter, the noncommunication between patient and potential donors. The purpose of Chapter 4 is to investigate how kidney patients who are eligible for transplantation manage to find a living kidney donor. We compared the group of patients who did have difficulty in finding a living donor to a comparison group of patients who had found a living kidney donor. We investigated and compared communication patterns in both groups. A notable finding is that in the comparison group, the donor almost always initiated communication about donation: being offered a kidney (or not) seems to be decisive for either or not pursuing living kidney donation. Some patients in the group who had difficulty in finding a living donor had tried to discuss the topic cautiously, but often received little or no reaction from their potential donors. Patients are likely to interpret this as a no and further discussion gets blocked. Following that, patients tend to create narratives to give meaning to these situations and how they affect their zelfbeeld. Although serving an important function, namely maintaining relationships and the contribution of these relationships to their personal identities, this may result in a missed chance of the preferred medical treatment. We conclude this study by saying that as patients find themselves in the difficult situation wherein both health and personal relationships are at stake, they may profit from professional support to find a way to deal with this situation that best suits their personal needs. This “professional support” is the focus of the final chapter of part one, Chapter 5 ‘Should health care professionals encourage living kidney donation?’. This study builds upon Chapters 3 and 4. Given the data on the psychological barriers for living kidney donation described in Chapters 3 and 4, Chapter 5 discusses to what extent health care professionals can or should encourage living kidney donation. We argue that active interference in peoples’ personal lives is justified – if not obligatory. The study descibed in Chapter 5 first addresses the ambiguous ideals of non-directivity and value neutrality in counselling. We describe the main pitfalls implied in these concepts, and conclude that these concepts cannot account for the complex reality of living donation and transplantation. We depict what is required instead as truthful information and context-relative counselling. We then consider professional interference into personal belief systems. We argue that individual convictions are not necessarily strong, stable, or deep. They may be flawed in many ways. In order to justify interference in peoples’ personal lives, it is crucial to understand the structure of these convictions. We made use of the interview-data from Chapters 3 and 4 to analyse the structure of patients’ beliefs and convictions about living kidney donation. For this analysis, we used three different models, referring to theories by Stephen Toulmin (the structure of logical argument), John Rawls (the “reflective equilibrium”) and Thomas Nagel (the particularistic position). For each model we ask whether interference in personal convictions in case of living kidney donation can be morally justified. We found that all three models apply to personal opinions on living kidney donation, and that objections to living kidney donation take on various structures. One such structure is the ‘general principle’ or axiom as described in the model of deductive reasoning (Toulmin), for instance “one should not cut a healthy body”. In other situations, the particularistic position is more prominent (Nagel). This occurs if a particular principle -rooted in personal and unique situations- seems decisive for not pursuing living kidney donation: “I cannot donate, because I have to take care of my little son”. Reluctance to living kidney donation can also be the result of the weighing of various facts, values and emotions: “All things considered, I prefer to wait for a cadaver organ”; a “reflective equilibrium” (Rawls). After analysis, we found that these various objections are open to change, and accordingly can be influenced by health care professionals. Such attempts to influence personal opinions in case of living kidney donation can only be justified if they have the intention to empower the patient in his decision making process.

PART II: INDIRECT DONATION

The second part is titled “indirect donation”. By indirect donation I aim at kidney exchange donation. Kidney exchange donation offers an opportunity for recipients who cannot receive directly from their original donor, due to blood type incompatibility or a positive crossmatch. Incompatible donor-recipient couples can register for an exchange donation procedure, wherein patients exchange donors in order to receive a compatible kidney. There are few kidney exchange programs in the world, South Korea has the longest existing program, and there is experience with this type of donation in Romania and in the USA. The Dutch kidney exchange program started in January 2004. One of the conditions for successfully implementing the kidney exchange program was the need to address the ethical and psychological implications involved. Chapter 6 'Starting a crossover kidney transplantation program in the Netherlands: ethical and psychological considerations' discusses the ethical and psychological considerations that accompanied the practical preparations for the Dutch crossover transplantation program. We identified five topics of interest: the influence of "donation by strangers" on the motivation and willingness of donor–patient couples, the issue of anonymity, the loss of the possibility of "medical excuses" for unwilling donors, the view that crossover is a first step to commercial organ trade, and the interference with existing organ donation programs. We concluded that whether viewed separately or in combination, these issues do not impede the efficient organization of a crossover program or raise worrying ethical issues. Chapter 7, 'The implementation of a kidney exchange program does not induce a need for additional psychosocial support' describes an evaluation study of the first year of the exchange donation program with respect to psychological outcomes. We studied 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. Interview data was 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. The interview comprised those issues that may influence the need for psychosocial support in participants in an exchange donation program: the decision making process on entering a new kind of donation procedure, the loss of the possibility of a "medical excuse" 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. Furthermore, there were several general questions on need for additional psychosocial support in the interview. We also included a comparison group of 48 donors and recipients participating in the regular living kidney donation program. Ten percent of the participants in our study 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 to the support normally offered to participants in the regular living kidney donation program. Although the living kidney exchange program is a successful program, blood type O patients are less likely to be selected for transplantation within a living exchange donation program. 'Altruistically unbalanced donation' could help these blood type O patients: one donor-recipient pair is incompatible (e.g. A-donor > O-recipient) and the other pair is compatible, but not identical (e.g. O-donor > A-recipient). Exchanging these kidneys would result in two compatible living donor kidney transplants. The aim of Chapter 8 'One donor, two transplants: willingness to participate in altruistically unbalanced exchange donation' is to investigate whether compatible pairs would be willing to participate in such procedure. We included 96 living kidney donors and recipients in our study; they were the same couples that participated in the study described in Chapter 8. All were asked whether they would be willing to participate in altruistically unbalanced exchange donation, as long as direct donation was also an option. We found no group differences. We found that one third of the donors and recipients are willing to participate in altruistically unbalanced kidney exchanges. We suggest that this form of donation may be a feasible addition to already existing living kidney exchange programs.

PART III: NON-DIRECTED DONATION

The third part of this thesis "non-directed donation", focuses on Samaritan, or so-called 'altruistic' kidney donors, people that are willing to donate a kidney to a patient they do not know at all. This third part consists of two chapters. Chapter 9 is entitled 'Altruistic living kidney donation challenges psychosocial research and policy: a response to previous articles'. This chapter addresses the challenge to bring together empirical and normative issues in the field of altruistic living kidney donation. Policies with respect to altruistic living kidney donation to strangers should, in addition to medical criteria, preferably be based on valid attitude research data. However, deciding on what data are relevant is a normative issue. By comparing two recent surveys, we shed light on the complex methodological and ethical questions surrounding altruistic living kidney donation. We found that the main methodological issues were the distinction between the willingness to donate and the acceptability of the offer, the difference between public attitudes observed in surveys ("facts") and well-considered moral judgments ("norms"), and biases caused by a misperception of central moral concepts (e.g. discrimination and injustice). We argue that transplantation centres have a good case for applying or initiating altruistic living donation programs; and advocate an interaction between research and policymaking. Social research can best influence transplantation policies in altruistic living donation by in-depth interviews into the complicated background beliefs underlying personal preferences. In addition, the public should be encouraged to judge the immanent issues in a morally responsible way. In the end, a fair balance should be established between the impartial requirements of social justice and the partial motivations of individuals involved in altruistic living donation. Although discriminatory acts should be rejected categorically, donation policies should be willing to consider, support, and accept motivations based on personal loyalties. Chapter 10 'Systematic review of the psychological screening of Samaritan kidney donors' shows the interweaving of clinical work and normative issues. This chapter is on the psychological testing of altruistic kidney donors. In the psychological testing for donor suitability one is continuously looking for norms: when to reject, and when to accept a volunteer as an altruistic living kidney donor? Chapter 10 comprises a literature review on the psychological screening of potential Samaritan kidney donors on donor suitability, and a proposal for the contents of such a screening. We have found five articles that at least in some detail describe the evaluation of potential Samaritan donors. For all five articles found, a consultation with either a psychiatrist or a psychologist is standard part of the donor evaluation procedure. This evaluation consists of an interview, and in most instances of additional psychometric testing. Basically, according to the articles found, the two major criteria for donor rejection are psychopathology / psychological instability and motivational issues. Three studies reported on the actual rejecting of potential donors on psychological grounds. The evaluation of Samaritan kidney donors is a developing field in clinical medicine. Given the scarcity of follow-ep data on this type of donation, we recommend the exchange of experience between centers that run a Samaritan donor program, in order to improve the evalution criteria and care for this type of donors.

PART IV: FUTURE DIRECTIONS?

The fourth part of this thesis is titled “Future directions?”. This part consists of two chapters on possible future developments in the field of living kidney donation, although donation is probably not the right term for the activities described in chapters 11 and 12. One of the most fiercely debated strategies to increase the number of kidneys for transplantation is the introduction of financial incentives. As the success of such strategy largely depends on public support, we performed a public survey on this topic; Chapter 11, ‘Public survey on financial incentives for living kidney donation’. We developed a questionnaire on financial incentives for living kidney donation. We investigated the public opinion on two different fixed compensations: either life long health insurance compensation or € 25.000. Furthermore, we investigated public preferences on the practical execution: either the patient seeks a donor or the donor registers for donation at an independent institute. For all examples, health insurance companies would cover costs of treatment. TNS NIPO, a professional organisation for market research administered the survey to an Internet panel that is made representative for the general population. 550 respondents filled out the questionnaire. We found that 46% considered the situation wherein health insurance companies would introduce financial incentives to increase the number of living kidney donors undesirable, compared to 25% who perceive this as desirable. The option wherein the donor registers at an independent institute to donate to a patient on the list and receives life long health insurance compensation was chosen as most favourable. Quite a different future strategy to increase the number of kidneys for transplantation would be xenotransplantation, the transplantation of genetically modified pig kidneys into human. Although potentially solving dire shortages, one of the conditions for implementing a new treatment is the willingness to undergo such treatment in patients who are eligible. This issue is addressed in Chapter 12, ‘Reluctant acceptance of xenotransplantation in kidney patients on the waiting list for transplantation’.

Previous research has shown contradictory results regarding the acceptance of xenotransplantation by kidney patients. This variance in attitude towards xenotransplantation could be explained by differences in knowledge of xenotransplantation, the availability of alternative treatment options, specific beliefs and cognitions of the patient, and differences in the health status of the patients. We studied 61 patients in this contention in the Netherlands waiting for a kidney transplant. All took part in in-depth interviews and filled out questionnaires on two occasions, once before and once after an information brochure on xenotransplantation had been read. We found that a better health status is correlated with a greater acceptance of xenotransplantation, but only before information was given. After information had been given, the acceptance of xenotransplantation decreased significantly. However, if xenotransplantation is the only possibility in a life-threatening situation, almost all patients are willing to accept xenotransplantation, except for a small group (approximately 10–15%) with fundamental religious and/or spiritual objections against such treatment. When alternative treatment options such as a human deceased donor, a living related donor or commercial donor are offered, the majority of patients would prefer those to xenotransplantation. The main reason for reluctance is uncertainty about the risks of xenotransplantation to personal health. Because alternatives are currently available, we expect that xenotransplantation will become more popular only if future results of this procedure have proved to be comparable to transplantation with a human donor kidney.

Discussion

Chapter 13, the final chapter of this thesis is a discussion of all previous chapters. The first issue addressed in this chapter is the empowerment of patients with end stage renal disease that are eligible for transplantation. The feasibility and conditions for several strategies to inform potential donors about living kidney donation are discussed: the Norwegian approach; a home-based education program; and interventions in the pre-dialysis period. Next, the counselling process of these potential donors is described. Furthermore, the relationships between various types of living kidney transplantation - exchange donation, Samaritan donation, paid donation, and xenotransplantation - are addressed in the Discussion. It is argued that although it may be tempting to interpret these types of donations as logical successors in time, it may for the moment be wiser to classify them as categorical activities. One common feature of these new types of kidney transplantation is, that they play against a background of the shortage of deceased donor kidneys. As long as no significant changes occur in the supply of deceased donor kidneys, these new types of donation will not leave stage. An ongoing discussion about the moral implications and psychological consequences of any new type of kidney donation / transplantation is a condition for decisions about if and how to implement new strategies to increase the number of kidneys for transplantation.

Nederlandse samenvatting

INTRODUCTIE

Het aantal niertransplantaties waarbij de nier afkomstig is van een levende donor is het laatste decennium flink gestegen in Nederland. Inmiddels wordt 40% van alle niertransplantaties uitgevoerd met behulp van een nier van een levende donor. Drie ontwikkelingen hebben vooral bijgedragen aan de toename van het aantal transplantaties met een nier van een levende donor. Deze drie ontwikkelingen worden beschreven in hoofdstuk 1, de introductie op dit proefschrift. Deze ontwikkelingen zijn: 1.) een toename van genetisch niet-verwante donoren, zoals echtgenoten en vrienden; 2.) de start van het 'cross-over transplantatie programma', en 3.) de groeiende acceptatie van de zogenaamde Samaritaanse nierdonoren, donoren die tijdens hun leven besluiten om hun nier af te staan aan iemand op de wachtlijst, met wie ze geen genetische of emotionele verbintenis hebben. Dit proefschrift richt zich op de implicaties van deze drie nieuwe ontwikkelingen op ethisch en psychologisch gebied. Elk van de drie ontwikkelingen die hierboven zijn benoemd worden behandeld in een apart deel van dit proefschrift. Het eerste deel van dit poefschrift verwijst dus naar de eerste recente ontwikkeling op het gebied van nierdonatie bij leven, namelijk de toename van genetisch niet-verwante donoren. Het tweede deel van dit proefschrift handelt over de ethische en psychologische vraagstukken behorende bij de start van een cross-over transplantatie programma. Het derde deel van dit proefschrift omvat morele en psychologische dilemma's die het gevolg zijn van de toegenomen acceptatie van Samaritaanse donoren. Dit proefschrift kent ook een vierde deel. In dit deel worden de psychologische barrières en morele implicaties van mogelijke toekomstige ontwikkelingen op het gebied van nierdonatie en -transplantatie behandeld.

DEEL I: DIRECTE DONATIE

Het eerste deel van dit proefschrift is getiteld "directe donatie", en richt zich op donaties van levende nierdonoren aan iemand die zij kennen, iemand met wie zij een genetische en/of emotionele band hebben. Het eerste deel bestaat uit vier studies. In de eerste studie "Postmortale of levende donor: preferenties van nierpatiënten" (hoofdstuk 2) wordt de bereidheid en motivatie van nierpatiënten om een nier van een levende donor te accepteren onderzocht. We bestudeerden 61 patiënten op de wachtlijst voor een niertransplantatie op twee verschillende meetmomenten. Tussen beide meetmomenten ontvingen patiënten algemene informatie over transplantatie, zowel over postmortale transplantatie als over nierdonatie bij leven. We onderzochten of demografische variabelen, medische variabelen en kwaliteit van leven verband hielden met de keuze voor een bepaald type transplantatie. We vonden dat 37/61 (61%) van de patiënten de voorkeur gaf aan nierdonatie bij leven boven postmortale nierdonatie. De belangrijkste motivatie voor deze preferentie was de betere kwaliteit van een nier afkomstig van een levende donor. De motivatie voor de preferentie voor postmortale nierdonatie was onwelwillendheid om een naaste te belasten met de donatieprocedure en de angst voor ongelijkheid in de persoonlijke relatie met de donor na donatie/transplantatie. Er was geen statistisch significante verandering in preferenties tussen beide meetmomenten, wel was er een tendens dat op het tweede meetmoment na het lezen van de informatie meer mensen de voorkeur gaven aan nierdonatie bij leven. Er was een statistisch significante positieve correlatie tussen een kortere wachttijd en de keuze voor nierdonatie bij leven. Op basis van deze bevindingen concluderen wij in hoofdstuk 2 dat het verder ontwikkelen en faciliteren van het nierdonatie bij leven programma wenselijk is. Verder bevestigen onze resultaten de noodzaak van het standaard aanbieden van psychosociale begeleiding aan patiënten. Nadat deze studie was gepubliceerd ontvingen we een reactie van een groep Spaanse onderzoekers dat de preferentie voor nierdonatie bij leven die wij vonden niet in overeenstemming was met de bevindingen uit hun onderzoek. We hebben hierop gereageerd met een brief, welke ook onderdeel is van hoofdstuk 2. Gegeven dat wij een sterke voorkeur voor nierdonatie bij leven vonden in hoofdstuk 2, vroegen we ons af waarom er dan toch een relatief groot aantal nierpatiënten uiteindelijk niet het traject van nierdonatie bij leven in slaat. Dit is de onderzoeksvraag van hoofdstuk 3 “Psychologische barrières voor het uitbreiden van het nierdonatie bij leven programma”. In dit hoofdstuk wordt de kennis en acceptatie van nierdonatie bij leven bestudeerd in de groep die daadwerkelijk in aanmelding komt voor deze vorm van transplantatie, de patiënten op de wachtlijst en de mensen uit hun naaste omgeving, de potentiële donoren. Het bestuderen van deze groepen biedt de mogelijkheid om te exploreren wat de (psychologische) barrières voor nierdonatie bij leven zijn, en of deze overkomen kunnen worden. We hebben 91 patiënten op de wachtlijst, die niet het traject van nierdonatie bij leven zijn ingeslagen, en hun potentiële donoren (n=53) geincludeerd. Tevens hebben we gebruik gemaakt van een vergelijkingsgroep, bestaand uit 53 patiënten en 51 donoren, die allen van plan waren om op korte termijn een nierdonatie bij leven procedure te ondergaan. Alle respondenten werden geïnterviewd door een psycholoog over onderwerpen die mogelijk hun bereidheid om al dan niet verder te gaan met nierdonatie bij leven zouden kunnen beïnvloeden: sociodemografische en medische variabelen, kennis en informatie, attitude ten opzichte van nierdonatie bij leven, communicatie, verwachtingen over de toekomstige relatie met de donor en risico-perceptie. We vonden wederom dat een hoog percentage bereid was om een nier van een naaste accepteren; 78% van de patiënten op de wachtlijst. De voornaamste reden om niet verder te gaan met nierdonatie bij leven was terughoudendheid om het onderwerp met de mogelijke donoren te bespreken. Patiënten namen dus een afwachtende houding aan ten opzichte van hun potentiële donoren. Als een potentiële donor het niet spontaan aanbiedt om een van zijn nieren te doneren, dan zijn patiënten geneigd om dit te interpreteren als een weigering om te doneren. Deze interpretatie is niet altijd correct: meer dan een derde (19/53) van de potentiële donoren stond open voor het idee om zelf donor te zijn. Aan de andere kant, een ongeveer even grote groep van de potentiële donoren (21/53) stond terughoudend ten opzichte van donatie. De voornaamste redenen voor deze terughoudendheid waren: 1.) angst voor de eigen gezondheid, 2.) de specifieke relatie met de patiënt en 3.) een gebrek aan informatie over nierdonatie bij leven. Hoofdstuk 4, “Het vermeden onderwerp, over de communicatie van nierpatiënten met hun potentiële donoren" gaat verder in op de gegevens uit hoofdstuk 3. Dit hoofdstuk 4 richt zich op een belangrijke bevinding van hoofdstuk 3, namelijk de afwachtende houding van patiënten ten opzichte van hun mogelijke donoren. Het doel van hoofdstuk 4 is om te onderzoeken op welke wijze nierpatiënten al dan niet proberen om in hun naaste omgeving een levende donor te vinden. We vergeleken een groep van patiënten die geen donor had met de groep patiënten die wel een levende nierdonor hadden gevonden. We onderzochten en vergeleken de communicatie patronen in beide groepen. Een opvallende bevinding is dat in de vergelijkingsgroep het bijna altijd de donor was die het gesprek over nierdonatie bij leven initieerde en aanbood een nier te donoren. Dus het aangeboden krijgen van een nier lijkt doorslaggevend te zijn voor het zich al dan niet begeven in het nierdonatie/transplantatie bij leven traject. Sommige patiënten in de groep zonder donor hadden voorzichtig geprobeerd om het onderwerp te bespreken met de mensen in hun naaste omgeving, maar ontvingen weinig tot geen reactie van deze mensen. Vervolgens zijn patiënten geneigd om dit op te vatten als een weigering om te doneren en het onderwerp komt verder niet meer ter sprake. Patiënten zijn geneigd om redenen te bedenken om betekenis te geven aan deze situaties. Hoewel dit proces een belangrijke functie heeft, namelijk om de situatie voor de patiënt zelf acceptabeler te maken en om de relatie met de potentiële donor in de toekomstig veilig te stellen, is de kans groot dat dit gedrag resulteert in een gemiste kans op de medisch betere behandeling. De conclusie van deze studie is dan ook dat, gegeven deze complexe situatie waarin patiënten zich bevinden, waarbij het aan de ene kant gaat om hun gezondheid, maar aan de andere kant niet de relatie met de personen in hun naaste omgeving op het spel willen zetten, zij baat zouden kunnen hebben bij professionele begeleiding vanuit het ziekenhuis, om een manier te vinden om met deze situatie om te gaan die het best past bij hun individuele situatie. Deze "professionele begeleiding" is het onderwerp van hoofdstuk 5 van dit proefschrift: "Moeten professionals uit de gezondheidszorg nierdonatie bij leven aanmoedigen?" Dit hoofdstuk bouwt voort op de hoofdstukken 3 en 4. Gegeven onze bevindingen uit deze eerdere hoofdstukken over de psychologische barrières die een rol spelen bij het vinden van een levende donor, is de vraagstelling van hoofdstuk 5 in hoeverre professionals uit de gezondheidszorg nierdonatie bij leven moeten aanmoedigen. In dit hoofdstuk betogen we dat actieve inmenging in het persoonlijke leven gerechtvaardigd is. Hoofdstuk 5 gaat eerst in op de ambigue idealen van non-directiviteit een waardevrijheid in het counselen van patiënten. We bekritiseren het gebruik van deze concepten, en concluderen dat deze concepten niet geschikt zijn voor toepassing op de complexe praktijk van nierdonatie bij leven. In plaats daarvan zou het moeten gaan om waarheidsgetrouwe informatie en context relatieve counseling. Vervolgens gaan we in op de inmenging van professionals in persoonlijke overtuigingen. Om inmenging in persoonlijke overtuigingen te rechtvaardigen is het noodzakelijk om te weten hoe deze overtuigingen in elkaar zitten, wat hun structuur is. Om deze structuur te bestuderen, hebben we gebruik gemaakt van de interview data uit de hoofdstukken 3 en 4. De argumenten voor en tegen nierdonatie bij leven hebben we geanalyseerd met behulp van 3 modellen voor de structuur van argumenten. Deze modellen verwijzen naar de theorieën van Toulmin (de structuur van logische redenatie), Rawls (het reflectieve evenwicht) en Nagel (de particularistische positie). We vonden dat elk model van toepassing kan zijn op de overtuigingen die iemand kan hebben ten aanzien van nierdonatie bij leven; bezwaren tegen nierdonatie bij leven kunnen dus verschillende structuren aannemen. Een van die structuren is het "algemene principe", of axioma volgens het model van deductief redeneren (Toulmin), bijvoorbeeld "men moet niet snijden in een gezond lichaam". In andere situaties kan het bezwaar beter gevat worden niet als algemeen principe maar als particularistisch principe (Nagel). Dit komt voor als een bepaald principe, ingebed in iemands persoonlijke en unieke situatie, doorslaggevend is voor de keuze om al dan niet verder te gaan met nierdonatie bij leven. Een voorbeeld van zo'n redenering is: "Ik kan niet doneren, want ik moet de zorg dragen voor twee jonge kinderen". Terughoudendheid ten opzichte van nierdonatie bij leven kan ook het resultaat zijn van het wegen van een veelheid aan feiten, waarden en emoties: "Alles welbeschouwd, wacht ik liever op een nier van een overleden donor", een reflectief evenwicht (Rawls). Hoewel bezwaren volgens de hierboven geschetste structuren op het eerste gezicht sterk en onwankelbaar lijken, vonden we dat alle drie de type argumenten de mogelijkheid voor verandering bieden. Hierdoor kunnen persoonlijke overtuigingen dus beïnvloed worden, bijvoorbeeld door professionals uit de gezondheidszorg. Pogingen om de persoonlijke overtuiging te beïnvloeden in geval van nierdonatie bij leven kunnen alleen gerechtvaardigd worden als ze de intentie hebben om de patiënt te sterken (empower) in zijn of haar beslisproces.

DEEL II: INDIRECTE DONATIE

Het tweede deel van dit proefschrift is getiteld "indirecte donatie". Hiermee wordt gedoeld op cross-over transplantatie. Cross-over transplantatie biedt patiënten die niet direct een nier kunnen ontvangen van hun oorspronkelijke donor (bijvoorbeeld vanwege bloedgroep incompatibiliteit) de mogelijkheid om toch getransplanteerd te worden. Incompatibele donor-ontvanger paren kunnen zich laten registreren voor een cross-over transplantatie procedure, waarbij patiënten hun donoren uitruilen teneinde een nier te ontvangen die wel compatibel is. Er zijn maar een paar cross-over transplantatie programma's in de wereld. Zuid Korea heeft het langst bestaande programma, en verder er is ervaring met deze vorm van donatie in Roemenië en de VS. Het Nederlandse cross-over transplantatie is in 2004 van start gegaan. Een van de voorwaarden voor de succesvolle implementatie van dit programma was een zorgvuldige analyse van de ethische en psychologische implicaties hiervan. Hoofdstuk 6: "De start starten van een cross-over transplantatie programma in Nederland: psychologische en ethische overwegingen" behandelt de psychologische en ethische overwegingen die vooraf gingen aan de praktische voorbereidingen voor het Nederlandse cross-over transplantatie programma. Vijf belangrijke overwegingen waren: of het doneren 'via een vreemde' van invloed zou zijn op dit motivatie en bereidheid van donor-ontvanger koppels, het kiezen voor wel of geen anonimiteit tussen de donor-ontvanger koppels, het verliezen van de mogelijkheid van een medisch excuus voor onwillende donoren, het idee dat cross-over transplantatie een eerste stap zou zijn naar commerciële donatie, en de interferentie van het cross-over transplantatie programma met bestaande donatie programma's. Hoofdstuk 6 concludeert dat zowel apart beschouwd als in combinatie met elkaar, deze 5 onderwerpen niet belemmerend zouden werken voor een efficiënte organisatie van het cross-over transplantatie programma, of zou leiden tot onoverkomelijke ethische bezwaren. Hoofdstuk 7 "de implementatie van een cross-over transplantatie programma leidt niet tot een verhoogde behoefte aan additionele psychosociale begeleiding" is een evaluatie studie van het eerste jaar van het cross-over transplantatie programma met betrekking op de psychologische uitkomsten voor de deelnemers. We bestudeerden of additionele psychosociale begeleiding nodig zou zijn voor donoren en ontvangers in het Nederlandse cross-over transplantatie programma. Hiertoe zijn gestructureerde interviews afgenomen bij alle 24 donoren en 24 ontvangers die cross-over donatie / transplantatie ondergingen in 2004. Interview data werd verzameld op twee momenten: voorafgaand (T1) en 3 maanden na donatie/transplantatie (T2). Het interview bestond uit die onderwerpen die in de literatuur benoemd waren als mogelijk van invloed op de psychologische uitkomsten voor donor en ontvanger: de beslissing om deel te nemen aan een nieuwe vorm van donatie, het verliezen van de mogelijkheid van een medisch excuus voor onwillende donoren, de invloed van anonimiteit op het welzijn van de deelnemers, de beperkte contactmogelijkheden tussen de ontvanger en zijn oorspronkelijke donor (aangezien beiden opgenomen liggen in een ander ziekenhuis), en negatieve psychologische uitkomsten voor mensen die niet op korte termijn geselecteerd worden voor een cross-over transplantatie procedure (en dus alsnog een lange wachttijd hebben). Verder waren er een aantal vragen opgenomen over de behoefte aan additionele psychosociale ondersteuning. Voor deze studie hebben we ook een controlegroep geincludeerd, bestaand uit 24 donoren en 24 patiënten die deelnamen aan het reguliere, directe donatie bij leven programma. Op deze manier konden vergelijkingen worden gemaakt op het gebied van de behoefte aan (additionele) psychosociale begeleiding en de incidentie van psychologische klachten na donatie. Tien procent van de deelnemers in onze studie had behoefte aan extra emotionele steun tijdens de procedure. In dit opzicht was er geen verschil tussen de "cross-over groep" en de "directe donatie groep". Met name om deze reden is de conclusie van hoofdstuk 7 dat de psychosociale begeleiding die wordt aangeboden aan deelnemers aan een cross-over transplantatie programma vergelijkbaar kan zijn aan de begeleiding die wordt aangeboden aan deelnemers aan het directe donatie bij leven programma. Hoewel het cross-over transplantatie programma een succesvol programma is, is gebleken dat patiënten met bloedgroep O minder vaak geselecteerd worden voor transplantatie binnen het cross-over transplantatie programma. 'Altruistically unbalanced exchange donation' zou een oplossing bieden voor deze patiënten. Bij deze vorm van donatie is een donor-ontvanger paar bloedgroep incompatibel (bijv. A-donor > O-ontvanger) en het andere paar is bloedgroep compatibel, maar niet identiek (bijv. O-donor > A-ontvanger). Het uitwisselen van deze nieren zou resulteren in twee compatibele transplantatie- combinaties. Het doel van hoofdstuk 8: "Een donor, twee transplantaties: bereidheid om deel te nemen in altruistically unbalanced exchange donation" is om een beeld te krijgen van de bereidheid van compatibele donor-ontvanger paren om deel te nemen aan een dergelijke procedure. We hebben 96 donoren en ontvangers geincludeerd in onze studie. Dit waren dezelfde onderzoeksgroepen die hierboven beschreven zijn voor hoofdstuk 7. Aan hen werd gevraagd of ze bereid zouden zijn deel te nemen aan altruistically unbalanced exchange donation, gegeven dat het voor hen ook mogelijk zou zijn om een directe donatie procedure te ondergaan. We vonden geen verschillen tussen de groepen. We vonden dat een derde van de donoren en ontvangers bereid zou zijn om te participeren in een dergelijke vorm van donatie, ook al zou het voor hen mogelijk zijn om gewoon direct te doneren / ontvangen. De introductie van deze vorm van donatie zou een haalbare aanvulling op het reeds bestaande cross-over transplantatie programma kunnen zijn.

DEEL III: NON-DIRECTED DONATIE

Het derde deel van dit proefschrift “non-directed donatie”, gaat over de zogenaamde Samaritaanse, of altruïstische nierdonoren, mensen die welwillend zijn om tijdens hun leven een nier te doneren aan een patiënt die ze niet kennen. Non-directed donation, een term die ook in Nederland zo wordt gebruikt, slaat dus op een donatie die niet gericht aan een bepaald persoon, maar eerder aan een groep als geheel (de nierpatiënten op de wachtlijst voor transplantatie). Dit derde deel bestaat uit twee hoofdstukken. Hoofdstuk 9, “Altruïstische donatie biedt een uitdaging voor psychosociaal onderzoek en beleid: een reactie op vorige artikelen” Dit hoofdstuk beschrijft de uitdaging om empirische en normatieve gegevens samen te brengen op het gebied van altruïstische nierdonatie bij leven. Beleid op het gebied van altruïstische nierdonatie bij leven zou naast de bestaande medische criteria ook gebaseerd moeten zijn op de resultaten van valide attitude onderzoek. Echter, het beslissen welke resultaten relevant en valide zijn is een normatieve kwestie. Door twee recente onderzoeken met elkaar te vergelijken, proberen we de complexe methodologische en ethische kwesties op het gebied van altruïstische nierdonatie bij leven te verhelderen. De voornaamste methodologische kwesties die hier spelen zijn het onderscheid tussen bereidheid om te doneren en de aanvaardbaarheid van het aanbod, het verschil tussen publieke opinie zoals gemeten in diverse surveys (feiten) en weldoordachte morele oordelen (normen), en bias die veroorzaakt word door een misperceptie van centrale morele concepten, zoals discriminatie en onrechtvaardigheid. We betogen dat transplantatie centra goede redenen hebben om altruïstische nierdonatie bij leven programma’s te initiëren en uit te voeren, en bepleiten een interactie tussen onderzoek en beleid. Psychosociaal onderzoek kan beleid het best beïnvloeden door gebruik te maken van diepte-interviews over de achterliggende gedachten voor persoonlijke voorkeuren. Verder zou het publiek aangemoedigd moeten worden om de relevante onderwerpen op een moreel verantwoorde manier te beoordelen. Uiteindelijk moet een balans bereikt worden tussen de vereisten van de onpartijdigheid van maatschappelijke rechtvaardigheid en de partiële motivaties van altruïstische nierdonoren. Hoewel discriminatoire daden categorisch afgewezen moeten worden, zou beleid op het gebied van altruïstische donatie open moeten staan om motivaties die gebaseerd op persoonlijke loyaliteiten te overwegen, ondersteunen en accepteren. Hoofdstuk 10 “Systematisch literatuuronderzoek naar de psychologische evaluatie van Samaritaanse donoren” laat wederom zien hoezeer klinisch werk en normatieve kwesties met elkaar verweven zijn. Dit hoofdstuk gaat over de psychologische evaluatie van altruïstische nierdonoren. In het beoordelen van altruïstische nierdonoren in psychologische zin is men continu bezig met het zoeken naar normen: wanneer dient een altruïstische nierdonor afgewezen te worden op psychologische gronden, en wanneer niet? Hoofdstuk 10 omvat een systematische literatuurstudie naar de psychologische evaluatie en psychologische uitkomsten van altruïstische nierdonoren. We vonden dat de evaluatie van deze donoren vaak uit twee delen bestaat: een interview met de psycholoog of psychiater en psychodiagnostiek middels gevalideerde vragenlijsten. In sommige gevallen worden ook nog een derde partij, zoals een familielid van de potentiële altruïstische donor geraadpleegd. Deze evaluatie is erop gericht om donoren met psychopathologie of met een onacceptabele motivatie op te sporen, omdat verwacht wordt dat voor deze mensen de voordelen van een altruïstische nierdonatie procedure niet zullen opwegen tegen de risico’s. Altruïstische nierdonatie is een zich ontwikkelend veld binnen de transplantatiegeneeskunde. Omdat er nog niet veel bekend is over wat psychologisch bezien de lange termijn gevolgen zijn voor deze donoren, is het van groot belang dat de transplantatie centra hun gegevens over de acceptatie, afwijzing en follow-up van dit type donoren blijven uitwisselen, zodat uniforme criteria voor de evaluatie en zorg voor deze donoren kunnen worden vastgesteld.

DEEL IV: TOEKOMSTIGE ONTWIKKELINGEN?

Het vierde deel van dit proefschrift heeft als titel “Toekomstige ontwikkelingen?”(“Future directions?”). Dit deel bestaat uit 2 hoofdstukken over mogelijke ontwikkelingen op het gebied van nierdonatie bij leven, alhoewel ‘donatie’ misschien niet de meest gepaste term is voor de activiteiten die worden beschreven in de hoofdstukken 11 en 12. Een van de felst bediscussieerde strategieën om het aantal nieren voor transplantatie te vergroten is de introductie van financiële prikkels. Aangezien het succes van een dergelijke strategie grotendeels zal afhangen van publiek steun, hebben we een publieksonderzoek uitgevoerd. Dit onderzoek wordt beschreven in hoofdstuk 11: “Onderzoek naar de publieke opinie over het introduceren van financiële prikkels voor nierdonatie bij leven”. Voor dit onderzoek hebben we een vragenlijst ontwikkeld. In deze vragenlijst, vragen we naar de mening over twee verschillende prikkels: ofwel levenslange vrijstelling van de kosten voor de zorgverzekering of €25.000. Ook waren vragen opgenomen over de praktische uitvoering van een systeem dat werkt met financiële prikkels om zo het aanbod van nieren voor transplantatie te vergroten: ofwel de patient zou zelf een donor moeten vinden (zoals nu het geval is), of de donoren zouden zich bij een onafhankelijk allocatie instituut moeten registreren voor deze vorm van donatie. In alle voorbeelden zouden ziektekosten verzekeraars de kosten vergoeden. Deze vragenlijst is verspreid door TNS NIPO, een professionele organisatie op het gebied van marktonderzoek, naar een panel dat representatief was gemaakt voor de Nederlandse bevolking. 550 mensen hebben de vragenlijst ingevuld. We vonden dat 46% van de respondenten de hypothetische situatie waarin verzekeringsmaatschappijen zouden overgaan tot het introduceren van financiële prikkels om het aanbod van nieren voor transplantatie te vergroten als onwenselijk beschouwden, terwijl 25% van de respondenten dit wel wenselijk vond. De situatie waarin een donor zich zou laten registreren bij een onafhankelijk instituut, en in ruil voor de donatie een levenslange vrijstelling van de kosten voor de zorgverzekering zou ontvangen, werd als meest wenselijk beschouwd. Een heel andere strategie om het aanbod van nieren voor transplantatie te vergroten zou de introductie van xenotransplantatie zijn, het transplanteren van genetisch gemodificeerde varkensnieren naar de mens. Dit is het onderwerp van hoofdstuk 12 "Voorzichtige acceptatie van xenotranplantatie door patiënten die in aanmerking komen voor een niertransplantatie". Eerdere studies hadden geen eenduidige resultaten aangetoond ten aanzien van de acceptatie van xenotransplantatie door patiënten die in aanmerking komen voor een niertransplantatie. Een verklaring voor deze verschillen in attitude zou kunnen liggen in de kennis van het onderwerp, de aanwezigheid van alternatieve behandelingen, specifieke opvattingen en overtuigen van de patiënten ten aanzien van xenotransplantatie, en verschillen in de gezondheidstoestand van de patiënt. We hebben dit bestudeerd voor 61 patiënten op de wachtlijst voor niertransplantatie. Alle respondenten werden geïnterviewd en vulden vragenlijsten in op twee meetmomenten, een keer voordat en een keer nadat informatie over xenotransplantatie was verstrekt. We vonden dat een betere gezondheidstoestand positief samenhing met de bereidheid om xenotransplantatie te ondergaan, maar alleen voordat informatie was verstrekt. Na informatieverstrekking, daalde de acceptatie van xenotransplantatie significant. Echter, indien xenotransplantatie de enige mogelijkheid zou zijn in een levensbedreigende situatie, waren bijna alle patiënten bereid om xenotransplantatie te ondergaan, met uitzondering van een kleine groep (10-15%) met fundamentele religieuze en/of spirituele bezwaren tegen xenotransplantatie. Indien alternatieve behandelopties zoals transplantatie met een nier van een overleden donor, een levende donor of zelfs een commerciële donor beschikbaar zijn, geeft de meerderheid van de patiënten hier de voorkeur aan boven xenotransplantatie. De voornaamste reden voor terughoudendheid ten aanzien van xenotransplantatie onder patiënten zijn de risico's van xenotranplantatie voor de persoonlijke gezondheid van de ontvanger. Aangezien andere behandelingen momenteel weliswaar niet beschikbaar, maar wel mogelijk zijn, verwachten we dat xenotransplantatie alleen dan aan populariteit zal winnen als toekomstige resultaten zullen uitwijzen dat de resultaten vergelijkbaar zijn met de resultaten van transplantatie van menselijke donornieren.

DISCUSSIE

Hoofdstuk 13, het laatste hoofdstuk van dit proefschrift is een algemene discussie van alle voorgaande hoofdstukken. Het eerste onderwerp dat wordt behandeld in deze algemene discussie is de 'patient empowerment' van patiënten met eindfase nierfalen. Er wordt ingegaan op de haalbaarheid van en de voorwaarden voor verschillende strategieën om potentiële donoren bij de behandeling van de patiënt te betrekken en te informeren over nierdonatie bij leven: de Noorse methode, een educatie programa bij de mensen thuis, en interventies in de pre-dialyse fase. In dit verband worden ook een aantal aspecten van de counseling voor potentiële donoren besproken. Verder wordt in de algemene discussie ingegaan op de onderlinge verhouding tussen de verschillende donatietypes en -programma's: cross-over transplantatie, altruïstische donatie, betaalde donatie en xenotransplantatie. Hoewel het verleidelijk kan zijn om de verschillende vormen van donatie achter elkaar te plaatsen als logische opvolgers door de tijd, is het beter om elke vorm van donatie als aparte, naast elkaar bestaande categorieën te beschouwen. Een algemeen kenmerk van nieuwe vormen van nierdonatie bij leven is dat ze alle opkomen tegen de achtergrond van een enorm tekort aan nieren van overleden donoren. Zo lang er geen significante verandering optreedt in het aanbod van nieren van overleden donoren, zullen nieuwe vormen van donatie blijven bestaan en mogelijk nog meer terrein winnen. Een voortdurende discussie over de morele implicaties en psychologische consequenties van nieuwe vormen of praktijken van nierdonatie en transplantatie is een voorwaarde voor beslissingen over of en hoe nieuwe strategieën om het aantal nieren voor transplantatie te vergroten moeten worden aangewend.

Dankwoord

Dankwoord. Dankbaarheid, om maar een van de vele voorname thema's die in dit proefschrift aan de orde komen te noemen. Eeuwige dankbaarheid, wordt het zelfs wel door sommige patiënten die een nier van een naaste ontvangen genoemd. Vaak met een connotatie van oprechte dankbaarheid voor de *gift of life*, soms ook wat angstvallig met oog op een mogelijke verschuiving van de machtsverhoudingen binnen de persoonlijke relatie. Zelf ben ik in ieder geval dankbaar voor de mogelijkheid om te promoveren op een zo ontzettend rijk onderwerp als nierdonatie bij leven. Het onderwerp raakt aan een veelheid aan alomvattende thema's als leven, dood, liefde, altruïsme, ziekte, gezondheid, plicht, verantwoordelijkheid,..... Het onderwerp was, is en zal voorlopig dus nog wel even voer niet alleen voor psychologen, maar ook voor filosofen, artsen en anderen blijven. In de eerste plaats wil ik mijn promotoren bedanken. Professor Passchier, beste Jan, heel hartelijk dank voor je support door de tijd heen. 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Curriculum Vitae

Leonieke Kranenburg was born on October 6, 1976, in Rotterdam, the Netherlands. She graduated from the secondary school, the Marnix Gymnasium, in 1995, in Rotterdam. Then she moved to Amsterdam, where she has studied psychology at the Vrije Universiteit. For her specialisation in clinical psychology, she has worked with chronically ill psychiatric patients at the mental health institution of GGZ Buitenamstel in Amsterdam. After her graduation in clinical psychology in 2000, she continued working at this institution for a year. She had learned to perform group therapies in social skills and the so-called Liberman training modules. She had been active in the initiating and further development of a cognitive behavioral group therapy for patients with psychotic disorders. During her studies, she had worked as a research assistant at the Vrije Universiteit, department of work and organizational psychology / NOA Foundation and at the Amsterdam University Medical Centre, department of Psychiatry / de Meren. Furthermore, she took extra subjects in neuropsychology and obtained the NIP accreditation for psycho diagnostics. From 1997 to 2002, she had studied philosophy at the Universiteit van Amsterdam. In 2002, she received her master title in philosophy, with her major in aesthetics and philosophy of culture. In 2001, she has started her PhD-studies at the Erasmus University Medical Centre in Rotterdam, at the department of Medical Psychology & Psychotherapy. During her PhD, she had been involved in teaching medicine students in professional attitude and communication skills, and she had been involved in the teaching of psychology students in quality of life research. In 2006, she had spent several months as a visiting PhD-student at the centre for Family Research, a multidisciplinary research centre within the Faculty of Social and Political Sciences of Cambridge University, United Kingdom. Furthermore, she had been active in fundraising for research projects in collaboration with the departments of Internal Medicine, Medical Ethics and Surgery. The most recent project was the organization of the international conference, “Organ Transplantation: Ethical, Legal and Psychological Aspects, held in Rotterdam in 2007.

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