

ORIGINAL ARTICLE

Postmortal or living related donor: preferences of kidney patients

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Summary

We studied the willingness and motives for accepting a living kidney donation in 61 kidney patients on the waiting list by a semistructured 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 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

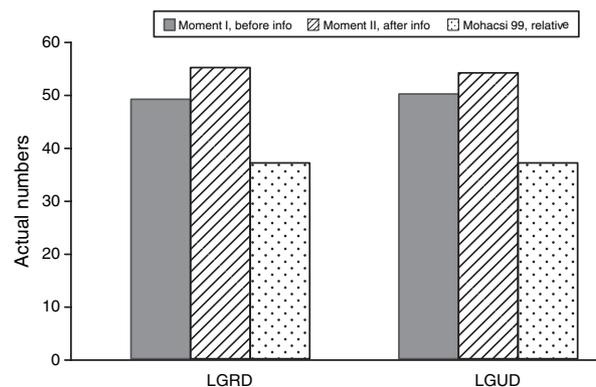


Figure 1 Statements on accepting a living genetically related donor (LGRD) or a living genetically unrelated donor (LGUD) in actual numbers, compared with the findings of Mohacsi [6] (percentages transformed into actual numbers for comparison with our findings). Moment I indicates the period before information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

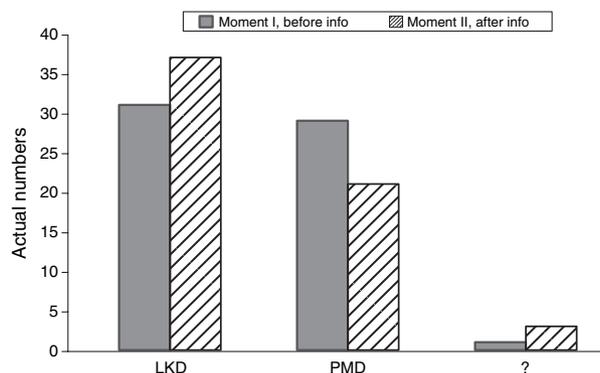


Figure 2 Results ranking exercise: LKD, living kidney donation; PMD, postmortal donation; ?, undecided. Moment I indicates the period before information was given in our study, at moment II information has been given and read (approximately 2 weeks later).

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 semistructured 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 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.

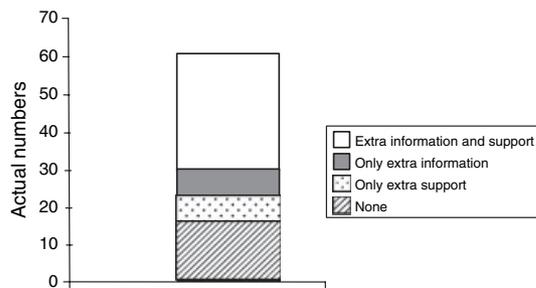


Figure 3 Need for additional information and support.

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-and-white 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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