Reviewer's report

Title: Decision making around living and deceased donor kidney transplantation: a qualitative study exploring the importance of expected relationship changes

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Reviewer: James Rodrigue

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This is an interesting qualitative examination of decision-making around live donor kidney transplantation. It is somewhat unique in that it includes interviews with former donors and both living donor transplant recipients and those recipients who decided not to pursue living donor transplantation despite having a potential donor available. The study is focused on a topic of high clinical relevance because we know relatively little about how donor-recipient relationship changes affect this decision-making process and how such relationships actually change after a living donor transplant. The qualitative methods used are standard and acceptable. The manuscript is well organized and written. The authors give good considerations to most of the major limitations.

There are several issues that warrant further consideration by the authors.

Major Compulsory Issues

1. The authors note in their Introduction that the motivations for pursuing living donor kidney transplantation (vs. deceased donor transplant) are unknown. However, there is a growing body of research on this topic, especially in the past five years or so. In fact, some of this literature comes from a group in The Netherlands. The authors should consider discussing some of these findings, especially those that are relevant to the primary topic of interest in this paper, i.e., concerns about the donor-recipient relationship.

2. Those with psychological disorders and patients with graft loss were excluded from participation. These exclusionary criteria warrant further commentary. In particular, why were these patients and donors excluded? Psychological disorders range from mild anxiety perhaps to those conditions that are quite debilitating – why would the former types be excluded? Also, patients who have lost their grafts would seem to be a clinically rich sample of patients to interview about changes in the donor-recipient relationship. For instance, one might expect more changes in the relationship if the graft was lost.

3. It is not entirely clear whether any of the donors and recipients who participated in the study were actual pairs. Clearly, this would provide the richest data since one could examine differences within the same dyad.

4. A major study limitation is the low participation rate, which the authors comment on in the Discussion. However, there is some variability in participation
rate among the three groups of participations and this warrants some comment – was this significant? How do these patient characteristics differ, if at all, from the general donor/transplant population at their institution?

5. It is difficult to know if these study findings can be generalized to other transplant programs. It is a single center study conducted in The Netherlands. Are there any unique societal, cultural, or practice issues around living donation that will make it difficult to extrapolate these findings to other centers – both in The Netherlands and beyond?

6. As noted by the authors, a primary limitation of the study is that the interviews were conducted many years after donor or transplant surgery. Of course, there is nothing that can be done about this now, but the impact of decision justification processes is likely to be substantial in this context. Did the authors examine whether those more removed from surgery had more/less perceived changes in the relationship?

7. It is surprising that 25% of donors experienced social pressure by physicians. The authors should discuss this finding in more detail since it is substantially higher than what has previously been reported in the literature.

9. Fear of donor-recipient relationship changes is noted as an impediment to pursuing living donor transplantation. The authors should discuss the clinical implications of this finding and how transplant staff can appropriately address these concerns clinically.

Level of interest: An article whose findings are important to those with closely related research interests

Quality of written English: Acceptable

Statistical review: No, the manuscript does not need to be seen by a statistician.