

# How does kidney transplantation affect the relationship between donor and recipient?

## Summary

**Background.** There is widespread use of kidneys from living donors in Norway. This results in reduced mortality and disease among recipients compared with the use of kidneys from deceased donors. However, there are numerous ethical issues connected with the use of organs from living donors. This article aims to examine how relationships between recipients and known, living donors are affected by transplantation.

**Material and method.** The article is based on a literature search in Medline.

**Results.** 32 relevant articles published between 1986 and 2010 were identified, of which 20 directly concerned the effect of transplantation on the relationship between donor and recipient. Most donors report having an improved or equally good relationship with recipients after transplantation. However, one study shows that when adolescent recipients receive a kidney from a parent, conflicts frequently arise. The material also shows that good relationships have a tendency to improve, while poor or unstable relationships more often deteriorate following transplantation.

**Interpretation.** It is important to examine the relationship between a recipient and a potential donor before transplantation to avoid relational conflicts.

*The article is based on a student assignment [1].*

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The use of living donors for patients with serious kidney disease has increased since this became standard practice in the 1960s. The first successful transplantation in Norway with a living donor was performed in 1963 (2). The use of living donors has contributed to maintaining transplantation activities, and the proportion of living donors in Norway has been almost 40 % for the most part (3). The number of persons in the kidney transplant queue has been falling in recent years. In 2009, 292 kidney transplantations were performed in Norway, and at the end of the year there were 179 patients on the waiting list (4). Anonymous donors may not be used in Norway, and there are stringent requirements regarding the health of the donor and his or her relationship with the recipient. Using kidneys from living donors compared with kidneys from deceased donors has been shown to give recipients increased survival and quality of life and to have little negative effect on the quality of life of the donor (3, 5–7). Donors state that they seldom regret their decision to be a donor, and that they would have made the same choice again had it been possible. The great majority also state that they chose to donate a kidney spontaneously and without pressure from other quarters (3, 8). The quality of life of donors who are closely related or otherwise close to the recipient proves to be generally higher than in the rest of the population, both before and after the kidney transplantation (9–13). The quality of life of recipients is poor before the transplantation because of their illness and possibly dialysis; after the transplantation it generally improves considerably (10, 11, 14). The risk of post-donation complications and death among donors is low (9, 15).

Kidney transplantation is a major intervention that involves recipient, donor, their families and close friends. This may prove challenging for the relationship between recipient

and donor. For example, conflicts may arise between a donor and a recipient who are close, even if it is not reflected in general quality of life. It is also possible that the recipient may come to feel such gratitude to the donor that this affects the relationship between them and influences the family dynamics. Third, the type of relationship between donor and recipient may be determinative for their relationship after the donation. A fourth possibility is that the donor feels a sense of unbearable guilt in the event that the transplant is rejected or the recipient dies a short time after the transplantation. We aimed to investigate how the relationship between a recipient and a known, living donor is affected by transplantation.

## Material and method

The article is based on a literature search in Medline via Ovid with a combination of the search words «living donor», «kidney transplantation», «quality of life», «family relations», «interpersonal relations», «psychol\*» and via PubMed with the combined search words «living donor», «kidney transplantation» and «quality of life». The searches were terminated on 10 February 2010. Only articles in English and the Scandinavian languages were included.

## Results

The two searches combined yielded 140 hits. 34 articles were excluded because they focused exclusively on relations prior to donation; 19 did not deal with the relationship between donor and recipient specifically; 40 did not

## Main points

- There are few studies that have investigated relations between known, living donors and recipients in kidney transplantation.
- The studies that have been made show that in the great majority of cases, the relationship between donor and recipient is unchanged or improved after the transplantation.
- It is important to evaluate the relationship between donor and recipient before transplantation, because poor relationships may have a tendency to worsen.

focus on the psychological aspects of transplantation and 17 dealt with unknown donors. Since there were few articles on the subject, none were excluded because of the age of the articles. The articles included are from 1986 to 2010. Two articles have been supplemented by findings in the reference lists (16, 17). The result was a total of 32 articles, one of them a review article (18) and the remainder original articles. 20 articles deal explicitly with the relationship between donor and recipient after transplantation. The results are summarised in table 1 (7, 11–13, 16, 17, 19–31, 32).

18 of the 20 articles revealed largely unchanged or improved relations (7, 11–13, 16, 19–29, 31, 32).

For example, most of the donors in a Norwegian study spoke of a close and stable relationship with the recipient through the transplantation process (19). Some donors explained that they thought their relationship became more dynamic and balanced as a result of the recipient's medical and psychosocial improvement.

In studies where both donors and recipients were involved, most of them stated that the transplantation process had substantially improved their relationship with one another (11, 20). However, the donors were inclined to believe that the transplantation had also had some negative effects on the relationship (11). The number who were of this opinion increased with the passage of time following donation.

A third of the respondent donors in one study who got divorced shortly after the transplantation explained that this process had been a contributory factor to the rupture (16). In another study, as many as 13 % of the donors stated that their relationship with the recipient had deteriorated since the transplantation (21).

#### *Family dynamics*

An Italian study found a positive effect on the relationship between donor and recipient, and in addition an unchanged or improved relationship between the donor and the rest of the family (12). The authors point out that a supportive family through the donation process has an effect on the donor's quality of life and closeness to the recipient. There was also a correlation between support from the family in the time prior to transplantation and improved relations with both the recipient and the family as a whole after the transplantation.

Christensen et al. showed that the family dynamics also influence the recipient's quality of life after the transplantation (22) and postulates that the importance of a supportive family circle varies depending on the source of the kidney. When the kidney was from a deceased donor, the recipient showed moderate improvement in quality of life independently of family support. There proved to be greater differences in the improvement in quality of life of patients who received

a kidney from a family member. Recipients with a supportive family circle reported better psychosocial functioning after the transplantation than recipients who had a less supportive family.

Many studies show an unchanged or improved family environment after kidney transplantation (7, 20, 23–26). Lumsdaine et al. concluded that relations with the family appeared to remain unchanged for the donors, whereas they tended more to be experienced as improved by the recipients (11). However, a Norwegian study points out that some donors had not been prepared for the fact that the donation would affect function and family dynamics as long as a year after the transplantation (19). Reimer et al. reported that 96 % of the donors would have done the same again; nevertheless, about 10 % reported that mild or moderately serious family conflicts arose after the donation (27).

#### *Exchange of gifts – gratitude*

Watanabe & Hiraga studied donation between spouses, and found stronger family ties and improved relations between husband and wife after the transplantation (23). The authors stress the advantages of not having to involve anyone other than the immediate family, thereby avoiding being indebted to anyone. This may be important in some cultures, like Japan, where the giving of gifts is linked to strong and rule-governed expectations of reciprocation.

The topic of gratitude recurs in a number of studies. In a Danish survey, some donors related that recipient and recipient's family demonstrated such gratitude that it felt like a burden (28). Three of 22 couples in a German study reported that their relationships became more difficult because of indebtedness (20).

Anthropologist Scheper-Hughes has investigated family relations, commitments and expectations of gratitude (17, 22). She gives several examples of donations where the donor-recipient relationship has become very unbalanced. For example, a donor aunt forbade her niece to get engaged to a man whom the aunt did not find worthy of the life she had saved, and a donor sister was so anxious about the kidney she had given to her brother that she did not want him to go to parties where alcohol was involved.

Gil & Lowes found that donors often tried to tone down their deed and show that they did not expect anything back (29). The recipients also felt intense gratitude, but were not obliged to show it the whole time. Many explain that this has enabled them to continue with an unchanged relationship.

#### *The importance of the roles*

Like Watanabe & Hiraga (23), Terasaki et al. stress the advantages of using the spouse as donor, and find that survival is as good as when biologically related donors are used, with the exception of donation between

HLA-identical siblings (7). At the same time this gives relational advantages (table 1).

Siblings in Franklin & Crombie mainly reported a better relationship after donation (30). A different tendency is seen in this study where young recipients receive a kidney from a parent; half of the recipients experienced conflict in the relationship in the form of an uncomfortably strong sense of gratitude or that their parents subsequently took too much control of their lives. Two of the adolescents thought that a kidney from a deceased donor would have been better. However, all donor parents in this group felt that their relationship with their children had improved, and did not regret the donation. The experience of the youngsters can be partly explained by the fact that typical parent-child conflicts are exacerbated in an intense situation of this kind.

However, in other studies with the emphasis on parent-child donation this does not appear to have had a negative effect on family dynamics or on the relationship between parent and child (24, 25, 31). In two of these studies, the children's points of view are not described (25, 31).

#### *Unsuccessful transplantation*

Few articles consider how the relationship between donor and recipient is affected in cases where the kidney is rejected. There are examples of donors and recipients who have been involved in unsuccessful transplantations being less willing than others to take part in studies (22, 23) or being excluded from them (22). A Norwegian survey shows that donors are not subject to unreasonable feelings of guilt or regret after an unsuccessful transplantation (19).

#### **Discussion**

Most studies reveal general satisfaction on the part of donor and recipient after a kidney transplantation. The studies that have considered the relationship between donor and recipient after a donation process show an equally good or improved relationship between the parties in the great majority of cases. This is consistent with a systematic review article from 2006, where a number of psychosocial aspects of living donors were reviewed (18).

One of the studies reveals nonetheless that when adolescents receive a kidney from one of their parents, conflicts frequently arise, as perceived by the recipient (30). Other studies dealing with child-parent donation in isolation report a positive outcome, but here the children are younger, or their points of view are not reported (24, 25, 31).

A number of authors point out that family dynamics have a bearing on the outcome when a known, living donor is used. Good relationships appear to tend to improve, while poor or unbalanced relationships more often deteriorate. It is therefore important that the relationship between potential donor

and recipient be examined before transplantation takes place. Perhaps greater efforts should be made to identify donor-recipient pairs with a high risk of developing a poorer relationship after the transplantation. It is essential that donor and recipient are informed that relational conflict may develop after donation, and that they have the opportunity to discuss this afterwards. Oslo University Hospital Rikshospitalet's information brochure for kidney donors takes up this subject (33).

As the data available are limited, the literature that is included does not provide adequate answers to how an unsuccessful transplantation affects a relationship.

Many will feel that it is impossible to reciprocate in purely material or financial terms for a kidney. Nevertheless, this review shows that there is a great sense of reciprocity. The donor gives away a kidney, but also gets something back: the joy that the recipient's health and quality of life improves, the recipient's gratitude, and the joy of giving. The studies that have been reviewed recount more about the donors' experiences than about the recipients'. This can give an unbalanced picture. More empirical data is needed, based on a comparison of donors' and recipients' experience of the transplantation process and how it affects their relationship. It would also be of interest to find out more about young recipients' experiences when a parent is the donor, and in general what type of relationships are most prone to be negatively affected by transplantation.

A number of studies show that, on balance, the quality of life of donors is higher than that of the general population. This is hardly a result of the donation in itself, but rather a prerequisite for it. At the same time, there is reason to believe that persons with a higher quality of life will also have the resources to maintain and nurture good relations with those around them.

There is a low response rate in some studies, and the possibility cannot be excluded that selection skewness may have resulted in a more positive picture than the reality of the situation (28, 29, 32). It may be easier to say no to participating if there have been problems along the way. In a few studies, one cannot be sure that the respondents were able to speak freely, as the interviews were carried out with both recipient and donor present at the same time (20, 24). Apart from that, the response rate was good on the whole, and anonymity well protected in the studies that were reviewed.

The studies that deal with the relationship between donor and recipient are few, limited in scope and stem from cultures that have widely different family and gift-exchange traditions. The absence of evidence of an effect must not be interpreted as evidence of the absence of the effect. The results must therefore be interpreted with caution.

## Conclusion

The literature shows that in the great majority of cases, the relationship between donor and recipient is unchanged or improved after kidney transplantation where a living, known donor is used. Use of a living donor must be viewed as advantageous; it has little effect on the donor's quality of life and substantially improves the recipient's physical and mental health. It is very important to identify donor-recipient pairs who have a high risk of developing a more complicated relationship with one another after donation, and in these cases to consider an alternative solution in order to prevent potential conflicts.

*e-tab 1 is only available on the online edition of the Journal*

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