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ORIGINAL ARTICLE

Experience of donation and quality of life in living kidney and liver donors

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Summary

Italian guidelines on living donation demand that we ascertain the donor's free and informed consent. Assessments to do so have to be conducted by an independent 'third party' who has nothing to do with the medical team treating the recipient. From February 2002 to December 2006, the Veneto Regional Authority's Third Party Commission evaluated 201 living liver and kidney donors. A sample of these were contacted after their surgery to assess their living donation experience and quality of life (QoL); 81 were eligible for the assessment and 69 (85.2%) responded. All donors involved in the study completed an anonymous document that included the SF-36 and a questionnaire on their donation experience. The majority (96%) of the sample expressed a positive global opinion of the experience. We concluded that the donation had positive effects on their QoL and that family support had a fundamental influence on their general well-being, and their psychic balance in particular. Some crucial issues emerged, however, i.e. 11% of donors judged the information received before the operation inadequate, 17% reported a subjective perception of bodily changes after the operation and 14% were concerned about their current health: these findings emphasize the importance of informing potential donors thoroughly before they submit to surgery.

Introduction

In recent years, the practice of living organ donation has affected considerable numbers of people in Italy; between 2001 and 2006, 741 kidney and 178 liver transplants from living donors were performed in this country (Italian National Transplant Center data).

There are numerous reasons for this growing phenomenon, the most important being the expanding gap between the availability of deceased donor organs and the demand for transplants, with consequently longer and longer waiting lists for transplant candidates. In fact, despite repeated campaigns to promote transplantation, there is a high refusal rate due, for instance, to a widespread misunderstanding of the religious precepts concerning transplantation, to fear and prejudice, and to complex social, cultural and personal attitudes in both the general population and the medical community [1,2].

Italian guidelines establish that living donations can only come from emotionally related donors and at the explicit, motivated and freely forthcoming request of the donor and recipient involved, after both parties have been properly and thoroughly informed about the potential risks to the donor.

So, in addition to the clinical and immunological assessments and a psychological exam, living donors are also assessed as concerns their reasons for donating, their understanding of the potential risks and of the real likelihood of the transplant being successful in terms of graft and patient survival, the bond of affection between the donor and *recipient, and the sincerity of their free and informed consent.*

For this purpose, in compliance with national guidelines on kidney and liver transplantation from living donors, the Veneto Regional Authority appointed a 'Third-Party Commission' in February 2002, comprising a specialist in forensic medicine, a clinical psychologist and a bio-ethicist, who examine the medical records and interview potential donors, then express a joint opinion.

Between 20/02/2002 and 31/12/2006 this commission assessed 201 potential kidney or liver donors.

From potential donors' reports and an analysis of the literature, it is clear that the decision to donate stems from the desire to ease a loved one's suffering and improve their quality of life (QoL), which is severely affected by their disease. This decision generally emerges in a highly stressful setting, in situations of physical and psychological suffering shared by the whole family [3–7].

In these conditions, the relative's decision to donate takes on the meaning of an active gesture, a means of release from anxiety and suffering [8]. In fact, the donation can put an end to a period of anxiously waiting for a suitable deceased donor organ, or even prevent the physical and psychological suffering that life on the waiting list invariably entails.

Generally speaking, potential donors appear to be strongly motivated in the decisional process; they show no signs of hesitation or concern about their future state of health [4]. If they show fear, this is only for the recipient.

It is generally agreed that living organ donation is usually a positive experience for the donors: it gives them a profound sense of satisfaction for helping to improve the recipient's QoL [4,8–10]. Many authors report that donors experience no long-term negative consequences as regards their own health, and they score higher than the general population in tests measuring perceived QoL [11–15].

It is rare for donors to regret their decision to donate [11,16–18] and in the majority of cases their gesture seems to have a positive effect both on the donor–recipient relationship and on the donor's self-esteem [9,11,19–23].

The incidence of surgical and medical complications in donors is very low [12,24–27]. Almost all of them recover physically within 3–6 months and can return to the jobs they had before the operation [24,28].

The literature highlights a few crucial issues, however: a small proportion of donors claim they were under strong pressure from their families to consent to the donation [5,7]; the pretransplant assessment is sometimes perceived as being highly stressful [4]; some donors report feeling abandoned by the hospital staff immediately after the donation [4]; others report having experienced economical and professional difficulties after the operation [29,30]; there is also evidence of psychosomatic disorders [18] and possible psychiatric problems in living liver donors [31].

Italian studies on living donation have confirmed the absence of postoperative mortality or morbidity in living kidney donors [32] and a low incidence of surgical and medical complications in living liver donors [33,34].

As no studies have investigated the psychological aspects and the relationship between psychological and physical aspects in Italian donors, we planned to verify whether the findings in the international literature were consistent with our sample.

Materials and methods

The aim of our study was to assess the QoL perceived by living organ donors, particularly as concerns their physical functioning, psychological well-being and any impact of their donation on their professional activities and financial conditions.

We also wanted to investigate any correlation existing between the donors' perceived QoL and a number of factors, i.e. their reasons for making the donation, their experience regarding the assessment procedure, their postoperative recovery, their perception of the adequacy/inadequacy of their medical follow-up after the donation, the consistency between their expectations and the actual physical consequences of the donation, the social and family support they received, the effect of the donation in terms of the recipient's well-being.

The study involved living kidney and liver donors assessed by the Veneto Regional Authority's third-party commission from 20/02/2002 to 06/07/2004.

During this interval, the commission conducted assessments on 120 potential kidney and liver donors coming from 14 different Transplant Centers in Northern Italy. A mean 14 months (range: 3–31) afterwards, we contacted these living donation candidates: of the 120 subjects originally assessed, 97 had already donated a kidney or liver lobe at the time of our investigation and we were able to contact 81 of them; the remainder were unavailable (15) or had died of causes unrelated to the donation (1).

The donor's willingness to take part in our study was ascertained by means of a preliminary telephone call: only one of the 81 subjects contacted refused.

The 80 subjects thus taking part in the study were sent an envelope containing:

a letter of introduction;

1 An information sheet concerning their privacy rights and a form requesting consent to treat their personal data;

2 The SF-36 self rating scale for assessing QoL, a short-form health survey with 36 items that yields an 8-scale profile of functional health and well-being, as well as psychometrically based physical and mental health summary measures and a preference-based health utility index. The

eight scales evaluate the following areas: 1. Physical functioning; 2. Role limitation physical; 3. Bodily pain; 4. General health; 5. Vitality; 6. Social functioning; 7. Role limitation emotional; 8. Mental health;

3 A self-administered questionnaire on the donation experience investigating the following areas: reasons for the donation, the donor's experience concerning the assessment procedure, postoperative course, perception of the adequacy/inadequacy of the medical follow-up after the donation, consistency between expectations and actual physical consequences of the donation, social and emotional atmosphere, effectiveness of the donation in terms of the recipient's well-being;

4 A stamped and addressed envelope for returning the documents.

The Padua General Hospital Ethical Committee for Clinical Experimentation (IRB) assessed the project and approved the study.

Pearson's chi-squared test and Student's *t*-test were used for the statistical data analysis.

Results

Sixty-nine of the 80 questionnaires were returned (response rate: 86%). Of these 69 subjects, 59 had donated a kidney and 10 a liver lobe (corresponding to a response rate of 83% of all liver donors contacted); 42 were females and 27 males, and they were a mean 51.5 years old (median = 52.5, SD = 10.8; range: 27–77 years old).

The relationship between donor and recipient involved parents donating to their children (55%), donations between brothers (19%), between husband and wife (16%), children donating to parents (9%), and one case of an uncle donating to a nephew.

In the majority of cases (62%), the donor was the only relative to volunteer for organ donation; in the remainder, the medical team had also considered other relatives who had come forward, but subsequently judged them unsuitable as donors for clinical reasons, or because of a weaker biological compatibility with the recipient.

The mean time elapsing between donating and answering the questionnaire was 16.2 months (range: 5–30 months).

From information provided by the transplant centers, we established that the outcome of the donation was positive in 65 cases and negative in 4. There were no complications in 57 recipients, while 3 had complications and 4 suffered from organ rejection leading to the failure of the transplant. Complications in donors were reported in two cases.

Analysis of the answers in the questionnaire on the experience of donation.

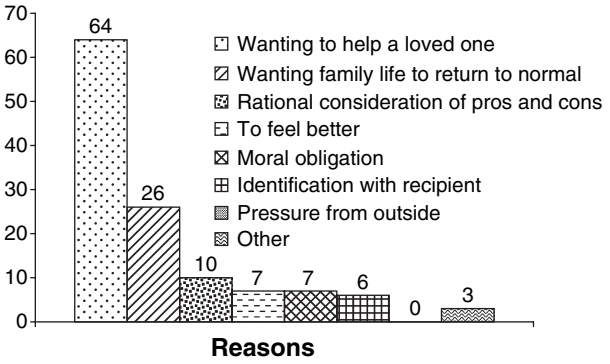

Figure 1 Reasons for decision to donate. The sum of the answers is more than 100% because this question could be given several answers.

The donation had been the donor's idea in 80% of cases, suggested by the physician taking care of the recipient in 16% and by the candidate recipient in 4%. For the majority of donors (64/69), the reason for the donation was 'to help a loved one who was suffering' (Fig. 1). Prior to surgery, the donors tended not to change their minds about the donation and its outcome, and they reported experiencing relatively little anxiety or concern. Their decision to donate was perceived as having been made freely and independently, under no pressure from the recipient. The recipient's reaction ranged from contentment and no attempt to influence the donor's decision (65%) to worrying about the risks related to the donation (25%), to an initial opposition to the relative's generous gesture (9%).

A month after surgery, most donors reported various health problems: medical or surgical complications (6%), pain (24%), difficulty in activities of daily living (32%), and in returning to work (24%). The intensity of these disorders was judged to be mild or moderate in almost all cases (90%), and lasted less than 30 days in 57%, and longer in the remainder of the sample.

It is worth emphasizing that, after the operation, their health became a source of worry for 14% of the donors, who particularly feared becoming ill, losing their remaining kidney, or being unable to take certain types of medication.

Seventeen per cent of the donors felt their body had changed after the donation and reported a very obvious scar and symptoms such as weight gain, distended abdomen, weaker physical resistance, insensitivity in the area of the operation and an increase in diuresis. The majority (81%) were convinced there would be no long-term consequences for their state of health, however, while 3% thought there would be positive effects, and 6% feared negative repercussions.

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The medical follow-up after the donation was judged very positively by all but 3% of the donors. As for the information received before the operation on the physical consequences of the surgery, 89% of the donors expressed a positive opinion, but 11% said this information had been more or less inadequate and 2 donors even claimed that they had received no information from the doctors.

The most common sentiment in the postoperative phase was of happiness for the successful outcome of the transplant and pride in having helped a loved one. The social reactions to their donation were mainly of respect and admiration, followed by gratitude, but 10% of the donors experienced indifference or no particular reaction.

Forty-one per cent of the donors felt their donation had positively influenced their donor–recipient relationship, by establishing a greater emotional intimacy between the two parties in this difficult experience, prompting the recipient's gratitude and improving the donor's peace of mind; 57% experienced no change in their relationship and one person reported a deterioration.

Relations with other members of the family did not change for most of the donors (82%), while 17% felt that family relations had been reinforced by sharing the physical and psychological suffering before the transplant, the stress of waiting and the satisfaction for the recipient's psychological and physical recovery.

When asked to express a global opinion on their donation, 96% gave a positive opinion, while 4% said they regretted their decision to donate.

Analysis of the results concerning QoL (comparing the SF-36 with the questionnaire on donation).

As in most studies in the literature, the donors in our sample also scored significantly higher for QoL than the normative data for the general population [35]. To be specific, donors obtained significantly higher scores for six of the eight scales in the SF36, meaning they report a significantly better state of health than the general population (Fig. 2).

The quality of family relations had an important influence on the donor's general well-being and psycho-physical balance. In fact, donors who experienced an improvement in their family relations had higher scores on almost all the scales, and the difference was statistically significant for the score for Mental Health (Fig. 3). In most cases, the improvement in family relations was also accompanied by a positive change in the relationship between donor and recipient.

Postoperative disorders influenced the donor's QoL (Fig. 4): donors who suffered from moderate-severe disorders (30 donors) had significantly lower scores in six of the SF36 scales than those who reported only mild disorders after their operation (18 donors).

	Our sample	Normative sample	*P*
	Mean ± S.D.	Mean ± S.D.	
PF	**92.69 ± 10.01**	**88.69 ± 14.9**	**0.03**
RP	80.51 ± 30.19	81.71 ± 30.27	0.76
BP	**82.66 ± 21.07**	**75.26 ± 24.07**	**0.02**
GH	**83.23 ± 12.10**	**66.45 ± 17.49**	**<0.0001**
VT	**69.24 ± 17.66**	**63.36 ± 18.19**	**0.01**
SF	**85.98 ± 14.95**	**78.37 ± 20.38**	**0.004**
RS	86.76 ± 27.10	79.2 ± 33.58	0.08
MH	**78.94 ± 16.53**	**67.76 ± 18.18**	**<0.0001**

Figure 2 Descriptive statistics of SF36: PF, physical functioning; VT, vitality; RP, role limitation physical; SF, social functioning; BP, bodily pain; RE role limitation emotional; GH, general health; MH, mental health.

	Mean ± S.D.		*P*
	No change	Changed	
PF	92.17 ± 10.58	95.83 ± 5.15	0.25
RP	78.70 ± 32.36	85.42 ± 19.82	0.49
BP	80.81 ± 22.22	89.50 ± 13.78	0.20
GH	82 ± 12.73	87.92 ± 7.76	0.13
VT	67.45 ± 17.69	76.25 ± 16.80	0.12
SF	84.20 ± 15.72	92.71 ± 8.36	0.07
RE	86.42 ± 28.61	86.11 ± 22.28	0.97
MH	**76.11 ± 16.72**	**90 ± 10.02**	**0.01**

Figure 3 Differences in SF36 scores between donors whose relationship with their families changed and those who experienced no such change in their family relationships relatives after the donation.

No unequivocal trends emerged from the comparison between kidney donors and liver donors to seek any significant differences in terms of QoL or the severity of any donation-related disorders (Fig. 5). Kidney donors obtained higher scores than liver donors for some scales and vice versa for others, with statistically significant differences only on two scales, i.e. Social-Functioning and Role limitation-Emotional, where liver donors obtained lower scores. The correlation between the type of organ donated and the severity of the complications reported by the donor was not statistically significant.

We must therefore conclude that, although it is more complex than living donor kidney transplantation, liver

	Mean ± S.D.		*P*
	Severe-mod.	Mild	
PF	89.83 ± 11.18	95 ± 9.68	0.12
RP	**65 ± 36.91**	**95.83 ± 12.86**	**0**
BP	**75.3 ± 25.23**	**92.44 ± 13.01**	**0.01**
GH	80.9 ± 12.67	83.53 ± 13.94	0.51
VT	**61.67 ± 14.58**	**75.59 ± 17.40**	**0.01**
SF	**81.25 ± 16.66**	**92.19 ± 11.06**	**0.02**
RE	**74.44 ± 34.67**	**96.30 ± 10.78**	**0.01**
MH	**72.53 ± 15.61**	**85.61 ± 16.35**	**0.01**

Figure 4 Difference in SF36 scores between donors reporting severe-moderate disorders after surgery and those reporting mild disorders.

	Mean ± S.D.		*P*
	Kidney	Liver	
PF	92.46 ± 10.57	93.33 ± 6.12	0.81
RP	82.46 ± 29.11	70 ± 36.89	0.23
BP	83.43 ± 21.36	79.2 ± 21	0.56
GH	82.77 ± 11.91	85.67 ± 14.26	0.51
VT	69.02 ± 17.01	71.11 ± 23.15	0.74
SF	**87.72 ± 13.46**	**73.44 ± 20.53**	**0.01**
RE	**91.81 ± 21.16**	**60 ± 40.97**	**0**
MH	79.34 ± 16.08	76.5 ± 20.48	0.62

Figure 5 Difference in SF36 scores between kidney donors and liver donors.

donation did not coincide with more severe complications for the donors in our sample. Liver donors do, however, have more difficulty than kidney donors in returning to work and other activities as a result of emotional problems, and their normal social life suffers more from the effects of their physical problems and emotional state.

Analyzing studies in the literature shows that a parent's decision to donate an organ to a son or daughter is seen as a natural gesture associated with giving birth and protecting one's offspring, while brothers and sisters seem to be motivated mainly by identification with the recipient. Spouses choose to donate an organ to their partner with a view to improving the couple's QoL.

In our sample too, there was a statistically significant relationship between the reason for donating and the degree of kinship. For almost all donors (64/69), the main reason for donating was 'to help a loved one in need', so we also considered the second reason they gave: 46% of parents donated an organ to a son or daughter so that the family could return to its former way of life, and 21.43% said their decision was based on a rational calculation of the pros and cons.

Identification with the recipient was the reason most often mentioned by brothers and sisters (38%), while for the majority of sons and daughters (71%) or spouses (50%) the decision to donate also stemmed from the conviction that they would benefit personally from the resulting improvement in the recipient's health. The one uncle in our sample who donated to a nephew said this was not a matter of free choice, but unavoidable, something that had to be done.

Finally, we investigated whether family support before the donation influenced the post-transplant relationship between the donor and other members of the family. All the donors who reported an improvement in their relations with both the recipient and the other members of the family claimed that they had received support from their relatives in the period preceding the transplant: this confirms the fundamental role of the family at all stages of the donation process, to support and assist donors in their decision before the operation and to follow up their convalescence and relieve the stress unavoidably related with the donation.

Discussion

Our study confirmed that living organ donation is typically a positive experience: the donors in our sample scored significantly higher for QoL than the general population. In particular, the increase in self esteem, the family's and society's acknowledgement of their generous gesture, the sense of pride for having helped a loved one, the happiness in seeing the recipient's recovery are all factors that contribute to a greater psychological well-being and consequently better QoL. Family support has a fundamental influence on the donor's general well-being, particularly their psychic balance, and this condition of general good health – in its widest sense – also has a positive fallout on the donor's other relationships. A better relationship with the recipient does not seem to influence the donor's QoL.

Future investigations should compare the donor's QoL before and after donation to see whether donors – being chosen for their healthy condition – have a higher QoL than the general population even before the donation.

Our data confirm that the decision to donate is pondered at length by the family before it is explicitly formulated and that it stems from the desire to prevent a loved

one from suffering. Unlike other reports in the literature, however, our results showed that the benefit to the donor deriving from the improvement in the recipient's health is one of the most common reasons for donating, irrespective of the degree of kinship linking the donor to the recipient. We can thus confirm Shanteau's theory [36] that, alongside the selfless reasons there are also selfish reasons involved.

We can also confirm the findings of other authors [4] that donors have a tendency, before the transplant, to minimize the likelihood of complications and to put the recipient's health before their own well-being: this seems to be a defense mechanism adopted by donors to cope with their fears of loss of a part of their bodily self.

Contrary to expectations, there was little or no change in the relationship between the donor and recipient, or between the donor and other members of the family after the transplant.

Some donors' perceptions of bodily changes after the operation warrant further investigation. We might wonder whether these are genuine physical changes or a case of some donors failing to cope adequately with the pain of losing a part of the bodily self, leading to a modification of their perception of their body image. Our study also pointed to a few other crucial issues. First of all, there is the difficulty some donors encounter in having genuine freedom of choice, uninfluenced by the expectations of recipients, relatives or society at large. Candidate donors must have the chance to see an independent consultant, with whom they can feel free to express themselves, their fears and their state of mind vis-à-vis the donation.

Another issue concerns the impression that information received before the transplant was inadequate, as claimed by 11% of the donors in our sample. It may be necessary to provide more information, or more effective information, though the donors' impressions on this matter may not coincide with the truth. Defense mechanisms of denial and minimization may be involved, making it advisable to fine adjust the strategies for evaluating a donor's understanding and to plan a follow-up that guarantees their long-term monitoring. For example, physicians should use simple words to explain the risks for donors and the real benefits for recipients, including the possibility of the recipient's body rejecting the organ or other post-transplant problems. They should also ask donors to explain what they have understood from the information they have been given. Providing written material also helps the donor to remember what they have been told.

This latter results must be considered when introducing 'cross-over' living donation as already introduced in other countries.

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Authorship

AF designed the study, performed the study, analyzed the data, and wrote the paper. RP, CR, PB, ME designed the study, analyzed the data. SP, PF, VB designed the study, performed the study, collected the data, analyzed the data, and wrote the paper. GR designed the study and analyzed the data.

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