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Psychosocial impact of living-related kidney transplantation on donors and partners

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Abstract Living-related kidney transplantation (LRKT) is an option for children with end-stage renal failure. In addition to medical concerns, there is uncertainty about the psychological impact of living-related donation on parent donors and families. A survey was conducted on the decision making process and medical and psychosocial consequences of LRKT. Between 1992 and 1999, 20 parents donated a kidney for their child. A questionnaire including 24 items was sent to parent donors and their partners. Nineteen parents and partners responded; the median time after LRKT was 3 years. Donors and partners reported an independent decision making process with no significant influence of partners, relatives, or hospital staff. Partners were more concerned about medical problems than donors themselves ($P < 0.02$). Donors and partners cited no medical problems except sustained pain. Both reported an improved personal relationship towards the transplanted child. Donors and partners also cited an improved personal relationship. The vast majority (18/19) of couples still supported the decision for organ donation. In conclusion, there was a high degree of satisfaction with the decision making process in LRKT. The great majority of donors and partners did not report negative medical or psychological consequences. The relationship between donor, partner, and recipient child improved after LRKT.

Keywords Living-related kidney transplantation · Child · Parent · Partner · Psychosocial · Donor

Introduction

Renal transplantation is the treatment of choice for pediatric patients with end-stage renal failure. Living-related kidney transplantation (LRKT) has become an important therapeutic option due to shortage of cadaveric donors and increasingly long waiting times. Therefore, LRKT was introduced in our unit in 1992. A previous report focused on the medical data of pediatric recipients and adult donors [1]. In addition to concerns regarding medical consequences of LRKT, there is some uncertainty about the emotional and psychological impact of living-related organ donation on parent donors and families. To date, this issue has only occasionally been studied [2, 3, 4, 5]. In particular, there is a lack of information on the impact of LRKT on the donors' partners and to what extent donors and their partners agree on living donation. To obtain more information about the psychosocial impact of LRKT, a study was conducted among the parent donors and their partners, focusing on the decision making process and the medical and psychosocial consequences of LRKT.

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Materials and methods

In our unit, the process towards renal transplantation in children with progressive chronic renal failure follows a strict protocol, including extensive medical and psychosocial evaluation. Parents and (older) patients are repeatedly informed on the availability of both living-related and cadaveric renal transplantation. Oral information is provided by nephrologists, renal nurses, social workers, and psychiatrists. In addition, written information ("handbook for parents and patients") and public meetings for parents and (older patients) are offered. There is also an independent parent group.

From the beginning of the LRKT program, it has been the declared intention of our unit to present the potential advantages and disadvantages of both procedures in a neutral and informative way. The assessment and consent process prior to LRKT takes on average 6 months. The psychiatrist undertakes a formal evaluation of

the family dynamics including siblings; a “positive” report is a prerequisite for proceeding with LRKT. The recipient child is actively involved in the decision and consent process from the age of 7–10 years onwards. To date, three adolescent boys have refused an LRKT and opted for cadaveric transplantation.

The medical and most of the social costs, including some reimbursement of the lost salary of the donor, are covered by the patient’s insurance, which is compulsory for all residents of Switzerland. Since the introduction of the Swiss Living Kidney Donor Registry in 1993, all donors have been followed annually, including clinical examination, analysis of renal function, and urinary testing [6].

Between 1992 and 2003, 67 pediatric patients underwent renal transplantation at our unit; 33 (49%) were LRKT. This study was part of the regular audit and quality assessment program of the unit, and encompassed the same population as in the first study [1]. Ethical committee approval was given. Between 1992 and 1999, 20 parents donated a kidney: There were 12 mothers and 8 fathers (age range 31–45 years), and the median age of the recipients was 10 years (range 2–18 years) [1]. All families were from Switzerland and spoke a Swiss national language; thus, all conversations took place without an interpreter. The donors underwent the traditional lumbar operation for nephrectomy, and all returned to normal life within 2 months.

All 20 LRKT recipients had their first transplant; 11 LRKT were pre-emptive whereas 9 patients had undergone dialysis for a median period of 0.8 years (range 0.5–5.6 years). Eighteen patients had a functioning graft with a median glomerular filtration rate of 61 ml/min per 1.73 m² (range 33–83), as assessed either by the Schwartz-formula or Cr-EDTA clearance. One patient lost his graft for medical reasons; he subsequently underwent a successful cadaveric retransplantation. A further patient died of acute decompensation of an associated cardiac disease with a functioning graft 4 months after LRKT [1]. Two patients had cytomegalovirus disease early after transplantation and 1 patient suffered a seizure of unknown cause with full recovery in all.

An anonymous survey was sent to the 20 parent donors and their partners, respectively; the median time after LRKT was 3 years (range 1.5–8.3 years). All parents were married and with two exceptions (one stepfather and one stepmother) were also the biological parents. The standardized self-developed questionnaire included 24 items using a five-point scale (1 very true, 2 true, 3 neutral, 4 not true, 5 absolutely not true) with 9 questions on the decision making process and 15 questions on medical and psychosocial consequences of LRKT. In addition, parents and donors were asked to make “free comments.” The median score of each answer in each group was determined. Nineteen (95%) parents (11 mothers, 8 fathers) and their partners responded. One parent donor, the mother whose child had died after LRKT, had left the country and could not be contacted. Differences in corresponding questions were analyzed by Mann-Whitney U-test with a significance level of *P* < 0.05.

Results

Decision making process

The donors and their partners reported an independent decision and no significant influence by partners, relatives, or hospital staff to donate a kidney (Table 1). Some encouragement, but no enforcement, by the hospital staff was stated. Both the available time period for the decision process and the information provided were regarded as sufficient. Partners were significantly more concerned about the medical problems in the donor following the surgical procedure than the donors themselves (item 8 *P* < 0.02).

Table 1 Decision making process: questions 1–9. Results are given as score of the five-point scale (median score in **bold**)

Questions (D: donor, P: partner)	Donors					Partners				
	Very true	2	3	4	Absolutely not true	Very true	2	3	4	Absolutely not true
1 D: Were you independent in your decision to donate a kidney P: Were medical reasons of your own the reason that your partner donated the kidney P: Were other reasons responsible	9	3	3	1	3	9	3	0	1	6
2 Were you influenced by your partner	1	1	3	1	13	3	1	1	2	12
3 Were you influenced by relatives	1	1	0	1	16	1	0	2	1	16
4 D: Were you encouraged by hospital staff P: Was your partner encouraged by the hospital staff	1	3	5	3	7	0	1	8	5	5
5 Were you enforced by hospital staff	0	1	1	0	17	0	0	2	0	17
6 Did you have enough time for the decision	14	2	2	1	0	11	8	0	0	0
7 Were you happy with the medical information given	8	5	4	2	0	8	6	3	2	0
8 D: Were you concerned about the medical consequences for yourself * P: Were you concerned about the medical consequences for your partner*	0	2	2	5	10*	2	3	6*	5	3
9 Did you have the opportunity to talk with someone from the hospital staff about your feelings/sorrows/expectations	2	8	4	0	5	3	5	7	0	4

* Significant differences in corresponding questions (*P* < 0.02)

Table 2 Consequences of organ donation: questions 10–24. Results are given as score of five-point scale (median score in **bold**)

Questions (D: donor, P: partner)	Donors					Partners				
	Very true					Absolutely not true				
	1	2	3	4	5	1	2	3	4	5
10	3	3	3	2	8	2	0	3	3	11
11	0	1	3	4	11	0	2	2	2	13
12	11	7	1	0	0	9	8	2	0	0
13	3	1	2	3	10	2	2	8	3	4
14	0	1	3	2	13	1	0	3	4	11
15	0	0	1	1	17	1	1	2	0	15
16	0	1	0	3	15	—	—	—	—	—
17	0	1	1	3	14	2	2	1	3	11
18	1	6	4*	4	4	5	5*	2	3	4
19	6	7	6	0	0	7	5	7	0	0
20	6	5	5	3	0	9	5	4	1	0
21	4	3	10	2	0	7	1	8	3	0
22	18	1	0	0	0	18	0	1	0	0
23	0	1	0	0	18	0	1	1	0	17
24	7	5	4	0	3	6	4	5	1	3

* Significant differences in corresponding questions ($P < 0.03$)

Consequences of organ donation

All donors were in good health and neither donors nor partners complained of medical problems; 9 donors and 4 partners complained that postoperative pain was sustained for several weeks (Table 2). The partners showed more concern about the donor's kidney function than the donors themselves. Financial or work-related problems were not reported. Both donors and partners reported an improved personal relationship towards the transplanted child, and the partners (but not the donors themselves) thought that the donor parent and the recipient child were more close after the operation (item 18 $P < 0.03$). Both donors and partners also stated an improvement in their own personal relationship. The vast majority of couples (18/19) still supported the decision for organ donation ("very true"=1). Only 1 donor and 2 partners regretted the decision to some extent, but gave no further explanation. Despite these positive comments on LRKT, many donors and partners would have preferred cadaveric transplantation if the resources had been better.

Free comments

Most donors and partners gave either no ($n = 14$) or a positive comment ($n = 2$). Two donors and their partners expressed a desire for intensified psychological support by the renal team, especially at the time of transplantation.

Discussion

LRKT is a medically safe procedure for the donor. Morbidity and mortality are low in the postoperative period for living kidney donors [7, 8, 9, 10]. In addition, if only healthy persons are accepted for donation, donors living with one kidney have no significant long-term risk of proteinuria, hypertension, or renal insufficiency [8, 9, 10, 11]. This positive outlook is highlighted by the fact that living kidney donors obtain health insurance at standard rates [12]. There is, however, considerable uncertainty about the emotional and psychological impact of living-related organ donation on donors and families. This issue has only occasionally been studied in pediatric LRKT where the donor is generally a parent [2, 3, 4, 5].

This survey on the psychosocial impact of living-related pediatric kidney transplantation on parent donors and their partners presents evidence that LRKT had no adverse psychological consequences for most donors and their partners. This is important information for counseling families, parents, and spouses. Although the study number was small, the almost-complete response rate (95%) enhanced the validity of our results and conclusions. There was a high degree of satisfaction with the decision making process, although better instruction on the short-term physical burden was needed. The medical and psychosocial outcome was beneficial, but around the

time of transplantation more psychological support should be provided.

There is some agreement of our results with the few published data [2, 3, 4, 5]. A study from Sweden showed that (1) the partners expressed more anxiety and stress before the LRKT than the donors, (2) the surgical procedure was more painful than expected, (3) many parents reported an improved relationship with the recipient child, and (4) neither donors nor partners regretted the donation [2]. There were, however, important methodological differences. In Sweden, LRKT is actively encouraged by the medical team. As a consequence, about two-thirds of pediatric renal transplantations are living related, and almost all children with a medically suitable parent donor finally undergo LRKT [2]. Thus, the lack of alternatives to LRKT may have imposed a bias and enforcement not only to the medical team, but also to the donors, influencing the psychosocial interpretation and consequences. In fact, there were a few donors who did not feel free to donate their kidney [2, 3]. A study from Poland reported that parental candidates for donation were strongly motivated, in particular by the wish that their child would not differ from healthy children in appearance and life style. Major concern was stated as both potential donor and recipient were anxious to undergo LRKT due to a close emotional relationship. In addition, overprotective relationships were noted [4]. There was, however, a major lack of medical and procedure-related knowledge of the potential donors and their partners. Only 22% of the relatives were provided with information by the physicians and the great majority had obtained their knowledge from other sources, e.g., mass media and other patients. A further study on the relationship between parent donors and pediatric recipients showed that LRKT had apparently no detrimental effect on family dynamics [5].

Our data reflect a more neutral and informative approach towards LRKT as probably practiced by many pediatric centers. The medical benefits must be weighed against the potential risks. LRKT offers several advantages, i.e., better planning, increased availability of pre-emptive transplantation, and improved short- and mid-term graft survival [1, 13, 14]. In addition, LRKT improves the relationship of donor, partner, and the recipient child. Yet, not all donor parents feel free to donate a kidney [2, 3], and there are specific concerns on limited organ half-life [14]. Up to one-third of children with end-stage renal disease suffer from a hereditary disease with often more than one child affected within a family. There is a risk that not all affected siblings can benefit from LRKT, either for medical reasons (e.g., blood group incompatibility) or the fact that only one suitable donor is available within a family. The issue of just allocation of LRKT under these circumstances is unsolved.

Two practical issues deserve further attention. Firstly, some donors and partners have complained of sustained pain after surgery, i.e., nephrectomy by lumbotomy. In 2000, transperitoneal hand-assisted laparoscopic nephrectomy was introduced for donors. Preliminary comments from recent donors and their partners suggest that

the extent and duration of pain has diminished. Thus, laparoscopic procedure and adequate postoperative pain control should be performed. Secondly, some donors and partners expressed a wish for more active psychosocial support around the time of transplantation. In addition, they expect all team members to show more attention, respect, and appreciation towards the donor.

The quality of life of living-related donors has been more extensively studied among adult donors and adult recipients. A study on adult LRKT in Switzerland assessing the decision process and medical and psychological consequences among donors revealed similar results as in our survey [15]. All (98%) remained in favor of LRKT, but unexpected pain, insufficient attention post-operatively, and some slight pressure from the family were mentioned. Comparable data were reported from centers in the United States [16] and Japan [17]. The great majority of donors had an excellent quality of life, but a few (<5%) did regret their decision to donate a kidney. Identified risk factors for poor psychosocial outcome were relatives other than first degree and donors whose recipient died within 1 year of LRKT; these donors were more likely to say they would not donate again [16]. In our study, it would have been important to know the feelings of the donor mother and the father of the child who had died after LRKT, but they could not be traced. The donor father and the mother of the patient with graft failure did not regret their decision.

Socioeconomic factors limit the rate of living-related kidney donation to children. Single parenthood, economic disadvantage, and co-morbid conditions among socially deprived parents were major obstacles towards LRKT [18, 19]. Also financial burden and unemployment were not uncommon among living donors [3, 17]. The financial aspects of having time off work and support from employers and insurances are crucial for LRKT. The favorable circumstances, however, in our country where the insurance covers not only all medical costs, but also reimburses a substantial part of the missed salary of the donor, are not prevalent in all countries.

In summary, there was a high degree of satisfaction with the decision making process in LRKT. The great majority of donors and their partners did not report negative medical or psychosocial consequences of LRKT, although there was a wish for intensified psychological support around the time of transplantation. Therefore, in addition to good medical outcome, LRKT also appears to have positive psychosocial consequences.

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