Psychological evaluation of living liver donors – a single centre experience

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Abstract

The psychological evaluation of living liver donors is a substantial part of the preoperative evaluation of donors in many transplantation centres around the globe and aims at securing decision autonomy and informed consent, verifying the psychological stability of the donor and ruling out psychosocial risks. The aims of this paper are to present a short overview of the current state of the psychosocial evaluation of living donors based on the existing literature and to discuss our centre's experience in the psychological evaluation of donors, the lessons we have learned in the past 10 years and an agenda for the future evaluation of donors and research. (Acta gastroenterol. belg., **2010**, 73, **383-388**).

Key words : LDLT, psychosocial evaluation, psychological evaluation, living donation, transplantation.

Introduction - Background

The psychological evaluation of the donor before living donor liver transplantation (LDLT) has been a substantial part of the donor's preoperative evaluation in many transplantation centres around the globe since the initiation of LDLTs in 1989 (1). Initially, there were no specific guidelines for the psychosocial assessment of living liver donors, and the evaluation was primarily based on prior experience of evaluating living kidney donors and on clinical practice. A consensus existed in the literature that the main issues to be evaluated concern the voluntary character of the decision, freedom from coercion, the psychological stability of the donor and obtaining informed consent and several factors have been pointed out for inclusion in the psychosocial evaluation, such as ambivalence, guilt, depression, substance abuse, vulnerability to psychological pressure, donor-recipient relationship, potential benefits and potential risks for the donor, capability of making a decision, competence to consent (2-5).

The person conducting the evaluation should be a trained transplant psychiatrist, a psychologist, a trained social worker or a psychiatric nurse taking the role of a donor advocate. For very specific clinical questions, a detailed psychiatric or psychological assessment would be indicated (3,6,7).

At least in the scientific community, there has been a consensus that the psychosocial evaluation of donors should be a part of the donor evaluation in all LDLT programs. In some countries, e.g., Germany, the evaluation of the voluntary participation and psychological stability of the donor is regulated legally by transplantation law. Based on the existing literature, the psychosocial evaluation seems to be a substantial part of many transplantation centres in other countries (e.g., in the USA, psychosocial evaluation has recently been mandated as a necessary practice for Medicare- and Medicaid-certified transplant centres). Yet, there are several countries for which no reports exist in the literature regarding the practice of psychological evaluation of donors. In addition, criticism has also been levelled against the lack of any standardised psychosocial evaluation, resulting in variation in the evaluation processes of different programmes (8,9).

Over time, the criteria regarding motivation, decision-making, risk assessment and psychological stability have been refined and explained in more detail, as have the conflicts and concerns arising in evaluating such concepts as informed consent (10,11). In 2002, the New York State Committee published a lengthy report on Quality Improvement in Living Liver Donation depicting in detail all LDLT-related pre- and postoperative aspects, including donor and recipient aspects, the impact of LDLT on the donor's family, the characteristics of the evaluating team and guidelines for the psychosocial evaluation and the evaluation of the decision autonomy and informed consent of the donor (12). Our team also published several articles concerning the motivation and decision-making of the donor, the donor-recipient relationship, as well as risk and protective factors to be considered in the evaluation (13-15). Furthermore, review studies have been published regarding the psychosocial factors to be evaluated in living donors and detailed guidelines for the psychosocial evaluation of living kidney donors, which could, to a large extent, also be applied to the evaluation of liver donors (8,16-19). All of these recent developments have added to the improvement of the psychosocial evaluation process and to its spreading to more transplantation centres.

The explicit percentages of donors not accepted for donation due to psychosocial reasons, as reported by several studies, strengthen the notion that the psychological evaluation contributes to donor safety and risk prevention. In the studies of Sterneck *et al.* and Renz *et al.*, 20% of the donors evaluated were excluded from donation for psychosocial reasons, though psychiatric

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history must not necessarily be an exclusion criterion (20,21). In the studies of Erim *et al.* and Beavers *et al.*, 13.2% and 36% of prospective donors, respectively, were excluded due to psychosocial issues, such as ambivalence, lack of adequate support, high anxiety, depressive disorders, substance dependence, family or financial problems or a history of suicide attempts (22,7). Erim *et al.* also showed some relation between the psychological characteristics of the donor and emotional response of the donor prior to donation (23).

Though the postoperative results regarding psychosocial complications after LDLT are rather encouraging, there have also been negative donor outcomes, such as psychosocial or psychiatric complications after surgery (24-26). One could argue that the rate is relatively low due to good preoperative psychosocial selection, but there has also been criticism that these numbers might not be representative as most results come from cross-sectional data from retrospective studies, with limitations such as biased or poor recall or a high drop-out rate, especially by donors whose recipient died (8). All of the above indicate the necessity of continuing and further developing the psychosocial assessment and support of donors before and after donation.

LDLT program in the Charité - University Medicine of Berlin

Living donor liver transplantation was introduced in Germany in 1991 as a complementary surgical procedure in order to help patients with terminal liver diseases and cope with the lack of organs from diseased donors. Due to the advancement of surgical techniques, immunosuppressive therapy and postoperative intensive care, LDLT has been established as a standard procedure in the treatment of patients with liver diseases and is now being performed in 13 centres in Germany (1). The annual number of LDLTs performed in Germany has increased five-fold since 1995. In 2001, LDLT reached its peak, constituting 12.5% of all liver transplantations performed in Germany annually (both adult-to-adult and adult-to-child donations). In 2008, LDLTs amounted to 4.9% of all liver transplantations in Germany (27).

The act of living liver donation, donor selection, information, management and financial coverage are regulated in Germany by the Transplantation Law, which allows living donation only from adult individuals who are first- or second-degree relatives of the recipient and/or have a close emotional relationship to the recipient and are informed and competent to decide without coercion to donate to a recipient in the event of lack of availability of a deceased donor organ (28).

The LDLT program at the University Hospital Charité in Berlin, Germany, was initiated in 1999. By 2008, more than 200 potential donors had been evaluated, and more than 100 LDLTs had been performed. From the beginning, the psychosocial evaluation of the donors has been an integral part of the evaluation due to medical ethical requirements (“do no harm”) that the donor risk be kept as low as possible, donor safety be ensured and quality standards in LDLT be maintained. Furthermore, postoperative evaluations of the donor 6 and 12 months after donation were planned to track donor recovery and post-donation outcome in order to determine whether and under what conditions LDLT is justifiable (29).

Overall concept of donor evaluation

Potential donors are usually expected to contact the transplantation office of the hospital if they are interested in an LDLT. In an initial step, they are briefly informed about the procedure over the phone. Potential donors receive informational material regarding LDLT, and if they wish to proceed, they are asked to arrange a personal informational meeting with a member of the transplantation team and a surgeon when further details of the living donation process are discussed. Blood typing is also necessary. If the donor decides to continue with the donation process, the evaluation procedure is started. The psychological-psychosocial evaluation is a standard part of this procedure and is usually performed after the basic medical tests are complete. If the contact person of the transplantation team identifies some fear or hesitation on the part of the donor or the donor shows signs of emotional instability, the psychosocial evaluation is performed first before proceeding with any medical examinations.

Though donors were more actively recruited in the early days of LDLT, in the sense that they were usually informed about the possibility of donation by the doctors in the clinic, with time the transplantation team has become more reserved in this regard. LDLT is by now an established procedure known by a large percentage of the population, who learned about it through various media, and by most physicians who may treat liver patients. In this way, the motivation of the donor is tested in a preliminary stage of the process, as he or she must become an active participant and contact the transplantation office.

After all medical and psychosocial examinations are finished and the donor is assessed as suitable for donation, he/she is referred to an independent ethics committee of the state. The committee consists of a physician with experience in medical ethical issues, a legal representative of the state and a professional with a background in psychology or psychiatry. This committee allows, or denies, the donation to proceed. Its role is to act as a safety measure for the donor against coercion or abuse of the donor or hidden incentives.

Psychological evaluation of the donor

The donor is invited to an almost two-hour psychological-psychosocial evaluation prior to donation. The assessment is conducted by a member of the department of psychosomatic medicine of the hospital and is either a clinical psychologist or a physician with training in psychosomatic medicine experienced in the psychoso-

cial evaluation of donors or transplantation patients. The evaluation consists of a semi-structured interview using a standard interview guideline developed by the department (30) that functions as the basis for a broad discussion of matters related to the donation process. Furthermore, the donor is given a battery of psychometric tests to evaluate physical or emotional complaints, anxiety, depression and quality of life (see Table I). All questionnaires used have proven to be valid and reliable in previous clinical studies. The scope of the preoperative interview is to :

- Assess the motivation for the donation,
- Ensure the absence of coercion,
- Assess the decision capability of the donor,
- Ensure informed consent,
- Examine the emotional relationship between donor and recipient,
- Ensure the absence of conflicts or financial arrangements,
- Exclude any form of trade,
- Estimate the psychological fitness of the donor and his/her availability of personal and social resources,
- Support the decision-making process.

The donor is informed at the beginning of the interview about its scope. It is explained that the interview is in the donor's interest and that it provides a protected setting in which he has the chance to express any questions, thoughts, fears or doubts regarding the donation. It is important to establish a confidential atmosphere in which the donor feels protected, free to express himself and not scrutinised. After the interview, the donor is given brief feedback about the interviewer's understanding of the donor's situation and the interviewer's opinion regarding the donor's suitability for donation. If needed, or if the donor requests it, a second interview is arranged, possibly involving both the donor and recipient or any other family member immediately involved in the situation.

The postoperative psychological assessments of the donors 6 and 12 months after the donation are an integral part of post-donation care and a measure for maintenance of quality standards regarding the treatment of the donor. The postoperative assessment consists of a psychological assessment using the same psychometric battery as before donation and a semi-structured interview. The aim of the postoperative interview is :

- To assess the current physical and psychosocial state of the donor,
- To assess the postoperative course of recovery and identify any physical or psychosocial complications and their impacts on the donor's life,
- To evaluate the postoperative relationship between donor and recipient,
- To evaluate the integration of the donation experience into the donor's life,
- To offer the donor the opportunity to reflect on his experience, his current state and future plans.

The overall goal of the postoperative assessment is to identify any complications related to the donation that could affect the recovery process and to offer support to the donor if needed in order to fully integrate the donation experience into his/her life and to regain the health status he/she had prior to the donation.

A single-centre experience of the psychological evaluation of living liver donors

In this section, we present data regarding the donors who underwent psychological evaluation in our clinic. The reasons for assessing a donor as unsuitable will also be presented, as well as three short evaluation cases and how our psychological evaluation concept was applied to them.

From 1999 to 2008, 190 donors underwent psychological evaluation in our clinic prior to donation (Table II). This is not the total number of potential donors who

Table I. — **Psychometric instruments used for the pre- and postoperative assessment of live liver donors**

Instrument	**Explanation**	**Measuring**
GBB	Giessen Complaint Questionnaire	Physical complaints
BSF-30	Berlin Mood Questionnaire	Psychological well-being
SWOP	Selbstwirksamkeit Optimismus, Pessimismus	Self-efficacy, optimism, pessimism
COPE-28	COPE	Coping behaviour
ALL	Alltagsfragebogen	Daily functions
WHOQoL BREF	Quality of Life Questionnaire	Health related quality of life
ACSA	Anamnestic Comparative Self-Assessment	Quality of Life
NI	Narcissism Inventory	Narcissistic self-organisation and self-regulation
PAS	Perceived Available Support from the Berlin Social Support Scale	Social support
PHQ-15	Patient Health Questionnaire	Depression, Panic, Psychosocial functioning
GAD 7	Generalized Anxiety Disorder Questionnaire	Anxiety
FKV	Freiburg Illness-Coping Questionnaire	Illness-coping strategies
PSQ	Perceived Stress Questionnaire	Subjective stress (Stressors and stress reactions)

Table II. — **Characteristics of donors evaluated psychologically between 1999-2008**

Donors evaluated psychologically	190 (male : 88, female: 102)
Donors actually donated	85 (male: 31, female : 54)
Rejected for psychosocial reasons	12
Age	18-65 years
Relationship to the recipient	
Parent	38 (mothers : 26, fathers : 12)
Spouse	45
Child	44
Sibling	32
Aunt/uncle	7
Brother/sister in law	7
Friend	4
Niece/nephew	3
Grandparent	2
Daughter in law	1
Cousin or extended family	7

initially contacted our centre and showed interest in donation. A high percentage of potential donors never reach the psychological evaluation phase as they drop out for various reasons : early change of mind, physical incompatibility, death of the recipient, or an unexpected deceased donation.

Of the 190 potential donors to undergo psychological evaluation, only 85 actually donated. The remaining 105 were assessed as physically unsuitable, the recipient died or the recipient received a deceased donation. Of these 105, twelve donors (6.3% of the donors undergoing psychological evaluation) were rejected for psychological and psychosocial reasons. These were lack of clear and strong motivation regarding the donation ; high anxiety, which could also be interpreted as partial lack of motivation ; previous severe psychiatric history with a recent psychotic episode ; and a complicated/dependent donor-recipient relationship, which indicated coercion and lack of capacity for realistic risk assessment on the part of the donor.

In Table III, we schematically present three different cases and compare them regarding some core aspects of the evaluation and their outcomes. The first two donors were assessed as suitable for donation although they differed in their psychological state and stability and had different kinds of relationships to the recipient and circumstances of donation, mostly regarding time pressure. Nevertheless, both were very definite regarding their desire to donate and continued with the surgery. The donor outcomes and postoperative coping were, as expected, different as well. In both cases, the recipient's outcome was very satisfying. In Case I, the donor showed a good recovery and successfully integrated the experience into his life, whereas in Case II, the donor showed a slower recovery, experienced continuous abdominal pain and demonstrated an ambiguous attitude toward the donation. Although she claimed she would donate again if needed, she obviously needed more support to cope with the experience and reach a stable state. The third donor initially presented herself as motivated for donation, but it soon became clear during the interview that she suffered from severe anxiety and psychosocial difficulties and did not actually want to donate, but felt pressured to do it. In a second interview in which a further family member was involved, she made the decision not to proceed with the donation.

Comparing these three rather representative cases for some types of donors who appear for evaluation, one could reach some conclusions regarding a suitable donor profile. Yet, the three cases would not be enough to support such conclusions. In a previous study in which the pre- and postoperative states and psychosocial profiles of a larger number of donors were analysed, we depicted the profile of a suitable donor and psychosocial risk and protective factors regarding the postoperative course and the integration of the donation into the donor's life (15).

Role of the psychological evaluation

Since the beginning of the LDLT programme in our centre, the psychological evaluation of donors has been an integral part of the evaluation process. In the early years of the programme, we were confronted with a relatively new situation, as up to then we had been evaluating mainly living kidney donors. Though there are similarities between the two situations, there are also inert differences that make the evaluation of potential liver donors more complicated, like the time pressure, the lack of any alternatives analogous to dialysis and the higher risk to which the healthy donor is exposed. At

Table III. — **Case comparison of donors**

	Case I	**Case II**	**Case III**
Characteristics	Father, 50y, for 21y old son	Aunt, 30y, for 8 months old nephew	Sister, 41y, for elder brother
Recipient	PSC, diagnosis 5y ago	Atresia, one LTX already conducted	Sick since childhood
Decision autonomy	High	Middle	Low
Time pressure	NO	YES	YES
Psychological state of donor	Stable	Hidden anxiety, desires psychiatric support after LDLT	First "stable", then high anxiety
Donation	Yes	Yes	No (excluded due to low motivation and high anxiety)
Donor complications	Minor	Some, slow recovery	-
Recipient autcome	Very good	Excellent	-
Reflections on LDLT	Positive	Ambiguous	-

that time, the existing literature regarding living liver donation was scarce compared to what is available today. The evaluation of the donors was based more on clinical experience regarding other cases and theoretical models and less on data. Over time, we rethought the role of the psychological evaluation of the donors several times, slightly changed the evaluation concept and identified specific issues regarding living liver donation that call for increased attention.

Specifically, the team tries to inform the donors in detail about the surgery at a very early phase of the evaluation procedure, and the donor is asked not to give a statement regarding his decision until he/she has been fully informed. In precarious or complicated cases, the psychological evaluation takes place before any medical examination, and more than one psychological interview session with the donor or family members is possible if needed in all cases. Continuous communication between the person conducting the psychological evaluation and the transplantation-coordination unit has been established to enable a complete picture of the donation dynamics.

It is enormously important to the psychological evaluation not to try to classify donors into precast categories regarding their motivation, but to try to understand the individual background of each donor that led to their decision, something that frees us to a certain extent from any moral judgement based on our values. We understood that donation is a great physical, emotional and moral challenge for all donors, who tend to present themselves as "super-healthy" in order to conform to expectations. We realise that the donors are under enormous pressure and that anxiety or ambivalence are difficult to express. For that reason, we try to keep a low-threshold attitude regarding the expression of doubts or fears and see the role of the psychological evaluation also as keeping a balance between assessing the deeper motives and psychosocial resources of the donor and not destabilising him/her. Furthermore, we acknowledge that the situation prior to donation is an emotionally intense time and that family and relationship conflicts can arise, which should be taken into account and addressed.

Regarding the clinician conducting the evaluation, we realise the importance of continuously checking one's own values and concepts of autonomy, which could interfere with those of the donors. There can be enormous time and moral pressure on the clinician to give a certain judgement as a result of the LDLT dynamics, and it is important to be aware of it, avoid misusing our role and always act in the donor's interest. Whenever possible, it is important for the clinician to give him-/herself and the donor time to complete the evaluation and the final decision. In precarious cases, we have always found it very helpful to supervise the case and come to a conclusion as a team regarding the psychological assessment.

We also recognise that it is not always easy to apply the popular definitions of informed consent and decision autonomy as criteria for the evaluation of the donors, as there is inert pressure in the LDLT situation and because in such circumstances a completely realistic understanding of the risks on the part of the donor is not always possible. In the mean time, several authors have addressed these topics, contributing to better treatment of these terms in the evaluation, and we consider it very useful for all clinicians conducting evaluations to engage in this discussion (10,11,31). Moreover, applying terms such as decision autonomy to donors with different cultural backgrounds has proven to be an even more challenging task, and this is an issue that clearly still needs to be further investigated. Lastly, concerning the postoperative period, it has become clear that there are always donors who might need psychological support irrespective of complications or a bad outcome of the recipient, though donors with complications would call for more attention from the team in offering psychological support.

In sum, we see the role of the person or team conducting the psychological evaluation of the living donors as including the following elements :

- The role of the evaluation is to identify high-risk profile donors, who could carry risks regarding their psychosocial state through the donation process.
- The person or team conducting the evaluation should try to avoid any moral judgement toward the donor that could arise in such an intense emotional situation.
- The role of the evaluating team/person is not that of a referee or decision maker, but of a facilitator of a conscious decision.
- A decision regarding a donation should be made by the evaluation team only in cases where the psychological health of the donor is at high risk or clear incentives are involved.
- A substantial part of the evaluation process is informing the donor about all psychosocial aspects regarding donation and its possible psychosocial complications.
- If necessary, the team should conciliate between donor and recipient or between family members.
- The person/team conducting the evaluation should also act in the donors' best interest (donor advocate), and its main task is to support the donor.

Agenda for the future regarding the psychosocial evaluation of living liver donors

We consider following points to be important aspects that should be further investigated in order to understand better the impact of the LDLT-possibility on the donors and further improve the psychosocial evaluation.

The development of a standardised protocol for the psychosocial evaluation would improve quality in LDLT and would allow comparison studies.

There is need for more longitudinal studies regarding the psychosocial state of the donor in order to identify

possible factors influencing the psychological condition of the donor. These can then be considered in the pre- and postoperative evaluation and support of the donor.

There is a high drop-out rate in the follow-up of donors whose recipients die after LDLT. This creates a bias regarding the postoperative psychosocial outcome of donors and regarding the extent to which the death of the recipient affects the psychosocial condition of the donors.

There is no evidence till now regarding the impact of the offering of the possibility of LDLT on the psychosocial condition of donors, who ultimately decide not to donate and how the family relationships are affected.

To identify risk and protective factors regarding the psychosocial condition of the donors ignoring the recipient's role and psychological state gives an incomplete picture of the phenomenon and needs to be further investigated in order to improve the evaluation and support.

There are clear differences in the understanding of decision autonomy in different cultures (individualistic and collective societies), which affect directly the art of the psychological evaluation of the donor. Most studies regarding the psychological evaluation refer to western societies. Further studies regarding this aspect, also from transplantation centres of non-western countries are needed.

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