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ORIGINAL ARTICLE

ETHICAL ASPECTS OF LIVING DONATION AND THE COMPLEX MANAGEMENT OF THE ORGAN DONOR

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Summary

This article describes the management of a potential living donor at our Center and the pathway across the complex donation process. The growing number of living donors is constantly leading us to ponder and reshape the psychological management of the donor/patient and, in this regard, the multidisciplinary team plays a crucial role managing the ethical challenges that the care team is called to face. Finally, in this context the ethical challenge is the possibility of creating multicenter teams that analyze emerging issues and redesign guidelines and protocols with continuing synergy.

Key words: living donor, living donation ethics, living donor global care, living donor psychological pathway

INTRODUCTION

Living organ donation is an important therapeutic strategy for organ failure patients on the transplant waiting list. At present, the number of deceased donors in Italy is unable to satisfy the increasing demand of patients on the waiting list, therefore living donor transplant programs are a viable therapeutic alternative for many organ failure conditions. Living donor transplantation in Italy is provided for by Law 458 of 26 June 1967 and regulated by Decree 116 of April 2010, and retains additional and not substitutive character compared to deceased donor transplantation.

Scientific evidence shows that living donor transplantation provides the best survival rates for the patient and graft, as well as best indicators for the graft functions and best quality of life for patients [1].

In Italy, living donation is currently regulated by laws and protocols defining its operating procedures, potential clinical contraindications for the donor, and the process to follow to become a donor. A kidney (Law 458 of 26 June 1967) and a portion of the liver (Law 483 of 16 December 1999) can be donated by a living donor. Since 2012, living donation of partial lung, pancreas and intestine are also allowed (Law 167 of 19 September 2012).

Many ethical issues are still open, and as these strategies become more and more widespread, the complexity of the scenarios increases accordingly.

A living organ donor is a perfectly healthy individual who undergoes major surgery for non-clinical reasons but to receive a predictable emotional and psychological benefit. The emotional link between donor and recipient is such that the disease of one causes a state of psychological distress in the other, and the possibility to manage the disease has significant emotional benefits for both the donor and the recipient.

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This implies that the potential donor has to be met and psychologically supported along this pathway, even before he or she is clinically assessed.
The psychology team responsible for taking charge of a potential donor assesses him or her from a psychological and psychosocial standpoint [2], in accordance with national and international guidelines, including an in-depth investigation of the following areas [3-7]:

- personality:
  - personality characteristics;
  - current and previous psychopathological disorders;
  - copying styles;
  - resilience.
- motivation and decision-making;
- awareness/information:
  - understanding;
  - awareness of status of disease;
- relationship:
  - relational models;
  - boundaries;
  - hierarchies;
  - limitations/constraints.

However, although thorough this investigation is often insufficient to seize the epistemological complexity that lies behind the choice of a potential donor.
A free and informed consent is the prerequisite for an ethical acceptance of living organ donation but, in fact, this concept implies several facets. The relational and emotional context of the donor especially makes the assessment of this requirement quite complex and controversial [8].
Concepts such as freedom of choice, non-coercion, awareness, and judgment are mixed up with numerous emotional facets such as life and death, health and illness, freedom and loyalty [9-11].
The history of our donors is made of all these elements: young parents of children with a severe neonatal diagnosis, spouses learning to integrate disease and treatment in their marriage, children preparing to reciprocate the gift of generativity, and much more that can hardly be enclosed in categories or defined with explanations.
All these considerations lead to the need of adapting the psychological evaluation protocols by turning the living donor assessment into a relational path to follow the patient through the process of making a choice, allowing him or her to elaborate it according to his or her personality, relational and value models, and eventually come to an authentic and nonjudgeable decision.
The relationship defined in terms of therapeutic alliance becomes a significant tool to face the numerous ethical issues that could potentially emerge while evaluating a potential living donor. The deal between the donor and the clinical team should be solid and marked by a mutual goal: finding any possible means to save the life of the patient/recipient. It is precisely this mutual interest, this unspoken agreement between donor and physicians engaged to save the life of the sick patient that sets the rules that govern the procedure. The aim of this study is to share and describe the relationships that the ISMETT team has established with the several people who embarked on a living donation journey over the years.

Table I. Summary data of living liver and kidney donors.

	January 2002 - April 2023
Living liver donor	200
Average age	33 years
Type of kinship	90 parents
	72 son and daughter
	8 husband and wife
	16 brothers and sisters
For adult recipient	109
For pediatric recipient	91
	October 1999 - May 2023
Living kidney donor	282
Average age	50 years
Type of kinship	93 husband and wife
	1 son and daughter
	51 husband an wife
	126 parents

MATERIALS AND METHODS

The clinical and psychological pathway of living organ donors: the experience of the ISMETT Psychology Service.
The living donor transplant is a major transplantation activity at ISMETT. Since 1999, 200 liver transplants and 285 kidney transplants have been performed from living donors (Tab. I).
Behind every living donor transplant is a story of care and life involving a donor, a recipient, as well as various relational dynamics. This emotional and relational complexity is reflected in the care pathway and psychological evaluation of the living organ donor (Fig. 1).
At ISMETT, potential living organ donors expressing a will to start a donation process are taken over by the living donation program team, and followed through a complex process that starts with the pre-donation phase and continues after the donation, ensuring donors undergo constant and continuing follow-up.
Along this pathway, the clinical psychological assessment is a key moment that can determine the success of the entire program.
The donation process usually begins with the clinical and psychological assessment of the potential donor.

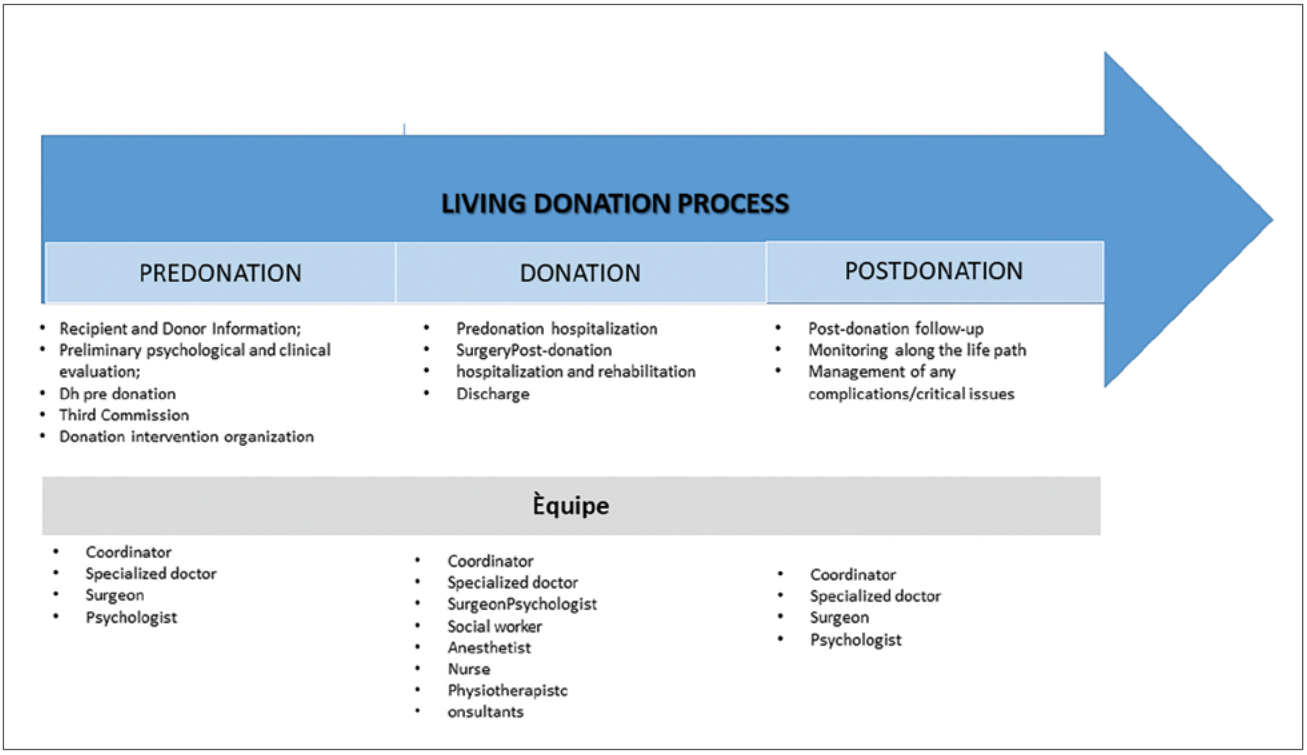

Figure 1. Description of the process of taking charge of a living organ donor.

The psychological assessment is intended to investigate various areas according to protocols and guidelines (see above), and create a relationship of trust with the potential donor discussing his or her choice of donation truthfully and without judgments.

During the psychotherapeutic relationship psychological challenges often emerge making the donation psychologically risky.

Very frequently, although the potential donor has a perfect psychological balance, awareness, and brilliant processing, no psychological disorders or external constraints, and if strongly motivated to donate, he or she could be caught in emotional, ethical or relational tangles making the donation unsafe from a psychological standpoint. In these cases, potential donors are encouraged to work out this complexity through a psychotherapy pathway until a choice is made free from external and emotional/internal coercion. This step is a prerequisite for subsequent clinical assessment, that determines whether or not the candidate is eligible for organ donation. By this time, effective communication within the multidisciplinary team becomes crucial to address the complex ethical issues related to living donation.

RESULTS

Over the last decade, the number of living donations performed at ISMETT has increased significantly and, along with this, the psychological complexity of potential donors. This persuaded the team to reflect on significant ethical issues and, in specific situations, review protocols and guidelines.

Below we briefly describe some of the main psychological and ethical issues the donation team frequently faces at ISMETT, and propose a management model for these aspects.

Loyalty/emotional obligation

At the time of making the decision to donate, the potential donor is overwhelmed with the painful experience of the disease shared with the recipient made of concern, altered quality of the family life, and anguish about death. This combination of painful feelings may compromise the ability to think clearly and consciously about the donor's choice. This situation may alter the motivation to donate without a real understanding by the donor. The potential donor is trapped in a dramatic dilemma: "losing my loved one scares me/losing my health scares me": whether I choose to donate or not, I will experience a significant emotional distress. In these cases, psychological care is a way to escape the vicious circle that makes the donor feel trapped, and the choice to continue with the donation must be made and shared with the entire team.

Psychiatric diagnosis

A new culture and awareness of psychological distress is spreading in modern society, effective psychological and psychiatric treatments are able to detect and manage psychological and psychiatric disorders that in the past led to labeling and social exclusion. Even the pool of potential living donors may include psychiatric diagnoses under treatment with psychopharmacology drugs. Nonetheless, if after a careful and in-depth psychological and psychiatric assessment, a psychologically-compensated overall functioning is detected with no evidence of symptoms related to the diagnosed disorder, the donor's choice to start the donation process should be respected. However, there could still be concerns on the potential risk of the clinical pathway disrupt the psychological balance and/or that the continuity of the psychopharmacology treatment is not adequately ensured. This requires a close cooperation with professionals taking care of the donor's mental health in order to ensure the least risk of psychiatric relapse without penalizing the freedom of choice. In this respect, the challenge entails the willingness of the entire clinical team to remodulate treatment protocols to adapt them to the needs of the donor with a psychiatric diagnosis.

Lifestyle and substance use

The living organ donor is a healthy individual and therefore his or her lifestyle and habits must be respected and cannot be assessed, judged or altered with the psychological or educational approach used for a patient suffering from a chronic condition. In the presence of habits or lifestyles considered dysfunctional to a possible donation (smoking, excessive alcohol consumption, social and non-social substance use, etc.) it is important to consider to what extent a request for compliance can be accepted by the potential donor without creating discomfort to his or her personal/existential/social dimension.

These scenarios are only a few of the many issues shared within the clinical psychology team dealing with living donors. Samaritan donation, multiple organ donation from the same donor (kidney-liver), jailed donors, donors with mild cognitive retardation, the choice to donate despite opposition from other family members, and many other issues should be addressed to provide a safe context that respects the personality traits and life habits of the donor who decides to make a choice of love and altruism.

DISCUSSION

The psychological complexity of the living donor, as described above, led the psychological team to not consider the time of the assessment as a single moment in time, but as a process during which the potential donor is supported throughout his or her decision, in line with personal features, values, lifestyle, relational and social context, to make a final nonjudgeable decision, free from pressures and self-constraints. This relationship of trust and respect is extended to the entire clinical team assessing and taking care of the donor, and lies at the basis of the entire donation experience: on one hand the donor can rely on the surgical team and, on the other, the recipient can accept the gift. We believe a continuing multidisciplinary exchange is key for co-building the most appropriate care path on the donor and reshaping it according to specific needs and requirements. This relational context is the foundation of success of the living donation transplant program, and an effective tool to deal with the complex ethical issues that increasingly challenge the donor's clinical and psychological pathway.

CONCLUSIONS

The purpose of this article is to review how to address significant ethical issues raised by the living donor transplant program that require continuous exchange and analysis. The establishment of a program for the care and support of the donor is a valuable instrument to identify and address the complex ethical issues that this type of work entails. Continuous interaction within the multidisciplinary team supports the collaborative implementation of this program, ensuring its success. Finally, we believe that debates and considerations should be extended to a multicenter level in order to effectively address the present and future challenges working with a living donor.

Conflict of interest statement

The authors declare no conflict of interest.

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Author contributions

The Authors contribuited equally to the work.

Ethical consideration

Not applicable.

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