

## Review Article

# Psychosocial evaluation of a living kidney donor<sup>☆</sup>



**Manuel Torres-Gutiérrez**

Médico Psiquiatra, Jefe Grupo de Salud Mental, Colombiana de Trasplantes, SAS, Bogotá, Colombia

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### ABSTRACT

The decision to become a living kidney donor is full of conflicts. It is generally believed that the candidates are aware of their reasons, that they have thought long about it, and have even asked questions about it. Thus it is surprising that, in many cases, they are only vaguely aware of their reasons and their validity. Sometimes, it is an impulsive decision guided by their emotions and entrusted to their luck or faith. Sometimes, they are undecided and put under pressure due to various circumstances. The mental health assessment should help to clarify their reasons, and to put them into words. It should be a positive experience, enriching their decision. It should give the candidate the inner feeling of having received help for taking the best decision.

The psychosocial evaluation should be the first of multiple assessment ratings that the living kidney donor must face. A well-taken decision is a requirement to start the process properly. The author reviews the conditions in which that interview should be developed, the requirements to be met by the decision, and the proper techniques to obtain accurate information.

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## La evaluación psicosocial de un donante vivo de riñón

### RESUMEN

La decisión de convertirse en donante vivo de riñón suele ser conflictiva. Generalmente se cree que el candidato conoce sus motivos, que es consciente de ellos, que ha pensado largamente su decisión y hasta ha consultado sobre ella. Sorprende corroborar que – en muchos casos – solo tiene una conciencia vaga, más bien oscura, de sus razones y de la validez de ellas. Otras veces ha tomado una decisión impulsiva, guiado por sus afectos, y se ha confiado a su suerte y/o a su fe. Y, otras más, viene indeciso, presionado por diversas circunstancias. La evaluación de salud mental debe ayudarle a poner sus motivos en claro, es decir, a hacerlos conscientes, a verbalizarlos. Debe permitirle analizarlos y afirmarse en

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E-mail address: [mtorres@colombianadetrasplantes.com](mailto:mtorres@colombianadetrasplantes.com)

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su decisión o arrepentirse de ella. Es decir, debe ser una experiencia positiva, que enriquezca la decisión, la madure o la descarte. Y debe dejar al candidato la sensación interior de haber recibido ayuda para tomar la mejor decisión posible en su caso.

La evaluación psicosocial debería ser la primera de varias valoraciones a las que debe someterse un candidato, porque una decisión bien tomada es requisito para realizar un proceso adecuado. El autor revisa las condiciones en que debe desarrollarse la entrevista, los requisitos que debe cumplir la decisión y las técnicas apropiadas para obtener la información indispensable.

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## Introduction

Today, kidney transplantation is considered the best treatment for end-stage chronic kidney disease. However, a relatively high number of patients remain on dialysis and waiting lists are growing every year.<sup>1</sup>

Needless to say, there are limitations regarding insurers authorising the procedure, but the main limiting factor is organ availability. Organs can come from both a living or deceased donor. The latter appears desirable because it minimises the risks to another human being. However, the demanding conditions of recovery make finding a suitable number difficult. If we compare the constant (and sometimes declining) number of deceased donors to the ever-growing number of patients on waiting lists, it becomes clear that the chance of receiving an organ is proving less and less likely for the majority of patients.<sup>1</sup>

Fortunately, the idea of living organ donation is gaining increasing acceptance. Perhaps the main reason that this idea is on the rise lies in improved medical evaluation criteria for the candidate (which are becoming increasingly clear and more accurate) and improved nephrectomy surgery techniques, which are becoming safer and yielding better results (aesthetics included). These two elements have given rise to a general perception that there is no injury and a low risk involved, which is gradually radiating from medical professionals to the general public. Moreover, it is not inconceivable that the average citizen's willingness to participate in this specific form of solidarity has also improved. What is certain is that there are more and more candidates for living donation. Furthermore, most notably, the number of candidates who are not biologically related to the recipient has also (moderately) increased (spouses, same-sex partners, in-laws, friends and even people with unusual motives).

Of course, this shift in attitude should be welcomed as a positive. Nonetheless, it carries with it new psychosocial risks that must be identified. Women generally – and wives in particular – tend to be generous towards their partners.<sup>2</sup> This generosity may prevent us from detecting the existence of undue pressures exerted by the ill husband, exploiting her frequent financial dependence. The decision to support a homosexual partner may be perfectly legitimate, but it is common for donors to hide their reasons due to censorship fears and this inhibits proper analysis. The emotional bond that sometimes unites in-laws and close friends may be a sufficient

and adequate motive. However, it is not uncommon for organs to be sold, concealed behind declarations of friendship which, for the interviewer, are difficult to prove or rule out. Abstract altruism (towards strangers, for example) is an admirable human trait, but let us not be too blind to recognise that behind it there may be deprived citizens subjected to financial pressures or the manipulation of unsuspecting individuals.

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## The interview

Almost all transplantation teams include a psychosocial evaluation of their living donor candidates. The World Health Organization (WHO) addresses this requirement in the comments made under Principle 3 of the WHO Guiding Principles on Human Cell, Tissue and Organ Transplantation.<sup>3</sup> The mental health evaluation – including those carried out by nephrology, the surgeon, the anaesthetist and any other person deemed necessary by the transplant team – seeks to confirm that the decision to donate justifies the risk assumed by the candidate.

The donation of an organ is a voluntary decision. Candidates have dominion over their bodies and have the right to dispose of them within the scope of the applicable legislation. It is thus usually assumed that they know their reasons for donating (that they are aware of them), that they have thought at length about their decision and have even sought advice from other people. It is surprising, then, to corroborate that in many cases candidates have only a vague or rather obscure awareness of their reasons and the validity thereof. Sometimes, candidates have made an impulsive decision, driven by their emotions and placing trust in their luck and/or faith. In other cases, they are undecided and under pressure due to various circumstances. The mental health evaluation should help them clarify their reasons, i.e. make them conscious or verbalise them. It should allow candidates to analyse them and to stand by or revoke their decision. In other words, it should be a positive experience that either enriches and develops the decision or disregards it. It should also leave candidates feeling as though they have had help in making the best possible decision to suit their case.

This interview should be the first of many that candidates have to undergo. A well-informed decision is the first prerequisite that allows the rest of the process to flow. The interview should be carried out by a psychiatrist integrated in the transplant team. Integrated means that the psychiatrist should not

only understand the phases and requirements of the process, but also have been present and had responsibilities during transplantation, so that he/she knows the pressures, risks, benefits and results thereof both in theory and from experience.

The professional training given to psychiatrists usually gets them used to pursuing and providing strict conditions in which they can properly undertake an interview of this nature. There are five such conditions: time, privacy, intimacy, warmth and sincerity:

- The interview requires time. It is about understanding the donor's reasons and helping him or her to clarify them. This sometimes constitutes a long and arduous task. Many patients fail to find the words to express themselves. Others believe, given the generosity of their offer, that the medical team is forced to accept with no further questions asked (under the assumption that the decision is one-sided). Patience and experience are required to convince patients of the need to express their reasons and to direct them towards them. This takes at least an hour, coinciding with the usual length of a psychiatric interview.
- The interview should take place between the psychiatrist and donor alone. This is not only a way of avoiding undue pressures. The candidate may be scared or feel undecided, and should feel able to raise any concerns or doubts in private. Sometimes it may be necessary to reaffirm the confidentiality pledge that is characteristic of psychiatric interviews. If the donor insists, a person in their trust (spouse, child, friend) may attend, but the recipient or any other related person (who would presumably be in favour of a positive decision) must never be present.
- Intimacy is an essential requirement of the interview. The interviewer should build trust. Candidates should feel as though they are being listened to and that the depth of their reasons is understood.
- Warmth, in other words, friendliness, patience, tolerance and understanding. These are characteristics that a good clinician always offers as the only possible compensation for the attitude expected from the interviewee: sincerity. When this fails (i.e. when we see that the candidate is lying and concealing information), it is difficult to maintain said warm and respectful attitude. And that is where the clinician's expertise is best measured.

### The conditions of the decision

The decision to donate an organ must satisfy several sets of requirements. It should be:

- Legally sound.
- Ethically acceptable.
- Psychologically mature.

The psychosocial evaluation (in particular if it is the first in the process) serves as the ideal opportunity to corroborate the donor's respect of and compliance with all three sets of requirements – legal, ethical and psychological – and the psychiatrist is the most suitable professional to do so.

### Legal requirements

In Colombia, the legal requirements are clearly set out in Law 9 of 1979, Law 73 of 1988 and Law 919 of 2004, as well as in regulatory decrees and resolutions (2363 of 1986, 1546 of 1998 and, in particular, 2493 of August 2004).<sup>4</sup> There are three aspects that are directly relevant to the psychiatric assessment of donor candidates, as follows:

- That they are in full possession of their mental faculties. The interview must rule out cognitive limitations (mental retardation, cognitive impairment or dementia), serious emotional disturbance (depression, anxiety), other mental illnesses (psychosis, factitious disorder) or serious personality disorders that impede full comprehension of their decision.
- That the decision is altruistic. The interviewer must ensure that the candidate has no other reasons besides the desire to help the recipient and that there is no financial benefit agreement or ulterior motive involved. In Principle 5 of the WHO declaration, it rightly states: "Payment for cells, tissues and organs is likely to take unfair advantage of the poorest and most vulnerable groups, undermines altruistic donation, and leads to profiteering and human trafficking. Such payment conveys the idea that some persons lack dignity, that they are mere objects to be used by others".
- That the donor is informed. The legislation of most countries in Latin American requires express informed consent, in writing, with a minimum term lasting from the signature of the document to the extraction of the organ.<sup>5</sup> In Colombia, a sworn statement before a notary public is also required.<sup>6</sup> Most teams hold one or several educational meetings that must be attended by the candidate before signing the informed consent. The interviewer must confirm that the candidate has received timely and suitable (comprehensible) information on the risks and implications of their decision regarding their general health, and that the implications pertaining to psychiatric health and later life have also been specified (including possible changes to their life plan).

### Ethical requirements

There are four ethical requirements:

- Autonomy. This is "self-rule that is free from both controlling interference by others and from limitations [...] that prevent meaningful choice".<sup>7</sup> Bioethics considers that normal, duly informed individuals are capable of making decisions on their health and any medical procedures offered to them, and that this decision should be respected over the physician's opinion. The Belmont Report<sup>8</sup> named this concept "Respect for Persons". The psychosocial evaluation should: respect (not interfere with or oppose) their decision to become a donor, ensure that they receive suitable information and protect subjects with limited autonomy (mental disturbance, immaturity or circumstances restricting their freedom). On the specific topic of living donors, it should always be borne in mind that most threats to autonomy do not come from the physician; more

often, they stem from the recipient and environment. We are explicitly responsible for confirming that the donor is acting free from coercion (violent imposition), manipulation (subtle control), seduction (promises and insinuations) and subordination (related to work, the military and other groups: church, school, etc.)

- Benefits for the donor. The beneficence principle calls for “maximiz[ing] possible benefits and minimiz[ing] possible harms”.<sup>8</sup> In the psychosocial interview, we must corroborate that the donor is benefiting in exchange for the risk. This seems paradoxical: if they are going to lose a healthy organ, what type of benefit could there be? The only possible answer is: a psychological benefit. There must ALWAYS be a benefit and this should be understood in two ways: genuine alleviation of the donor’s suffering (caused by the illness of a loved one) and their psychological satisfaction (due to alleviating said suffering). This means that the recipient and donor know one another and have a mutual and significant affection. This condition obligates us to act very carefully in certain cases of alleged abstract altruism. It is thus worth highlighting the comment made by the WHO under Guiding Principle 3: “In general living donors should be genetically, legally or emotionally related to their recipients”.<sup>9</sup> Experience shows that one only donates an organ to somebody for whom they feel great affection and devotion – someone who is of special significance in their life, who they cherish. However, donation is not emotionally neutral either. Once it is decided upon, it strengthens the preexisting bond between those two people and gives the donor a sense of satisfaction and accomplishment that can last for many years, positively influencing many of their subsequent decisions. Conversely, when there are flaws, it tends to distance the two people, leaving the donor with an emotional void, regret and the sense of being used.
- Absence of harm In the Belmont Report, the concept of non-maleficence falls under the beneficence principle: “maximiz[ing] possible benefits and minimiz[ing] possible harms”. However, most bioethicists now consider this to be a separate principle. The psychosocial evaluation should forecast that there will be no psychological harm. This should be understood not only in terms of the decision not affecting (exacerbating, triggering or aggravating) any previous mental disorders, but should also rule out any expectation of personal sacrifice and avoid future disability. Donation should not be experienced by donors as a voluntarily accepted sacrifice, but as an act of solidarity with a loved one, which is only permissible if it does them no harm, i.e. if their life can continue without limitations or changes to their medium- or long-term plan.
- Justice. “An injustice occurs when [...] some burden is imposed unduly”.<sup>9</sup> We are responsible for verifying that the donor has not been “selected simply because of their easy availability, their compromised position, or their manipulability”.<sup>9</sup> In other words, we must rule out all forms of vulnerability: financial (e.g. a poor relative), psychological (e.g. the individual with the least emotional independence in a family), social (e.g. a single mother who is the head of the family and has children under 18) or legal (e.g. a relative with mild mental retardation or borderline intellectual functioning).

## Psychological requirements

There are three psychological requirements:

- That the decision is psychologically understandable. This means that the interviewer understands the premises of the decision and how the donor has come to their conclusions. It also signifies that he/she not only understands the content, but that the logical structure thereof has also been shared. Such a perspective is vulnerable to the accusation of subjectivity. However, we must not forget that, in most cases, the donor and interviewer belong to the same culture and share similar feelings, ways of acting, priorities and value scales about what is right and wrong. This “understandable” rating also implies that the donor has made an effort (has sought out arguments) to make it comprehensible to us. Few other exercises can provide greater certainty of the reasons’ transparency, the autonomy of the decision and the subjective benefit received by the donor. Of course, any difficulties understanding the decision could hypothetically be due to the psychiatrist’s inability or prejudices. And I believe a responsible clinician should never lose sight of this possibility.
- That it is mature. In essence, that it has been reflected upon and not made impulsively. There is no “reasonable time period”, of course, but it is easy to determine what constitutes “reckless”. “Mature” also means that the decision is composed and not conditioned by emotions. Two immature feelings must be ruled out: guilt (due to alleged or genuine aggressions and psychological debts to the recipient in relation to other points in their shared life) and fear (that the recipient will die, stop loving them or abandon them, etc.).
- That it is stable, i.e., that it has been upheld in the face of objections and advice to the contrary. This assures us that it has been carefully considered and discussed with other important people in the candidate’s life for some time.

We usually only have one session to complete this task. It is thus worth following a protocol to make it more efficient:

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## Interview technique

Like any evaluation, we should begin by getting to know the donor. Clinical histories nowadays tend to be systematised and most programmes provide the patient’s identifying and sociodemographic data in advance. In my opinion, it is useful to begin the interview by checking these data. The previously standard practice of the patient and clinician verbally identifying themselves serves as an introduction, breaks anonymity and respectfully opens the conversation. We should seek to corroborate their name, age, background, marital status, employment and the name of the recipient. Moreover, it would appear necessary to acquire clear and extensive knowledge on the donor’s family. To do so, we ask the candidate to help us draw a detailed genogram. Together, we can construct a genealogical diagram of their parents, siblings, spouse and children. The genogram is produced from the patient’s point of view, using standard conventions (differentiating between men and women, adding their names, ages and blood or civil



relationships, drawing these with a straight line when they are still applicable and cutting through them when they have broken down).<sup>10</sup> It is useful to outline groups on the diagram (who lives with who) and to record the city and neighbourhood (or municipality and village) in which they live. When the recipient is not part of the same family, we ask the donor to help us draw their respective genogram. Doing so alongside the donor makes the relationship between both individuals visible from the outset. Encircling the home of each person not only shows relationships of consanguinity and/or affinity, but neighbourhood relationships too.

The second part consists of a longitudinal review of the candidate's life. This is directed at establishing their legal and mental capacity: Childhood, adolescence, education and academic level attained, adult life, work undertaken, marriage(s), children, etc. Clear evidence of their maturity should be sought, such as signs of their emotional and economic independence. Next, try to identify their main personality traits (insofar as possible in a single interview). This section always includes a full, cross-sectional mental examination, corroborating the statements made by the donor about their life history.

The third part examines the formal ties between the candidate and recipient (siblings, married couple, friends, etc.). We then clarify the emotional ties between them (they grew up together, they have been happily married for many years, etc.) and explicitly note any evidence of this bond. Experience reveals that suitable donors can perfectly describe the daily life of the recipient, as well as their family environment, finances, underlying disease and any treatment they are receiving. Collecting anecdotes about their life together is useful. If the donor and recipient are siblings, corroborate their joint upbringing, shared education and stories from their childhood; if they are married, confirm their day-to-day involvement, responsibilities regarding any children they have together and that they have matching life plans. If they are friends, verify their shared upbringing, education, work, neighbourhood and social life.

We must also specifically analyse the financial relationship between the donor and recipient, clarifying the sources of income of both. This allows us to establish any financial dependence, subordination or hierarchical dependence with relative certainty.

In the fourth part, the donor's decision-making is analysed. It is necessary to ask the date on which the decision was made, to clearly establish who proposed the initiative, how the donor told the recipient (or how the latter expressed his/her request) and the donor's reasons for making it (why this person as opposed to another family member?). The goal is for the donor to express his/her reasons in terms of his/her own feelings and personal interest, and to dismiss vague and generic phrases about the virtue of altruism as insignificant, and those regarding the benefit to the recipient as obvious.

As part of this section, we must find out whether there is any opposition to the donation within the family, especially when married women or young people who have recently come of age are concerned. After all, while these two groups do not legally require authorisation, they often depend emotionally and financially on their husband or parents. The candidate's attitude towards any such opposition should also

be explored (how important is it in his/her life, how will he/she manage said opposition) and he/she should be clearly and formally asked about the existence of undue pressures from the recipient or the relatives thereof, as well as whether they are receiving money in exchange for the donation. Negation is relatively insignificant, since it is normal for donors (all of them) to vehemently deny this. We should note, however, if any evidence of undue pressure or monetary compensation is observed during the interview.

The fifth section assesses the candidate's knowledge of the two surgical procedures (their nephrectomy and the transplant). It is necessary to ascertain their level of knowledge regarding the recipient's disease: cause, treatments, type of dialysis, compliance, complications. This usually reveals what the donor thinks about the prognosis of the procedure (will the recipient be able to take care of the graft?) and dismisses the common belief – which is almost always false – that the recipient will die without the donation. Among the topics of knowledge concerning the surgery, it is always necessary to include a question about the donor's support mechanism (carer and postoperative accommodation). The donor's independence with respect to the recipient's support network is usually reassuring as regards his/her autonomy. In our working group, it is common for the donor to have attended the educational meeting held for the recipient and his/her family, so knowledge is usually adequate.

The interview ends by gathering background information to exclude a history of mental illness and illustrate the donor's tendency to adopt either healthy and/or high-risk behaviours: use of tobacco, alcohol and other substances, hospital admissions, surgeries and previous medical consultations, accidents, extreme sports, previous psychiatric care. The use of alcohol, tobacco or other substances is not a formal contraindication for donation. However, any such habits require special analysis. Substance abusers tend to have little regard for their health and often carry other risks (e.g. accidents) which may discourage donation.

At this point, it is very rare for an expert interviewer to not have a clear sense of the donor's suitability. In our group, we use a checklist to ensure compliance with the aforementioned requirements and we decide between two different ratings: suitable and unsuitable. When the candidate is deemed suitable, we inform them of our decision and refer them immediately to the nurse to receive laboratory orders and appointments for other assessments (nephrology, surgery, anaesthesia). If the evaluation is positive, we advise donors that they will undergo many other examinations and interviews to:

- Establish their risk level for the nephrectomy.
- Establish the capacity of their remaining kidney.
- Ensure that they will not be forced to implement any lifestyle change (diet, medication, physical limitation, job change, etc.).

Colombian legislation<sup>11</sup> requires the donor to have been previously informed that it is impossible to be sure of all of the risks that might materialise during the procedure, due to the occurrence of unforeseeable circumstances. We also feel it is advisable to add that we cannot predict future events such as

an accident involving lumbar spine trauma or an abdominal injury, which may affect the only remaining kidney. Donors are also clearly informed that they may withdraw from the donation procedure at any time.

As regards patients deemed unsuitable, we explain the reasons behind our decision and suspend the process initiated. Occasionally, candidates come to the interview with serious doubts about their decision, changing their mind part-way through. Voluntary withdrawal tends to make donors feel guilty for getting the recipient "excited" and they are often scared and ashamed to tell them. In such cases, we make it clear to the donor that the interview is totally confidential and that we will not inform the recipient or his/her representative of any such reasons.

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### Conflicts of interest

The author has no conflicts of interest to declare.

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