

## New Classification of ELPAT For Living Organ Donation

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In the literature, varying terminology for living organ donation can be found. However, there seems to be a need for a new classification to avoid confusion. Therefore, we assessed existing terminology in the light of current living organ donation practices and suggest a more straightforward classification. We propose to concentrate on the degree of specificity with which donors identify intended recipients and to subsequently verify whether the donation to these recipients occurs directly or indirectly. According to this approach, one could distinguish between “specified” and “unspecified” donation. Within specified donation, a distinction can be made between “direct” and “indirect” donation.

**Keywords:** Classification, Living organ donation, Specified and unspecified donation.

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**B**ecause deceased kidney donation falls short of the need (or in some countries does not exist or is not encouraged), in many countries, living kidney donation has be-

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come the most important alternative to cope with the increasing amount of patients with end-stage renal disease in need of a transplantation (1). Consequently, the donor pool has expanded from genetically related donors only to spouses (2), friends, acquaintances, and even anonymous donors (3). New schemes, such as paired donation, have increased the complexity of these relationships. In the literature, many different terms are used to describe the nature of living organ donations. Because of this lack of consistency, confusion commonly arises both within the literature and during discussions at national and international conferences about different aspects of living donation, because they largely revolve around the issue of terminology and classification. Classification of living donor terminology has been an issue of lively debate among the members of the organization Ethical, Legal, and Psychosocial Aspects of Transplantation (ELPAT), a section of the European Society for Organ Transplantation. ELPAT is a European platform that aims to bring together professionals, such as (bio-) ethicists, philosophers, lawyers, psychologists, physicians, sociologists, anthropologists, policy makers, and criminologists, to debate and stimulate research on these issues surrounding transplantation. In this article, we wish to provide clarity on the issue of definitions and terminology. The aim is to propose a workable classification system for living organ donation that avoids morally or religiously loaded concepts and enables coherent discussion and comparisons. The discussion in this article will not concern organ trade.

Table 1 shows the classification for living organ donation that we propose. The remainder of the article will explain the shortcomings of existing terminology and the meanings of and reasons for preferring our classification.

**TABLE 1.** New ELPAT classification for living organ donation**Specified donation**

## Direct donation

When a person donates directly to his or her intended recipient

Donation to genetically and emotionally related recipient (e.g., to one's child, parent, or sibling)

Donation to genetically unrelated but emotionally related recipient (e.g., to one's spouse, friend, or acquaintance)

Donation to genetically related but emotionally unrelated recipient (e.g., to an estranged child, parent, or sibling)

Donation to genetically and emotionally unrelated recipient, but the recipient (or the group to which he/she should belong) is specified (e.g., to persons younger than 18 yr or a specific person in need of a transplantation, who was interviewed by the media)

## Indirect donation

When a person donates indirectly to his or her intended recipient

Donation to a specified recipient through an exchange program

**Unspecified donation**

Donation to an anonymous and unspecified recipient (e.g., donation to the waiting list or to the recipient of an exchange couple in the case of domino-paired exchange)

ELPAT, Ethical, Legal, and Psychosocial Aspects of Transplantation.

## RELATED VERSUS UNRELATED (OR NONRELATED)

Living organ donation is often described as directed or nondirected. Dictionary definitions of related include “to be connected by blood or marriage,” “to feel sympathy for,” and “to identify with” (4). The term “related donation” is used to describe transplantation involving genetically related donors and recipients, that is, between family members. In the early days of transplantation, all donors were genetically related: transplantation programs initially focused on identical twins and gradually expanded to include other blood relatives. In many countries, this type of living donation is still the only form that is legally permitted. Over the years, it has become medically possible to donate an organ to a recipient with whom the donor has no genetic relationship (2). As a consequence, the term unrelated was introduced as a counterpart to related.

But what does the term unrelated incorporate? These so-called unrelated donors can be spouses, partners, friends, family in-law, colleagues, neighbors, or other acquaintances who have an emotional rather than a genetic connection with the recipient. Given the emotional bond and bearing in mind the aforementioned definitions of related, the use of the term unrelated in this context seems inappropriate. In light of these considerations, the term related alone is not sufficient and would need to be specified with the clauses “genetically” or “emotionally.” Donors can be “genetically and emotionally related,” “genetically unrelated but emotionally related,” “genetically and emotionally unrelated,” and even “genetically related but emotionally unrelated.” For example, it is common for estranged parents to donate to children whom they have not seen for many years (5).

To make matters even more complex, the group genetically and emotionally unrelated donors includes altruistic strangers. Although such donors have no specific emotional or genetic relationship with the recipient, they may think they have a bond with kidney patients in general (e.g., because of personal experience), with chronically ill patients or with humanity as a whole. In fact, research has shown that individuals who donate a kidney to a stranger are commonly motivated by

personal experience with kidney disease in their social environment (6). Therefore, the term unrelated for these donors may not accurately describe the nature of the donation (7).

## ANONYMOUS

In the literature, we often see the term “anonymous donor” (8–10). In principle, such a donor does not know the identity of the recipient and vice versa. One of the reasons for this is to prevent commercialization (11). However, in some countries, such as the United States and Canada, anonymity is only maintained for the first 3 to 6 months after transplantation (12–15). Thereafter, identification and exchange of information or meetings are often arranged by the transplant center if both parties are willing. Apart from its possible temporary nature, it is also unclear whether the term “anonymous” refers to the donor or the recipient. For example, donors who have a specific recipient in mind with whom they have no emotional or genetic relationship are often included in the group of anonymous donors. In this case, the recipient is known (ie, not anonymous) to the donor and the recipient may or may not know who their donor is depending on the protocol of the transplant center. Hence, the term anonymous is not strictly appropriate in all cases for which it is currently used. Furthermore, some “altruistic” donors may specify that they do not wish to be anonymous, for example, by seeking media coverage.

Another example of anonymous donation is participation in (regional or national) kidney paired exchange or domino-paired exchange programs. Donor–recipient pairs who participate in these exchanges may remain anonymous to one another, because this was shown to be preferred by the donor–recipient pairs (16). However, anonymous might not be the most suitable term to describe this type of donation. After all, although the donors and actual recipients may remain unknown to each other, the donors and originally intended recipients are usually familiar to each other.

## GOOD SAMARITAN

“Good Samaritan donation” is a term occasionally used to describe donation to a stranger with no apparent material

benefit for the donor (15, 17). However, this term is strongly associated with Christianity because of its Biblical origin. It is likely that some (potential) donors or recipients with other religious backgrounds may not identify themselves with this term. In practice, individuals who donate to a stranger often express dissatisfaction or discomfort with the term “Good Samaritan.” There is also mixed evidence regarding religion as a driving force behind donation to a stranger (6, 9, 12, 18–20). In most religions, organ donation during life is considered a supremely generous and karmically positive act (21, 22).

## ALTRUISTIC DONATION

Living organ donation can be described as an act of altruism, whether the donation is to a loved one or to a stranger, provided there is no apparent material benefit for the donor. It has been suggested that organ donation by individuals who are total strangers to the recipients constitutes the only true form of altruistic donation (23). This belief stems from the fact that these donors derive the least personal benefit from the donation in the improved health and quality of life of the recipient and that external pressure to donate accordingly is at a minimum. However, this should not obscure the possibility that, in exceptional cases, potential donors may expect strong personal benefits, especially in the spiritual realm (e.g., a place in heaven) (24, 25).

Sometimes, the term altruistic is also used in cases where the kidney donation is not anonymous but the donor is expected to derive hardly any tangible benefit, for example, when the donor and recipient are acquainted, although they do not have a direct emotional or genetic relationship. In some of these cases of so-called altruistic donation (where anonymity is not guaranteed), there can be doubts about the motivation of the donor and suspicions regarding payment for donation by recipients who have no obvious relationship with their donor, especially if donation was previously solicited by the recipient (26) (e.g., through the internet site [www.matchingdonors.com](http://www.matchingdonors.com)).

It has been suggested that the term “altruistic donation to a stranger” is more accurate (27) and there were even attempts to propose regulations for this type of donation (28). However, it remains to be seen whether all nonpaid donors are truly altruistic or whether truly altruistic donors even exist, because there is always some form of personal gain.

## DIRECTED VERSUS NONDIRECTED

Living organ donation is often referred to as directed or nondirected (3, 11, 12, 29). Essential to this distinction is the intention of the donors: is the organ intended for a specific person or to a member of a specific group of people, or not? Directed donation can aim both at genetically related and genetically unrelated recipients, but usually aims at someone with whom the donor has an emotional relationship. However, cases do occur when people offer to donate an organ to an anonymous recipient, provided that the recipient meets specific criteria (e.g., regarding age or ethnic group) or is a well-defined individual (e.g., a famous person).

Even though nondirected donation is aimed at an anonymous recipient, nondirected donations can occur where the original intention of some nondirected donations

could be to donate to a specific person, but this proves impossible (e.g., because of incompatibility), and the motivation to donate instead to an anonymous recipient is that the intended recipient benefits from a transplant as a result of the donation. This typically happens not only through kidney exchange programs such as paired exchange or domino-paired transplantation but also occurs in unbalanced kidney exchange programs where kidneys from compatible and incompatible couples are exchanged (30). Donors who have neither an emotional nor a genetic relationship with their recipient, but designate a specific recipient or member of a specific group of recipients, fall into a gray area. Strictly speaking, they are “directed” donors as they specify a particular recipient or group of recipients, yet the relationship with the recipient is lacking. Nevertheless, such donors are often, and in our view incorrectly, categorized into the group of nondirected (anonymous) donors (6).

To avoid the terminological confusion that could arise, a more straightforward and finer distinction should be made. In addition to using the broad notion of the intention of the donor, one should also incorporate the degree of specificity with which the donor identified his or her intended recipient. After this approach, one could distinguish between “specified” and “unspecified” donation, and discriminate further depending on whether the donation to the specified recipient happens directly or indirectly. Eventual conditionality is taken into account within the specified category. Specified donation refers to donation aimed at a specified recipient, whereas unspecified donation refers to donation aimed at an unspecified recipient. “Direct specified” donation refers to donation directly to the specified recipient, whereas “indirect specified” donation concerns cases where the donor does not donate directly to the (initially) specified recipient, for example, because of ABO incompatibility or positive crossmatch, but does so to an alternative recipient through an exchange program.

## CONCLUSION

When formulating this new classification, we have considered the motives of the donor rather than the relationship with the actual recipient. The word “donor” is derived from the Latin “donare” (to give) and we consider that the donation process and the donor’s intentions should be the basis for these definitions, rather than the resulting transplantation, as is usually the case in the existing literature. As has been argued above, the best way to focus on the intention of the donors without getting stuck in terminological confusion is by concentrating on the degree of specificity with which the intended recipient is identified and subsequently verifying whether the donation to this recipient happens directly or indirectly.

ELPAT encompasses professionals from many different cultural and professional backgrounds, allowing a multidisciplinary approach to this discussion. Our goal is to determine which choice of terminology is the most acceptable, succinct, and workable for each of the scenarios described above, from a multidisciplinary and international perspective. By providing terminological clarity free from moral or religious bias, we aim to allow the field of living organ donation to progress to other important research questions.

Based on the evaluation of the advantages and the disadvantages of each term, we concluded that:

The terms specified and unspecified living organ donation are the most appropriate and unequivocal.

Within the category of specified donation, a finer distinction should be made between “direct” and “indirect” donation.

The main benefits of our classification are that it avoids morally loaded (such as altruistic) or religiously loaded (such as “Samaritan”) terms; and that it is much less susceptible to interpretation than most of the existing terminology, as it is descriptive rather than evaluative.

We express our strong hope that national and international transplant societies will use our proposed new classification for living organ donation.

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