

ARTICLE

# The Ethical Acceptability of a Recipient's Choice of Donor in Directed and Nondirected Transplantation: Japanese Perspective

Eisuke Nakazawa<sup>1</sup>, Margie H. Shaw<sup>2</sup> and Akira Akabayashi<sup>1,3\*</sup>

<sup>1</sup>Department of Biomedical Ethics, School of Public Health, Faculty of Medicine, The University of Tokyo, Tokyo, Japan

<sup>2</sup>Department of Health Humanities and Bioethics, University of Rochester School of Medicine and Dentistry, Rochester, New York, USA

<sup>3</sup>Division of Medical Ethics, New York University School of Medicine, New York, New York, USA

\*Corresponding author. Email: [akira.akabayashi@gmail.com](mailto:akira.akabayashi@gmail.com), [akirasan-tky@umin.ac.jp](mailto:akirasan-tky@umin.ac.jp)

## Abstract

In organ transplantation, there is a lack of ethical discussion about the recipient's right not to receive a transplant. Using the current situation of living organ transplantation and deceased organ transplantation in Japan as an example, we prospectively discussed to what extent the recipient's right not to receive a transplant is ethically acceptable. In directed transplantation from a living donor, a recipient may refuse organ donation from a particular donor. It is preferable that a recipient's request for organ donation from a donor occurs as part of a transparent process. In nondirected transplantation from a deceased donor, refusal of transplantation from a particular type of donor appears potentially justifiable. There are both moral and pragmatic considerations. Certain refusals based solely on belief are morally unacceptable, and refusal to transplant a recipient based on the donor's age jeopardizes the entire transplant system. When religious beliefs affect mental and physical health, individualized measures are required for transplant rejection. We also deductively developed a prospective argument based on the current status of donor–recipient communication in living organ transplantation in Japan and the 2010 amendment of the law allowing relatives to be given priority in organ transplantation from deceased donors.

**Keywords:** Directed; Nondirected; donor; recipient; Japan

## Introduction

Living and deceased donors are critical components within both directed and nondirected organ transplantation. Directed transplantation is where an organ is intended for an individual named or specified (directed) by the living organ donor. Therefore, this transplantation process is onymous, with the donor and recipient entering a known one-to-one pair relationship.

Directed donations theoretically involved family members, friends, or colleagues as donors, although social media is increasingly identified as a tool to expand living donor transplantation.<sup>1</sup> In Japan, however, this is actually limited to family members. Although there is no law in Japan that regulates living organ transplantation, ethical guidelines issued by the Japanese Society for Transplantation limit living donors to relatives within the sixth degree of kinship (in Japanese terms, which is equivalent to fourth-degree relatives in the United States, i.e., second cousins) and relatives by marriage within the third degree of kinship (in Japanese terms, which is equivalent to third-degree relatives in the United States, i.e., uncles-in-law and aunts-in-law).<sup>2</sup> Organ trading, which possibly involves nondirected transplantation via third party, is prohibited by law even in Japan, as it is in many other countries.<sup>3</sup>

Nondirected transplantation is where an organ is intended for an individual neither named nor specified (nondirected) by the donor. Therefore, this transplantation process occurs anonymously. Organ transplantation from deceased donors tends to comprise nondirected transplantations in Japan.<sup>4</sup> Despite this situation in Japan, discussions have occurred outside Japan, due to the continuous shortage of organs, on institutionalizing directed systems for deceased organ donation and on the respective ethical issues.<sup>5</sup> Since the number of deceased donors in Japan is significantly low probably due to cultural factors,<sup>6</sup> similar discussions have started in Japan. This eventually led to the Revised Act on Organ Transplantation (2009)<sup>7</sup> and allows relatives in Japan to be given priority in organ transplantation from deceased donors, which has the effect of partially allowing directed transplantation. This is a significant change in the allocation of deceased donors in Japan.

Protection of the human rights of donors and recipients is critical to the promotion of organ transplantation. The rights of donors and recipients can be summarized as follows: (1) the right to donate organs: donors have the right to donate their kidneys, liver, and pancreas to recipients for living organ transplantation, and to donate other required organs for deceased organ transplantation, but this right is restricted if donors are minors or commit suicide<sup>8</sup>; (2) the right not to donate organs: donors and minors have the right not to donate their organs for transplantation, and no one should be obliged to donate against their will; (3) the right of the recipient to receive an organ: anyone who can be freed from the suffering of an illness by organ transplantation has the right to have organ transplantation, as determined equitably; and (4) the right of the recipient not to receive an organ: the recipient has the right not to proceed with organ transplantation.

In this paper, we discuss the right of a recipient not to receive an organ in the Japanese context. The right to donate organs and the right to withhold organ donation have been debated in terms of autonomy and, especially in Japan, in relation to the definition of death.<sup>9</sup> However, there is a lack of research on ethical aspects concerning the right of a recipient not to receive an organ, in other words, recipient rights or free choice in transplantation. This paper discusses prospectively the ethical acceptability of the right of a recipient not to receive an organ in relation to both directed and nondirected transplantation using Japan as an example. Such a discussion is important in other countries, too, because, for example, if the right of a recipient not to receive an organ includes the right to refuse an organ donation from a specific type of person, that right is inextricably linked to the right of a recipient to direct a donor.

## Discussion

### *The Right of a Recipient Not to Receive a Donated Organ Transplant in Directed Organ Transplantation*

With respect to living organ transplantation, it is permissible for a recipient to refuse organ donation from a particular donor, usually family members in Japan. The relationship between recipient and donor in living organ transplantation that is directed is basically a gift relationship.<sup>10</sup> As the relationship between the two is a gifting relationship, it would follow that a recipient should be allowed to refuse a donor's gifting act. This conclusion does not change even if the act could be regarded as a kind of contractual relationship, as donors are given the freedom to choose the recipient with whom they can enter such a contract.<sup>11</sup> Rather, it is in terms of a request for organ donation from a recipient to a donor that an ethical issue may emerge in directed living organ transplantation. Directed living organ transplantation is based on a recipient's request to a donor, whether mediated through medical professionals or family members who are not candidates, or whether understood implicitly. Japan is a family-oriented society.

Here, we will raise two Japanese scenarios. These are one of the authors' fictitious cases but based on long-term experiences in observing donor selection process in the Japanese context.

#### *Scenario 1*

A father in his 50s needs a liver because of his end-stage liver cirrhosis. The constitution of family is: spouse, the first son in his 30s (married) with two children, the first daughter in her 30s (married) with

one 2-year-old infant, and the second son in his early 20s (single) who is a student in graduate school, and tuition fee is supported by parents. Through the donor-selecting process, the father says to the second son that “You will be a donor, since you are young and your liver is vital. Also, it is not hard to take a leave of absence of your study for 2 months since you are single. I am paying your tuition fee, right?” In response, the second son said “Yes, since there is no one in the family other than me. Others are responsible for their family.”

This directed living organ transplantation is based on a recipient’s (paternalistic) request to a donor. In this scenario, the second son has a right to refuse to be a donor.

### *Scenario 2*

A father in his 50s needs a liver because of hepatoma without metastasis, which means there is a medical indication. The constitution of family is: spouse, the first daughter in her late 20s (unmarried), and the second daughter in her early 20s (unmarried). The father’s body weight is 90 kg, and his liver is large, which means he needs a large liver. The daughters are thin, and a liver from one daughter would not be enough. The spouse had hypertension and fatty liver, which means she cannot be a donor. After discussion with the transplant coordinator, two daughters say they both would be happy to donate liver to their father. With two livers, one right lobe, the other left lobe, the transplant surgery is possible. The father hesitates because two daughters are unmarried yet, and there would be large scars in their abdomen after surgery. However, the daughters’ positions are firm, and they persuade their father to accept their livers.

This directed living organ transplantation is based on a recipient’s request to a donor, though the recipient’s request comes after donors’ earlier decision.

Looking at these two Japanese scenarios, regarding directed living organ transplantation, the power relationships within the family concerned should be properly monitored and regulated by medical professionals (including transplant coordinators) or public institutions. The key issue involves maintaining the donor’s autonomy in the transplant contract. If relevant negotiations are confined to the private sphere, the validity of the gift agreement can be undermined. Appropriate safeguards also need to be in place to ensure that gift contracts in directed living organ transplantation do not encourage organ trading.

In directed living organ transplantation, it is preferable that a recipient’s request for organ donation from a donor occurs as part of a transparent process, that is, as a collaborative process in which the recipient, donor candidates, and medical professionals are all involved, rather than as a process entirely controlled by the recipient. Such a shared collaborative process can procedurally avoid unreasonable recipient candidate selection. An unreasonable selection of recipient candidates and subsequent requests for organ transplantation are likely to generate significant issues concerning living organ transplantation within the family concerned. Selection factors that are not based on medical utility require special attention when selecting donor candidates. In situations where personal likes and dislikes, gender identity, age, occupation, and position within a family could influence the selection of donor candidates, the selection process should be a collaborative process in which all the relevant stakeholders are involved.

Directed organ donation for transplantation from deceased donors is beneficial in terms of increasing the number of organs for transplantation in Japan, and the 2009 revision of the Organ Transplant Law allows limited priority donation of organs from determined donors to relatives; however, it is regulated to address certain risks, including money exchange or encouragement of suicide for the purpose of directed donation. When considering the right of a recipient not to receive an organ in directed organ transplantation, this revision to the Japanese law raises a further question concerning whether a recipient has the right to refuse transplantation of organs preferentially donated by a relative. At first glance, this type of recipient could appear unreasonable in that they both want an organ transplant and turn down the opportunity to have one. However, it is understandable that recipients may prefer to have organs donated anonymously for the following reasons. First, a recipient may recall the death of a relative through having that person brought to mind frequently due to receiving a new organ from that deceased relative, and feel deeply saddened as a result. This felt presence of the donor may threaten the recipient’s

sense of self-ownership concerning the new organ. Second, receiving an organ donation from a relative may make future relationships with relatives difficult. Given these plausible reasons, it should be acceptable for recipients to refuse to accept transplantation of organs that are preferentially donated by relatives. However, the recipient's refusal does mean that the donor's intention has not been fulfilled or their generosity accepted. This refusal belongs to the recipient's own right, but it may be not virtuous in the Japanese context. Japanese culture praises the recipient who accepts the donation, receives the organ gratefully, and enables to continue living alongside other relatives as intended by the deceased relative.

### *The Right of a Recipient Not to Receive a Donated Organ Transplant in Nondirected Transplantation*

In living nondirected transplantation, a recipient may refuse an organ transplant from a donor if the recipient wants to avoid the risk of subsequent contact with the donor or wants to maximize anonymity. Such concerns arise in terms of both paired exchange and transplantation chains as extraction and transplantation tend to occur within the same medical settings to facilitate more effective living organ transplantation. The risk of contact is even higher if both the recipient and donor families are linked. Japanese are typically reluctant to know who the donor is. Japanese people tend to want to close their human relationship network within their relatives. However, medical institutions can reduce the risks of contact and take steps to support anonymity. If a recipient or donor was to doubt the efficiency of an institution's management in this regard, a refusal to allow transplantation to proceed would appear reasonable. In such cases, a recipient may wait for an organ transplant from a deceased donor or, more rarely, accept only a directed transplantation from a relative whose donation would not raise similar concerns. Such situations need to be considered concerning living nondirected transplantation.

When considering nondirected transplantation from deceased donors, a refusal of transplantation from a particular type of donor because of certain views of the recipient may be considered as a recipient's right, but may also be considered potentially objectionable if based on factors such as age, gender identity, ethnicity, cause of death, residential area, or judgments based on biases unrelated to biological factors. In the Japanese organ transplantation system, information that can link the identity of a donor to the organ donated is not initially provided, but once the organ transplantation is completed, the name of the hospital where the donor died and related disease information, as well as details on age and gender, are made available. If a recipient could acquire the publicly available information beforehand, the recipient could refuse organ transplantation from a donor belonging to a particular category, simply because of a personal preference.

However, such refusals might be considered objectionable as a donor's generosity has been spurned for reasons unrelated to the medical needs of the recipient and the resources available. Organs donated by deceased donors for nondirected transplantation can be considered as forming part of the public resources in this domain, which need to be fairly distributed among those who need them. An organ transplantation system that incorporated personal preferences into its allocation criteria would introduce anomalies, inefficiencies, and delay, as well as potentially perpetuating racism, xenophobia, and other biases.

Refusing a transplant from a particular type of donor based on a medical evaluation is preferable to a refusal based on personal preference as the former involves objective criteria in relation to a patient's precise medical condition, whereas the latter involves considerations that are irrelevant to that condition. The following two cases illustrate the differences between the two types of refusal. The first case concerns a recipient's age-based rejection of an organ transplant. The second case concerns a rejection where a recipient believed that the transplant would affect the recipient's mental and physical health.

The first case, involving an age-based rejection of transplantation by a recipient, can be justified in terms of recipient rights, but raises issues concerning the coherent management of the organ transplantation system. For example, if both the kidney donated by a 20-year-old donor and by a 60-year-old donor were of acceptable transplant-tolerant quality, and a recipient was free to choose which to receive, the recipient would very possibly choose the kidney from the 20-year-old donor. A question arises,

however, as to whether it is appropriate to have a system that can approve organ transplantation according to the age of the donor of the organ when asked to do so by a recipient. In the so-called “I’ll pass this time” system, a recipient can decline an organ donation and wait for the next organ donation to appear, which would seem to take into account an individual’s rights in this regard. However, this situation would also seem to compromise the coherence of the waiting order system through allowing a distortion in what should be an equitable distribution of public resources. In addition, it is possible that, within the organ transplantation system, the place in the waiting list of a recipient who rejects a donation may become significantly lower. In allowing the possibility for this type of organ transplant rejection, an organ transplantation system may unintentionally act to compromise the health of a recipient.

The second case, where an organ is rejected due to a recipient’s belief (which may be religious or otherwise) that the transplant would negatively affect the recipient’s mental and physical health, can lead to a more difficult situation. For example, if a male recipient wished to reject an organ donation from a female donor because of concerns about sexual identity, such a refusal would not typically be considered reasonable. However, regardless of how unreasonable a choice not to accept an organ may be, it could have implications for a recipient who genuinely believed what they were saying, in terms of leading to a deterioration in their mental and physical health if the transplant were to proceed. Certain beliefs in this regard may appear implausible, but negative effects on health could not be ruled out if such beliefs were ignored. It would appear, therefore, that determining acceptable grounds for refusing an organ transplant remains a challenging exercise.

## Conclusion

In this paper, we discussed how ethically acceptable it might be for a recipient to refuse an organ donated from a certain type of donor in directed and nondirected transplantation in the Japanese context. In directed transplantation from a living donor, a recipient may refuse organ donation from a particular donor, although their reasoning may sometimes be considered objectionable. In nondirected transplantation from a deceased donor, refusal of transplantation from a particular type of donor appears justifiable. For example, in the case of transplantation involving a determined donation or preferential donation by a relative, a recipient may have reasonable cause to refuse such donations. However, issues may arise in seeking to accommodate certain beliefs considered reprehensible in other contexts, or in managing age-based selection or rejection of donors by recipients coherently within the overall transplantation system.

We deductively developed a prospective argument based on the current status of donor–recipient communication in living organ transplantation in Japan and the 2009 amendment of the law allowing relatives to be given priority in organ transplantation from deceased donors. Various Japanese scenarios considered in this article suggest the need for quantitative and qualitative research in other countries on the reasons transplant organ offers were refused, including an ethical analysis of the data.

**Acknowledgment.** The authors greatly appreciate Dr Richard Demme, University of Rochester, for his insightful comments on this paper.

**Funding Statement.** This study was funded by the Mitsubishi Foundation (201920005).

**Conflicts of Interest.** The authors declare that they do not have any conflicts of interest with respect to this paper.

## Notes

1. Henderson ML, Adler JT, Van Pilsum Rasmussen SE, Thomas AG, Herron PD, Waldram MM, et al. How should social media be used in transplantation? A survey of the American Society of Transplant Surgeons. *Transplantation* 2019;**103**(3):573–80.
2. The Japan Society of Transplantation. *Nihon-ishoku-gakkai Rinri Shishin [Ethical Guidelines of the Japan Society of Transplantation]*; 2015; available at [http://www.asas.or.jp/jst/news/doc/info\\_20151030\\_1.pdf](http://www.asas.or.jp/jst/news/doc/info_20151030_1.pdf) (last accessed 2 Apr 2022). See also Fujita M, Matsui K, Monden M, Akabayashi A.

Attitudes of medical professionals and transplantation facilities toward living-donor liver transplantation in Japan. *Transplant Proceeding* 2010 Jun;**42**(5):1453–9.

3. Act on Organ Transplantation (Japan). Act No. 104, 1997; Revised Act No. 160, 1999; Revised Act No. 83, 2009. See also, 42 U.S. Code §274e.
4. Although paired kidney transplantation has a directed property, it has the same mechanism as the transplantation chain system and differs from standard directed transplantation. Therefore, in this report, paired kidney transplantation is classified as nondirected for convenience.
5. D'Alessandro T, Veale JL. Innovations in kidney paired donation transplantation. *Current Opinion in Organ Transplantation* 2019 Aug;**24**(4):429–33. See also Bianchi A, Greenberg R. Deceased-directed donation: Considering the ethical permissibility in a multicultural setting. *Bioethics* 2019 Feb;**33**(2):230–7; Sherwin T, Coster DJ, La Nauze J, Merry A, Pendergrast D, Armitage WJ. Is directed donation misguided? *Clinical and Experimental Ophthalmology* 2004 Feb;**32**(1):5–8.
6. Akabayashi A, Nakazawa E, Ozeki R, Tomiyama K, Mori K, Demme R, et al. Twenty years after enactment of the Organ Transplant Law in Japan: Why are there still so few deceased donors? *Transplantation Proceedings* 2018;**50**(5):1209–19.
7. See note 3.
8. See note 3. See also Ministry of Health, Labor and Welfare (Japan). “Zoki no ishoku ni kansuru horitsu” no unyo ni kansuru shishin (guidelines) [*Guidelines for the Operation of Act on Organ Transplantation (Japan)*]; 2012; available at [https://www.mhlw.go.jp/bunya/kenkou/zouki\\_ishoku/dl/hourei\\_01.pdf](https://www.mhlw.go.jp/bunya/kenkou/zouki_ishoku/dl/hourei_01.pdf) (last accessed 2 Apr 2022).
9. Bagheri A. Individual choice in the definition of death. *Journal of Medical Ethics* 2007 Mar;**33**(3):146–9. See also Handa H. Waga-kuni niokeru noshi rongi [Controversy over brain death in Japan]. *Journal of UOEH* 1990;**12**(3):309–14.
10. Nakazawa E, Maeda S, Yamamoto K, Akabayashi A, Uetake Y, Shaw MH, et al. Reuse of cardiac organs in transplantation: An ethical analysis. *BMC Medical Ethics* 2018 Aug 17;**19**(1):77.
11. Nakazawa E, Yamamoto K, Akabayashi A, Shaw MH, Demme RA, Akabayashi A. Will you give my kidney back? Organ restitution in living-related kidney transplantation: Ethical analyses. *Journal of Medical Ethics* 2020 Feb;**46**(2):144–50.