

How to Reforge the Lost Chances? Organ Donation in Japan

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Abstract

This paper aims to examine the complex situation of organ donation (from brain-dead donors) in Japan and to make an insight into the multifaceted context of amendments in the organ transplantation law (in 2009).

Streszczenie

Artykuł ten ma na celu zbadanie złożonej sytuacji dawstwa organów (od dawców ze stwierdzoną śmiercią mózgową) w Japonii oraz dokonanie wglądu w wieloaspektowy kontekst zmian poczynionych w japońskim prawie transplantacyjnym (w 2009 roku).

Key words: organ transplantation, gift, Japan.

Słowa kluczowe: transplantacja organów, dar, Japonia.

Introduction

Organ donation has been discussed for many years in Japan. Along with these discussions, the law in this respect was shaped. Apart from the mentioned discussions and legal frameworks, the kernel of this problem is psychological readiness to tame, accept and realize the idea of tissue and organ donation, particularly from brain-dead donors. In this article I will examine only a small part of this intricacy. Let me bring you closer to this issue to pinpoint how to reforge lost chances for transplantation into a precious *Ray (Relay [1]) of life*.

1. Legal frameworks

A serious social and political debate on changing organ transplantation law could be seen in Japan in 2009. On 19 June 2009 the House of Representatives accepted amendments to Organ Transplantation Law (passed in 1997) and afterwards, on 13 July 2009, the House of Councilors passed the revised bill. The amendments entered into force on 17 July 2010. What are the changes?

- 1) The change from an “opt-in” to an “opt-out” system (the removal of organs from a brain-dead patient is allowed, if the patient did not openly refuse to become a donor and if surviving family members do not have objections);
- 2) It is allowed that children under the age of 15 can become donors of organs (if parents/surviving family gave their consent);
- 3) The priority of organ donation is given to the family of brain-dead donor (problematic issue);
- 4) The concept of “brain death” was legally recognized as the actual death.

The law has been revised. However this removal of legal obstacles is only “a tip of the iceberg”. Many Japanese people hesitate to make a decision in this respect. Some Inquisitive Reader might be perfectly confused – what is the impact of the law and its perception? Let me investigate this intriguing issue.

2. The norms of the law and its perception

The law has been changed from an “opt-in” to an “opt-out” system. In practice it means that a person who wishes not to donate his/her organs has to make a record in this respect, but his/her family still has the right to refuse organ of donation. Such a situation reveals the discrepancy between the law and the perception of its norms in the society. People might acknowledge the norms of law, but it does not mean that they incorporate them into their internal system of values (they might not internalize the norms of law and emotionally disagree with them).

Here we are considering some very delicate type of law which touches a very intimate sphere - organ transplantation. And this for many laymen directly means using some parts of their body or a body of their beloved family. Thus, if the norm (“it is noble and desirable to donate your organs after death to other people in need”) is not internalized by a layperson, the law cannot bring expected resonance in the society and cannot fulfill the role of encouragement (however, might fulfill the role of protection - from coercion, trafficking and other illegal cases). In the “opt-out” system people are forced to make a negative decision, but those who do not, both adherents of donation and the undecided, are left within the system.

Thus concluding the second point, it is very important to examine how laypeople perceive the relation between legal and ethical norms. Then we have to explore the field of individual patterns of attitudes towards organ transplantation in certain groups of society (in selected target groups). “Nihil novi sub sole” (Ecclesiastes 1, 9) - the Inquisitive Reader might snort with ironical laughter, being under the melancholic craving for some “greater” truth. But it is indeed very difficult to have an insight into the Japanese thoughts and attitudes. Furthermore, a proper framework needs to be applied.

3. What kind of framework?

In what categories, in what type of concepts an act of organ donation should be considered? If we take the context of the law, the first thought is the notion of some “duty” - “I am inwardly obliged (by law/conscience) to decide, whether I am explicitly against”. However, many people do not want to make a decision openly (that is why a mandatory choice is problematic). Therefore using the framework of “duty” might be quite inappropriate in the case of organ transplantation.

The other framework is a popular (particularly in Western countries) concept of the “gift of a second/new life” or the “gift of love” to people in need. It is important that there is no need to reciprocate this gift. However, taking such a gift might cause a lot of problems. Some people do not know how to accept it and live with it, as they might feel guilty, embarrassed, depressed, ambiguous or helpless. Particularly in the Japanese context, the act of giving is inscribed in the framework of *Giri* (義理) which says that the recipient of the gift is obliged to reciprocate to the donor - the bigger the gift, the greater the return should be. Many Japanese people are troubled by this situation - in what way received organs can be repaid, how the recipient can reciprocate to brain-dead donor's family? These feelings may be really intense and even pose a risk that the recipient's organism rejects a transplanted organ.

The framework of “transaction” in which the organs are subject to selling and buying are not taken for consideration here. However, illegal vendors and desperate buyers have existed and will continue to exist all over the world.

To conclude the third point, there is an urgent need to publicly rethink the concept of “pure” gift which will be free of return, but also devoid of any negative connotations. People do not know how to behave, how to give or accept the gift of organs (they might not have a proper behavioral “script”). Perhaps people should have some theoretical possibility to envisage a situation of giving and receiving (with all socio-cultural and psychological

difficulties). Such a possibility could be offered by professionals (psychologists, mediators, support groups), who could organize special meetings and workshops near Transplant Coordinating Centers for anyone who feels such a need.

The Inquisitive Reader might be bewildered and even lost in all these scripts, words, behavioral “translations”: “Where am I?” Well, it is better to ask where the “self-determination” is?

4. Hunting for “Self-determination”

In Japan “family-determination” within medical practice is much more visible than “self-determination”. In the light of the amended law the family of a patient has the right to refuse organ donation. And in the case of organ donation from children, organs can be procured only after obtaining the permission from the family.

The focal point here is the interest and the right of an individual adult and the interest and the right of the family. If they have the same view, there is no problem. The conflict arises when the wish of an individual differs from the wish of the family (or is unknown). The family has the right to refuse organ donation. And that is a crucial legal “obstacle” which was not removed in 2009. It even looks like a few steps back were taken as it is remarked here: “The 2009 revision widened the family's role, and now organs can be procured even when donors have not expressed their wish to donate, as long as their families give consent to the donation. Because the individual's right to self-determination in medical practice has not been well-established in Japan yet, this revision concerning the donor's consent can be understood as a retreat from the struggle for the establishment of the principle of self-determination.” [2]

To conclude this point, I think that the “hegemony” of the family in the context of organ donation might bring rather counterproductive effects:

- 1) Family might put a veto or at least might hesitate in the situation, when a quick decision must be taken and such situation will probably not move forward the situation of organ donation;
- 2) Prioritized donation limited to the family of brain-dead donor (the first degree of affinity) might inhibit the will of altruistic donation to the strangers;
- 3) Patients in urgent need for transplantation [those who are leaving for foreign countries to receive organs because no family member can be a suitable donor] might consider the system of prioritized donation from brain-dead donors as unfair.

But to the mind of the Inquisitive Reader some puzzling anxiety might percolate - does brain death really mean a person is dead?

5. When the brain is dead...

The amended law (in 2009) acknowledges that “brain death” is the actual death of a person. The number of brain-dead donors according to the statistics of the Japanese Organ Transplantation Network is as follows: 1997 (Japanese Organ Transplantation Law was established) - 0 brain-dead donors; 1998 - 0; 1999 - 4; 2000 - 6; 2001 - 8; 2002 - 6; 2003 - 3; 2004 - 5; 2005 - 9; 2006 - 10; 2007 - 13; 2008 - 13; 2009 - 7; 2010 (31/08/2010) - 8. It means the total number of brain-dead donors is 92 (1997-31/08/2010) [3]. Brain death can be declared and confirmed only by a team of medical representatives not involved directly in organ transplantation. Members of the patient’s family can only accept (or not) this medical confirmation, this does not make the family implicated in the act of determining donor’s death (however, Inoue and Hong underline: “A bereaved family’s decision on organ procurement from the “brain-dead” means that they must simultaneously consider whether to accept the notion of brain death as legal death and whether to start the organ procurement process. This may be a difficult task for a family, because it seems that the family members must determine the individual’s death.” [2].

That moment reveals a very visible hiatus between the norms of the law (in the light of the law brain death is so-called legal death) and personal system of values and beliefs (“I am not convinced that brain death is really death”). And the “inner split” between these two systems of norms might lead to dramatic, irrational decisions. A medical team is there to check and pronounce objectively whether brain death occurred or not. Family will not pronounce it, but it has to take its position whether to accept this declaration or not.

To conclude this point, the concept of brain death was medically and legally acknowledged, but it was not “psychologically” acknowledged and internalized by many laypeople in Japan. And here we are again coming back to the first point: if the concept is not internalized by a layperson, the law cannot bring expected resonance in the society. The Inquisitive Reader might not withstand and impatiently alluding to the words of Francis Bacon (“The understanding must not therefore be supplied with wings, but rather hung with weights, to keep it from leaping and flying” [4]) might ask: what can be done with it?

Conclusions: What can be done?

The law in Japan tries to reflect the mentality of citizens in this country and their system of values. However, the amendments demonstrate: 1) the urgent need to “do something” about the shortage of donors (particularly brain-dead donors), as well as 2) perfec-

tly visible traces of haste (the law has been changed without reaching a consensus in the Japanese society).

The way of thinking about organ donation and brain death are failing to “catch up” with the legal norms. This hiatus has to be filled. But not through pushing amendments “by force” into society, which visibly is not ready for it. This is not the appropriate way to achieve self-sufficiency of organs in Japan.

The favoritism given to the “family-determination” which can be observed in all legal resolutions is striking. Further examinations should be pursued in this area. What can be done then?

1. Try to explore the way of communication within family to seek first germs of unanimous statement towards an organ transplant;
2. Try to make opportunities for laypeople to talk about organ transplants and to share their objections in some open meetings;
3. Try to reconsider the manner of talking to people about transplantation as inadequate language might contribute to the phenomenon of the reactance;
4. Try to check the mechanisms of community involvement (and the concept of altruism) in groups/communities which openly express the pro-transplant attitude;
5. Try to explore or look for the factors, motives, which can strengthen the altruistic model of organ donation.

Perhaps two things can reshape situation of organ donation:

1. Better communication between people involved in the organ transplantation process (psychological counseling and support encompassing: medical team, donor/recipients with families);
2. Taking time to comprehend/tame/accept the idea of transplantation. People need time to cope with emotions.

It is not my aim to make the Inquisitive Reader believe that the only “One Way” to solve problems of transplantation in Japan is “public involvement and management of emotions”. There are many other ways. One of them is for example the development of artificial organs (and problems of their status, psychological acceptance). It still has a very long way to go, however, we can prepare for it in advance and talk about it next time.

Take Home Message

People might be more susceptible to change their behaviour when they can clearly see the chances which they had already lost rather than when they watch new/future chances. Because

they do not like to feel that they are “losing something”. And this is not only the matter of guilt, the power of shame (“losing face”/high self-esteem) or whatever else. This is exactly the great power of reactance which can reforge the lost chances into the unfading *Ray (Relay [1]) of life*.

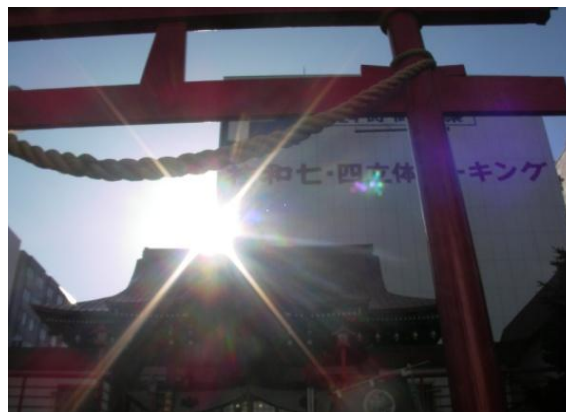
But this same power of reactance may also reforge the Inquisitive Reader into the ruthless Inquisitor of the only One Truth, as it was in the case below:

“L'Anticristo può nascere dalla stessa pietà, all'eccessivo amor di Dio o della verità, come l'eretico nasce dal santo e l'indemoniato dal veggente. Temi, [Adso], i profeti e coloro disposti a morire per la verità, ché di solito fan morire moltissimo con loro, spesso prima di loro, talvolta al posto loro. [...] Forse il compito di chi ama gli uomini e di far ridere della verità, *fare ridere la verità*, perché l'unica verità è imparare a liberarci dalla passione insana per la verità.”¹ [5]

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¹ Eco, U. (1980). *Il Nome Della Rosa*, Bompiani: Milano: “The Antichrist can be born from piety itself, from excessive love of God or of the truth, as the heretic is born from the saint and the possessed from the seer. Fear prophets [Adso], and those prepared to die for the truth, for as a rule they make many other die with them, often before them, at times instead of them. [...] Perhaps the mission of those who love mankind is to make people laugh at the truth, to *make truth laugh*, because the only truth lies in learning to free ourselves from insane passions for the truth.”, 493.