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Individual choice in the definition of death

A Bagheri

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While there are numerous doubts, controversies and lack of consensus on alternative definitions of human death, it is argued that it is more ethical to allow people to choose either cessation of cardio-respiratory function or loss of entire brain function as the definition of death based on their own views. This paper presents the law of organ transplantation in Japan, which allows people to decide whether brain death can be used to determine their death in agreement with their family. Arguably, Japan could become a unique example of individual choice in the definition of death if the law is revised to allow individuals choose definition of death independently of their family. It suggests that such an approach is one of the reasonable policy options a country can adopt for legislation on issues related to the definition of death.

There are three major issues at stake with regard to the ethics of organ transplantation. The first major issue is deciding when human beings are dead. Except for living donation, non-renewable organs for transplantation must be removed only from a dead body. The second issue concerns who is entitled to authorise organ removal, or in other words, how organ procurement can be ethically sound. Finally, there are ethical issues related to organ allocation and deciding who should receive the organ.

I would like to clarify that my focus in this paper is on the first issue because for transplantation policy it is critical to define what human death is.

The worldwide controversy on alternative definitions of death has shown that cultural, religious and ethical issues have a prominent role in accepting or refusing brain death as a definition of human death. Medicine alone can establish medical criteria to diagnose the brain-dead state, but cannot show whether a brain-dead patient is ''alive'' or ''dead''. In the current situation, following organ procurement policy, in many countries people are just asked whether they agree to organ donation, without asking whether they believe that brain death is equal to human death.

Correspondence to:
A Bagheri, Graduate School of Law, Kyoto University, Sakyo-Ku 606-8501, Kyoto, Japan;
bagheri@research.mbox.media.kyoto-u.ac.jp

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UNCERTAINTY IN DETERMINATION OF HUMAN DEATH

Regarding the decision on when human beings are dead, two questions should be answered:

1. When should a person be treated as dead?
2. Who should decide what concept of death is to be used? (Who is authorised to answer the first question?)

Let us focus on the first question: the definition of death is a matter of controversy and there is a lack of consensus.[1] Even the cardio-respiratory definition, which comes from centuries of human experiences, has been the subject of doubt and criticism in terms of its application to transplant technology. Critics argue that irreversible asystole can be equated only with a clinically determinable point of no return in the process of dying and cannot define human death.[2] Many authors have stated that the definition of human death is beyond the scope of medicine alone, and philosophical, cultural and religious issues have a great role.[3 4]

If transplant technology had never been developed, we would still need to face and deal with the definition of death. The definition of death would also affect other health policies such as futile treatment and withdrawal of life-sustaining treatment because of the lack of health resources, for example, ICU beds. Therefore, it has been suggested that the definition of death should not be linked solely to the use of the body for transplantation.[5] Several alternative definitions for death have been proposed so far, such as loss of whole brain function, loss of higher brain function, and there are many others. As there is huge ambiguity and controversy among alternative definitions, Veatch[6] has argued that ''when there is a doubt about which of the definitions to adopt, we should take the safer policy course especially in matters that are literally life and death''. After a careful examination of different alternatives, he says that the higher-brain formulation has little practical importance in the clinic, although it reshapes our theoretical understanding of what it means to be dead, and concludes that we should choose a whole-brain definition at this time.

Here, on the basis of his argument, I would like to emphasise that, to be more individualistic or more conservative in terms of preventing any possible violation to individuals' rights, the opinions of individuals have to be taken carefully into account, especially when the question is one of life and death. However, by choosing the safer course, no one should be considered dead based on irreversible loss of entire brain function if he or she, while competent, has asked to be pronounced dead based on a conventional cardio-pulmonary definition of death.

In the transplant scenario we have two groups of people, recipients and potential donors, who have moral claims on society. An ethically sound organ procurement policy should ignore neither the vital needs of the recipients nor the dignity and interests of the potential donors. Although providing organs to deal with the organ shortage and so

save more lives is an important task, that goal should be achieved by morally acceptable means. It should not ignore individual autonomy or violate a person's rights and dignity. As Kant says, to treat a person merely as a means, with no regard for that person's own goal violates that person's autonomy. [7] However, in the case of a cadaver donor, there is no doubt about the vitality of the donor and the concern is just the issue of authorisation for organ removal. Much more attention should be paid to the pronouncement of death of a brain-dead person before organ removal. This is because it relates to a ''person'' whose vital status is not clear.

The individuals' perspectives are being ignored when the legislation announces that ''according to the law the brain dead patient is dead''.

If we accept that the principle of autonomy refers to ''self-rule'' or ''self-governance'', then it may include concepts such as liberty rights, privacy, individual choice and freedom of will. In other words, it simply means being one's own person and as Beauchamp and Childress[7] (p 58) say, it means the individual ''acts freely in accordance with a self-chosen plan''. If policy makers do care about the principle of autonomy then, in the situation where there are doubts and controversies concerning the definition of death, respecting the autonomy of individuals requires us to approve the ''conscience clause'' in the law, permitting an individual to specify the standard to be used for determining death. Therefore, an individual's preferences should take precedence over others' preferences (Veatch,[6] p 37).

On the question of who should decide when a person is dead, there are three options, as discussed below.

Definition of death by the state's authority

This model, which appears in many organ procurement laws, declares that ''People with dead brains are dead''. On reviewing the related laws in practice in some countries, such as the ''Uniform Determination of Death Act'' in the US and organ transplantation laws in some Asian countries, we can see that these laws presume that brain death is equal to death and in fact there is no room for an individual's discretion on this matter.[8] Consequently, it just asks people, whether they agree to organ donation or not. For example, the US ''Uniform Determination of Death Act'' says, ''An individual who has sustained irreversible cessation of all functions of the entire brain, including the brain stem, is dead''.[9]

If we think citizens should consider their own death or life just ''according to the law'', it suggests that societal interests in a convenient uniform definition outweigh individual choice.

Autonomy-loving ''individualistic'' American society also allows no choice except being treated as a dead person ''according to the law'' when the brain-dead state occurs. It is worthwhile to note that only the New Jersey Declaration of Death Act authorises individuals to reject the state's default definition of death based on whole-brain definition, but the law limits its provision to religious objection—that is, when there is a religious reason to reject whole-brain definition.[10]

Professional judgement by a doctor standing at the bedside

As a matter of public policy, the question is whether the treating doctors should be given the authority to determine a patient's death by choosing a particular definition of death based on their own preferences.

In fact medicine can only explain the medical condition of the patient and confirm the diagnosis or rule out the chance of brain function, and that is why the medical professional obviously should be asked to establish the criteria for measuring a condition such as brain death (Veatch,[6] p 47). We should distinguish between defining human death and establishing the criteria for diagnosis of brain death. However, as has been mentioned above, the loss of ''life'' or whatever makes a person ''alive'' and what is to be called ''death'' is a philosophical and moral question rather than a mere medical question. It is worthwhile to mention that doctors also, as members of society, have their own personal beliefs about life and death, and also self-interest, which would inhibit their independent medical judgements. Furthermore, as Veatch argues, definition of death leads to policy confusion because different doctors seeing the same patient could use different standards for pronouncing death.

Individual preferences

Although there are some arguments concerning the role of individual autonomy after death,[11] there is no doubt that human autonomy must almost always be respected when the person is alive.

It may be justifiable to say that for the purpose of saving lives, it is ethical to remove an organ from a dead body. Some ethicists even believe that it is ethical to remove an organ from a deceased person without prior consent. In fact an attempt is being made internationally to override the necessity of donor's consent by giving the priority to recovery of organs over respect for individual autonomy.[12] But how is it ethical to pronounce somebody's death based on a controversial and doubtful basis and against the person's own beliefs and values?

After evaluating the recipient's need on the one hand and harm to the cadaver donors on the other hand, defenders of procurement without consent conclude that, because of the great benefit to the recipients, respect for the wishes of cadaver donors can be ignored.[13] Even if we accept this argument about cadavers, we should be careful to distinguish between failing to respect the wishes of the cadaver if the individual's organ is being removed without consent (either on the basis of the salvaging model or the opting out system) and the harm to a brain-dead person while her or his vital status is still doubtful. However, removing an organ from an individual who may believe that brain death is not equal to human death constitutes harm to that person.

A critic would claim that giving individuals the right to choose the definitions of death would cause public chaos. If the law permits individuals to decide when they should be treated as dead, then it may happen that a patient with diabetes or a patient undergoing dialysis may ask not to be treated if he or she becomes comatose and loses consciousness, based on her or his definition of death. The answer to this problem could be that, if a conscience clause is permitted, individuals would have a right to choose only a single definition among socially accepted alternatives. Individuals would not be able to choose a bizarre definition. It should be stressed that an individual would be allowed to choose on the basis of their own views and preferences between socially accepted standards, which so far are cardio-respiratory death and whole-brain definition. This does not mean that they are allowed to choose their definition arbitrarily.

A question we may raise is whether there is any conflict between this approach and other organ procurement models. In fact all models of organ retrieval come into play after the pronouncement of death (no matter whether death is pronounced for a person with a dead brain or for one without a heart beat). The area on which this approach has focused is independent of application of any organ procurement model. The conscience clause emphasises giving the right to individuals to refuse the brain-oriented definition if it violates their beliefs and values. With the use of a conscience clause, a patient is dead based on either the traditional definition or the brain-oriented definition according the individual's prior agreement. In fact, at the point of death pronouncement, nothing related to organ procurement is different. How organs are to be procured

will depend on which procurement system is established, that is, organ removal based on donor consent (opt in or opt out), salvaging or other models. It should be noted that this approach concerns not just organ procurement; it emphasises ''individual choice in death definition'' as an individual right in any other clinical situation in which death determination becomes an issue.

INDIVIDUAL CHOICE: COULD JAPAN BE AN EXAMPLE?

Japan is the only country, which permits individual choice in death definition for the purpose of organ transplantation, and in agreement with the person's family. In this section, the Japanese situation is examined.

The Japanese organ transplantation law of 1997 is the fruit of a long debate on brain death and organ transplantation. Over almost three decades, medical, legal and public discussion has occurred; a lack of consensus on the definition of human death caused a long delay in adopting a law on organ procurement. Finally, policy makers in Japan have adopted a law with unique features, such as giving an opportunity to individuals to choose the definition of death based on their own views. Therefore, in Japan individuals may choose either cessation of cardio-respiratory function or loss of entire brain function for their death pronouncement, which Morioka called ''pluralism on brain death definition''.[14]

However, the choice is permitted in Japanese law only if organs can potentially be used for transplant with the agreement of the family, which means that although individuals can choose the definition of death based on their own views, the law gives power to the family to confirm or reject the choice.

I will explain later how the role of the family according to the law—which allows the family to override the individual choice in death definition—made it hard to call the Japanese law a pure individual choice in the definition of death in the current situation.

The first effort to pass a law on organ transplantation following brain death failed in 1994. The main reason why the proposed law was rejected by the Diet in 1994 is said to be because it stated that brain death is equal to death, and also because it approved surrogate decision making by the family. These issues raised serious arguments and concerns among some parliamentary members, resulting in defeat of the legislation.[15] However, the situation has changed since then and, as public polls show, the number of people who accept the concept of ''brain death'' has increased from 29% to 60%.[16]

The current law states that for organ removal, the donor's prior declaration and family agreement are both necessary requirements.[17] The organ donation provisions of the law apply for brain dead donors as well as any cadaver. A very important article of the law authorises organ removal from a brain-dead person only if the donor has, during his life expressed in writing his consent to the diagnosis of brain death (as human death) as well as his intention to donate his organ(s). Therefore, the law authorises individuals to choose between the traditional definition or the alternative standard based on brain function by signing an ''Organ Donation Decision Card''. Individuals can state their wishes at the back of this card by marking one of the following items: (1) I wish to be a donor based on the brain-oriented definition; (2) I want to be a donor after cardiac death; or (3) I refuse to donate organs.

The law is not free of criticism, especially in terms of adopting a double standard regarding the role of the family. On the one hand, it gives the family the power to veto an individual's willingness to donate. On the other hand, it does not authorise the family to be a surrogate decision maker based on the interests of their beloved ones when they are in a brain-dead state and the organ donor card cannot be found. Nevertheless, the unbalanced role and power of veto of the family under the present law can be seen as an obstacle to organ procurement in Japan.[18] It should be noted that the efficacy of the Japanese law is influenced by the negative effect of the above-mentioned factors, and the transplantation rate shows that the law did not succeed in terms of increasing organ donation.[19]

INDIVIDUAL CHOICE AND THE ROLE OF THE FAMILY IN JAPANESE CULTURE

Many commentators have shown the important role of the family in Japanese society. Kimura mentions that the process of dying is regarded not as an individual event but as a family event in the Japanese culture.[20] There is no doubt that any transplant-related legislation should be concerned with inclusion of the opinion of the family in the decision-making process. This forms a basis for social acceptance of the legislation. However, in any culture a practical question arises: to what extent is the family's opinion to be taken into consideration?

According to the law, family consent is required both for organ procurement and for declaration of death according to brain-based criteria. Therefore an individual can choose the definition of death with the agreement of her or his family, but not independently.

Japan is the only country that allows individuals to choose either the traditional definition or the brain-oriented definition of death, but individual choice must be confirmed by the family and it makes it hard to present Japanese law as an example of a truly individual choice in death definition—it is more a family-based choice. This limitation also exists in the New Jersey Declaration of Death Act, which authorises individuals to reject the state's default definition of death only on religious grounds and not in all situations.

However, the family cannot make a choice of the definition of death on behalf of a member of the family. The law is currently under revision and some proposals have been submitted to the authority. The role of the family is one of the main concerns in the proposals.

CONCLUSION: INDIVIDUAL CHOICE OVER THE DEFINITION OF DEATH

In the current situation there is no single definition for human death, and neither of the alternatives has yet gained a consensus. The existence of worldwide doubt about whether brain-dead people are dead or alive and dependency of the definition of death on religious, cultural values and philosophical grounds support such a policy of allowing individuals to choose under which condition they wish their death to be pronounced. A fair, ethical approach in this situation would be to consider brain death as an accepted alternative for human death, which an individual may choose or reject based on his or her values. This paper has advocated the individual right to choose the definition of death from among currently applicable definitions for any clinical purposes and not just for organ transplantation. If some day higher brain criteria or any other alternative definitions become an accepted definition for human death for most of society and applicable by law, the position of this paper is still firm and would advocate people's right to choose among those two, three or more alternatives. By imposing a group's preferences others may feel violated, but in this approach nobody may be ''harmed'' and individual autonomy would be more respected if choice were permitted.

In the case of organ transplantation, this approach also gives the opportunity to declare willingness to donate after death based

on the traditional definition if the brain-oriented definition of death is opposed. Allowing individuals to accept or refuse the alternative definition of death may also increase public confidence in the organ procurement system and will promote voluntary organ donation. It also encourages a person to be a donor, if not as a brain-dead donor at least as a cadaver donor. A very important point is that by adopting such a policy, cultural, social and religious issues will be addressed and it makes the organ procurement system ethically sound. Japanese organ transplantation law could become a unique example of individual choice in the definition of death by allowing individuals to choose the definition of death independently of their family. This approach is one policy option that a country can adopt for legislation on issues related to the definition of death.

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