

A Comparative Study of Organ Donation after Brain Death in Japan and Australia

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Key words : organ donation, brain-death, death education, organ procurement, family discussion

Abstract

Objective : (1) To compare the status of organ donation from brain-dead donors in Japan and Australia. (2) To identify the possible reasons for the low rates of organ donation from brain-dead donors. **Background** : The shortage of available organs for transplantation has prompted many countries to develop a system for the use of organs from brain-dead donors, including Japan and Australia. Yet, there is a wide range of organ donation rates and policies between Japan and Australia in the current status of brain-dead organ donation. **Discussion** : Comparison of transplantation from brain-dead donors in Japan and Australia reveals significant differences with respect to the frequency of transplantation, legal regulations, organ donation policies and decision-making for consenting to cadaveric organ donation. These differences are determined by a variety of factors, including the policy on organ donation and medical infrastructure for Australia, and anthropological issues for Japan. **Conclusion** : Death education can be required in order for Japan to increase donation rates, whereas the improvement in the organ procurement system and its public acceptance are for Australia.

1 . Introduction

The shortage of available organs for transplantation has prompted many countries to develop a system for the use of organs from brain-dead donors. The procurement of organs for transplantation involves the extraction of organs from deceased donors. This process must act in accordance with legal requirements, including the definition of death and consent. There is evidence that the shortage of organ donors is not primarily the result of a lack of suitable donors, but rather the result of the failure to identify them, obtain consent and procure the organs¹⁾. Previous studies identified a number of barriers to improve that result — for example, an ineffective organ procurement system, unwilling to think about death, a lack of social solidarity and anthropological issues around organ donation. Some countries successfully manage all of them for the purpose of increasing deceased organ donation, whereas some are

not.

This paper will discuss and compare the current situation of deceased organ donation in Japan and Australia in order to show the changes in brain-dead donation rates in recent years, and to highlight the effective strategies Australia is using to increase donation rates. The paper then offers a possible explanation for the low rates of deceased organ donation in each country for the purpose of making the contrasts more apparent. These contents of each country are separately presented because each country has distinctive medical, social, cultural background, including the manner in which families are involved in decision-making about health care generally.

2 . Setting the scene — Japan

In 2 July 2013, the Japan Organ Transplant Network announced the results of the questionnaire about whether the respondents express their intentions to be donors after cardiac arrest or brain death. The object of this study was 1000 people aged between 10 and 60 and being conducted in 2013 and 2012. The result is that 15.7% of the respondents answered “to reveal somehow their will”. This was an increase of 4.6% compared to the same survey

(平成25年10月23日受理)

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from last year. However, 84.3% of the respondents referred to as “not to reveal the will of their own”.

The revised organ transplant law in 2010 has allowed the deceased family to give a written consent to the removal of organs if the intention of the deceased is unknown. Since then, there have been only 138 cases. Of these, only 20% had expressed their intentions to be donors. The Transplant Network commented that they would make an appeal to increase public awareness of expressing the intentions of being donors because not many people express their intentions. Further, it should be emphasized that nearly 70 percent of people who do not express their donation intentions answered “do not want to express their intentions”.

In 2008, the Transplantation Society issued the “Istanbul Declaration”. This declaration states that the provision of organs to meet the transplant needs of its residents from within its own country. Lack of organs is that it can be said that common in any country, concerns organ friction also, there is a work around to the reality that the wealthy are buying the organs of people in developing countries.

In addition, the media reports that it has succeeded in making a small liver moving in the body of the mouse to use iPS cells in July 25, which 2010 had been made. It has announced that it recommended a study for the treatment of hepatic diseases of children, and wants to send to the patient within 10 years in the future, but it will not be easy. It can be said further, you are working on making organ by genetic manipulation of using pigs in Jichi Medical University, but that there is a need more than a number of hurdles, including the ethical as well. Therefore, the “organ transplant law” has been established. At present organ transplant operation is the only solid and practical way of prolonging life and returning to normal life. But why only less than 200 cases have been conducted over the three years since a revised organ transplant law was enacted. What is the meaning of being unwanted to express the donation intention? What lies at the root of the organ donor shortage in Japan? Considering the life-prolonging treatment practice for the elderly in Japan

may hold the clue to understand these questions. Further, comparing with Autonomy-supportive society like Australia may highlight the major problems facing Japanese society today.

【1】Brain death and life-prolonging treatment

The aging of our country is progressing at a furious pace. The current proportion of people age 65 is one in four Japanese and will soon become one in three. Furthermore, the rapid progress in medical technology allows the survival of viable difficult cases, contributing to an extension of life expectancy. However, it is necessary to confront a problem constantly if the elderly who need nursing care on the other hand will be hospitalized and life-prolonging treatment applied. Respiratory arrest at the time, or put a ventilator to breathing difficulty at the time, it is determined gastrostomy when greeted treatment of defibrillator of cardiac arrest at the time, the state of being difficult to swallow, such as the treatment of tube feeding.

And thus the state to live and kept alive just to be the treatment of gastric fistula once to continue. It means that you continue to live by the body to digest and absorb nutrients fed into the stomach automatically apart from the will of their own. It may be regarded as similar to the brain-dead patient in terms of live kept alive. The case of the gastrostomy, human dignity is lost. A person has been kept alive by the nutrition given to the digestive system automatically, may have a pressure ulcer everywhere and groans with pain. In the case of brain death, a person even cannot normally be long-lived like the gastric fistula, and there is no self-determination present in the backside of humanity no life by. If it is to define “refers that realizes autonomously all the possibilities that exist in the individual, toward the oneself original”²⁾ temporarily self-realization, humanity approximately not is also figure towards the self-realization as well.

By the way, I would like to measures such as gastrostomy inserted or a ventilator, to determine its introduction or whoever. On bedridden, also state, consciousness even not clear as well as the clear

judgment, the elderly person himself is in the cognitive level, such as those using adult guardianship, hope of the family as an agent is incorporated naturally. It is possible to receive that you wish I want to postpone death even for a short time as it were the family, the hope to delay the arrival of death is a matter of course. However, if the state in which the ability to express denial is lost, and are not intended to embody the will of a spontaneous elderly person himself. It is only a decision that was standing on the assumptions and arbitrary wishes of the family as it were.

In this instance, it is necessary to discuss one's end of life wishes with their family before a life-threatening illness occurs or a crisis hits. In other words, it is too late "to start thinking about these issues when the need arises". Further, the contents of such discussion should focus on what would be in the patient's best interests. However, unless the elderly person is already admitted to the hospital, it is questionable whether family discussion about their end of life wishes is held while people are well. Rarely has such conversation been discussed. Besides, the elderly person could be enraged at such conversation because it is considered as a taboo subject. Even people cannot discuss life-sustaining treatment options for the elderly, much less discuss the issue of death or organ donation. So long as death is perceived as an unclean, evadable and unwanted truth, it could barely be on the table. This may explain the significantly low rate of publicly expressing organ donation-related wishes in the survey of Japan Organ Donation Network.

Over the next decade, the postwar generation will have reached 75 and over, thereby accelerating in an aging population. While an increasing demand for long-term care, the number of hospital beds function like nursing homes has been reduced due to the present policy. The consequences of inadequate long-term care beds available have led a long waiting list as well as a diminution in hospital death and a need for home medical care and community care. Foreseeably, home-based end-of-life care will be expanded. In this case, people have to directly

confront their decision-making about withdrawing or withholding life-sustaining measures like AHN. This shift in end-of-life care can be an opportunity to start discussing about death or exercising individual autonomy despite the fact that Japanese attach little importance to exercise self-determination.

[2] The application of life-sustaining measures and related decision making in Japan

The American Medical Association and medical experts have developed guidelines for deciding life-sustaining measures. It indicates that when the application of life-sustaining measures is no longer beneficial to the patient, withdrawing or withholding those measures is considered legally and ethically acceptable. There is no ethical difference between withdrawing and withholding life-sustaining measures. These statements are not only agreed by the medical associations in the UK and the US³⁾, but also being commonly practised in Europe. This is a particularly widespread practice in Northern countries, accounted for a half of all deaths in ICU⁴⁾.

On the other hand, the Japan Geriatrics Society published guidelines on artificial hydration and nutrition for the elderly individual with dysphagia in 2012. It elucidates the state of living: 'being alive is good enough per se, and mostly beneficial...This means that in so far as improving a general well-being of an individual, such life should last longer'. It is reasonable to infer that if the potential benefit of applying AHN is weighed against the state of dying, it is worth doing. In the AHN related decision-making process, the guidelines explain that physicians must inform individuals and their families of the risks and benefits of the proposed and alternative treatment. Then, the individuals and their families should have a better understanding of that information, so this will allow them to make an informed decision. Further, in order to draw an optimum decision, an informed decision should relate to personal values and priorities. It is recommended that informed choices should be led by a reasonable informed consent provision.

Concerning family discussion, an appropriate informed consent provision can facilitate it and self-

determination. Nowadays, the principles of informed consent get established. The disclosure of relevant information includes : the patient's symptoms and prognosis, proposed treatment, any other alternatives, side-effects, medical expenses, the risks of not receiving a treatment, surgery success rates, cure rates, and welfare and medical services if necessary.

Informed consent concerns the medical information patients need to know. Respecting patient autonomy is an essential prerequisite for informed consent⁵⁾. This view raises concerns about the patient's capacity for 'autonomy' and 'consent'. Autonomy rests on the premise that an adult patient has capacity, so he or she has the ability to make decisions independently. That is to say self-determination. The notion of self-determination is the overarching ethical consideration that protects the dignity of man. However, in Japan, the traditional paternalistic doctor-patient relationship is still firmly embedded in the elderly. In other words, their decisions rely on medical experts. The reason for this is that the doctor's professional expertise and dominant position make patients uneasy to express their opinion. The patients, therefore, become incapable of making their decisions about their surgery and lifestyle after receiving a treatment. Unlike Western standards, it is unaccustomed for both elderly and young people to exercise autonomous decision-making and express individuals' opinion. It is generally recognized that a majority of Japanese do not express their opinion in their daily lives. Instead, they concern other peoples' opinions due to the Japanese custom of stressing a climate of homogeneity⁶⁾. Conversely, America emphasises the principle of an individual's self-determination based on the paradigm of bioethics that considers the interest of the individual. The principle of 'individual autonomous decision making' or 'self-determination' is at the core of bioethics that was established in the early 1970s in America. The traditional paternalistic approach regarded doctors as only responsible for treatment decisions. However, the patients have countered paternalistic approach and insisted their rights to control their own decisions with

responsibility for the outcome of their decisions. This embodied the right of self-determination⁷⁾. The embodiment of this basic right can be seen in America's historical background : for example, the civil rights movement and the women's liberation movements. These movements actively empowered minorities and gave them assertiveness in the problem solving process. By contrast, it is unaccustomed for Japanese to make decisions autonomously and express individuals' opinion via interpersonal communication. For this reason, many Japanese responded that they would not express their organ donation-related decision.

Similarly, given the issue of living will, it is questionable whether Japanese could make a formal document in which they provide direction about their end-of-life care wishes. Nowadays it is not unusual for Japanese to discuss about living will in terms of death with dignity. Yet, it is unlikely that it becomes a custom to write a living will when facing the fact of developing cancer. Another possibility would be the delay in writing a living will or avoidance of the fact of dying. Their attitude towards death is perfectly understandable from the viewpoint of ordinary people.

【3】 Summary

Since the bombings of Hiroshima and Nagasaki, it has been almost 70 years have passed. At present day, we do not have to get away from war, or suffer from hunger. It is unusual for us to have a realization of death that we would face in conflict with other country. Despite the fact that we have not had war experience, we went through mega-earthquake twice ; the great Hanshin earthquake and the 2011 earthquake off the Pacific coast of Tōhoku. In total, hundreds of thousands of earthquake victims lost their lives under the debris or in a debris flow. While people in affected areas are still suffering from aftershock and they are traumatized, some enjoy a carefree life. Such attitudes towards death, including not confronting the fact of death, these attitudes can be the cause of a shortage of donors. In order for Japanese to consider death as an immediate issue, it is necessary to

recognize the importance of death education. Then, organ donation-related problems will be solved.

3 . Setting the Scene — Australia

In Australia, each state and territory has their own legislation covering organ donation, but all states and territories of Australia have adopted an opt-in model of organ donation. The present policies on organ donation basically rely on voluntarism, with consent received by donors and their families.

There have been over 18,000 transplant operations performed since 1989⁸⁾. While 600 patients receive life-saving organ transplantation from deceased donors each year⁹⁾, Australia still holds the lower rates of deceased donation in developed countries. Note that there is widespread of public support for organ donation, which has exceeded 80% in recurrent surveys over many years¹⁰⁾. More than 1,500 Australians are on the organ transplant waiting lists at any one time¹⁰⁾. As such, there is a strong need to identify ways of increasing the rate of deceased organ donation in Australia.

The real reasons for Australia's poor performance in deceased donor organ procurement have not been comprehended. This paper will focus on two possible reasons : the organ procurement system and family refusal.

【 1 】 The organ procurement system

Until recently, the country suffered from the fragmented nature of coordination, organ procurement procedures, information and community awareness campaigns, and funding. In 2008, the Australian Government launched a \$151 million reform initiative⁹⁾. In 2009, the Organ and Tissue Authority was re-established under the Act as an independent statutory authority to establish the nationally coordinated organ donation processes. Since then, the Authority has provided funding to each state and territory government to establish a national network of organ donation agencies. Those agencies aim at implementing organ donation coordination services, community education, donor family support services, and data collection of hospital deaths across 74

hospitals. The results have been considerable. Donor rates per million (dpmp) rose to 13.8 in 2010 from 11.3 dpmp in 2009, 12.1 dpmp in 2008 and 9 dpmp in 2007⁸⁾. In 2012, total actual deceased donors were 354 donors. 277 of those donors were heart-beating brain-dead patients⁸⁾.

However, there is a wide range between the states of 9 dpmp in the Northern Territory to 20 dpmp in South Australia⁸⁾. One outstanding observation is an internationally competitive organ donor rate achieved in South Australia. South Australia has consistently out-performed the other states since the state adapted the philosophy of the Spanish model in 1995. The Spanish model, which is a world-famous integrated approach to improving the numbers of deceased organ donation, includes the coordination network at all three levels — hospitals, regions and nation, proactive donor detection programs, systematic death audits, management of mass media, and economic reimbursement for the hospitals¹⁾. This comprehensive approach has brought Spain the highest donor rate ever reached by a whole world. South Australia adapted many aspects of the model at the first opportunity, thereby having more than twice the rates of other states.

This marked variation in the donation rates between the States points to the probability that the barriers to increased organ donation are the fragmentation of the organ procurement system. Further, it appears that the organ procurement system needs a proactive approach rather than waiting for voluntary donation. Despite the fact that the proactive approach can save numbers of lives, it contradicts the doctrine of voluntary donation in an opt-in system. Whether or not the proactive organ procurement system would work would, therefore, depend on publicity via social education.

【 2 】 Family refusal

Until recently, States and Territories had different ways of recording people's intentions about organ donation : for example, driver's licenses and donor cards. Many Australians believed that the national registration system was needed to prevent a deceased

family from overruling a donor's decision¹¹⁾. Hence, a national registration system was established. However, whether or not one has registered, the final decision to allow deceased organ donation is made by next-of-kin¹²⁾. This process is required confirming any changes of the donation wishes of the deceased since they registered.

In Australia, over 40% of families refuse to allow organ donation to proceed¹⁰⁾. While high rates of refusal are reported in other countries, Spain has only 9% refusals. Thus, decreasing family refusal is another way of increasing organ donation rates. One study in 12 Victorian hospitals, for example, found that consent for deceased donation was withheld in 47.3% of eligible cases by the next-of-kin¹³⁾. This refusal to allow organ donation is often actuated by lack of awareness regarding the donation wishes of the deceased¹⁴⁾. In other words, families who have discussed each other's donation wishes are more likely to uphold the donation wishes of family members. It is therefore important to firstly discuss organ donation intentions with families, and secondly to register as a donor. While Australia's current approach to family refusal is to encourage discussions about their donation wishes, 77% of Australians have now discussed their donation wishes with their family¹⁰⁾.

However, there are a number of factors influencing the likelihood of families consenting to donation, for instance, the attitude of staff who approach the family to request donation. On the evidence of the Spanish Model, it emphasises that for family satisfaction, transplant coordinators who have participated in treatment of the deceased is a pivotal role in the consent process¹⁵⁾. As part of the new national reform of organ donation in Australia, the family of every potential donor will now be asked to give their consent to donation by trained health professionals. In practice, Marck et al., reported a range of resource barriers to facilitating organ donation in Australian Emergency departments, most notably a lack of time to discuss organ donation with a patient's family¹⁶⁾. Given this, it can be inferred that the issue of family refusal is not merely caused by the donor's family, but

also by resource barriers.

4. Conclusion

Comparison of organ donation in Japan and Australia reveals significant differences: for example, the frequency of transplantation, the likelihood of family discussion about their donation wishes and organ procurement system. They are at least partly related to different cultural traditions and value assumptions. While Australia's organ donation rates are far from that of world-leading Spain, it is significantly higher than that of Japan. It is a fact that the concept of brain-dead organ donation and family discussion about organ donation is more accepted in Australian society than in Japanese society. Thus, the new national reform of organ donation in Australia has led positive outcomes. This achievement has led by a strong national determination; a government-sponsored reform; nation-wide network and staff organization; public media campaign; developed supports the care of donor families; and disconnection from the voluntarism of the organ procurement system.

In Japan, not only many Japanese people are unwilling to express their intentions of whether they become a donor or not, but also their practice of self-determination is restricted by some sociocultural factors, including a paternalistic doctor-patient relationship, and avoiding talk and think about death or dying. So far, what creates the different perceptions of death and brain death is not well-understood. For Japan, social education, including death education, can be essential to improve the country's readiness for accepting the concept of brain death or even death. Rather than focusing on one approach, a holistic approach as Australia has been taking might be an effective method of educating and transforming Japanese society.

The Governments of both countries have shown national determination to improve their organ donation practice and improved legal systems for organ donation. Nevertheless, this cross-cultural review has shown that caution must be taken to translate Australia's success to Japan. Their degrees of

accepting the concept of organ donation practice vary considerably. Japanese are less likely to express their donation intentions and discuss about death, whereas Australians are more likely to discuss their donation intentions with the family in order to respect the individual's best interest. Although a holistic approach can be effective in both countries, each country needs to get their priorities right. Death education can be a top priority for Japan, whereas the improvement in the organ procurement system and its public acceptance are for Australia.

When trying to draw a better understanding of the actual relations between value assumptions and the differences in the procedures of organ donation, further investigation is required.

5 . Competing

The authors declare that they have no competing interest.

6 . Acknowledgements

The authors wish to thank Prof. Fujiwara for his contributions and helpful insights and comments on various drafts.

7 . References

- 1) Matesanz, R : Factors influencing the adaptation of the Spanish Model of organ donation, *Transplant International* 16(10) : 736—741, 2003.
- 2) Yoshiaki Nakajima : *The dictionary of Psychology*, Tokyo, Yuhikaku, p. 331, 1996.
- 3) Kaoruko Aita, *Life sustaining treatment and clinicians in Japan*, Tokyo, University of Tokyo Press, p. 8, 2011.
- 4) *ibid*, p. 12.
- 5) Kouichi Asakura, : *Medicine and Life*, Kyoto, Nakanishiya Press, p. 36, 2007.
- 6) Kazumasa Hoshino : *Bioethics around human death*, Tokyo, Sokyusha, p. 57, 1997.
- 7) Kaoruko Aita : *Life sustaining treatment and clinicians in Japan*, Tokyo, University of Tokyo Press, pp. 13—14, 2011.
- 8) Australia New Zealand Organ Donation Registry (ANZOD), *The Full Report 2012*, 28th May 2012, <http://www.anzdata.org.au/anzod/ANZODReport/2012/summary_p01-27.pdf>, viewed 15th Jun 2013.
- 9) Newton, JD, Burney, S, Hay, M and Ewing, MT : Profile of Australian adults who have discussed their posthumous organ donation wishes with family members', *Journal of Health Communication*, 15(5) : 470—486, 2010.
- 10) The Organ and Tissue Authority, *The Donate Life Homepage*, Australia, n.d, <<http://www.donatelife.gov.au/discover/facts-a-statistics>>, viewed 15th June 2013.
- 11) Thomas, M and Klapdor, M, *The future organ donation in Australia : moving beyond the 'gift of life'*, Department of Parliamentary Services research paper no. 11, 3rd October 2008, Department of Parliamentary Services, Canberra, <[http://parlinfo.aph.gov.au/parlinfo/download/library/prspub/R5SR6/upload_binary/r5sr60.pdf;fileType % 3Dapplication % 2Fpdf](http://parlinfo.aph.gov.au/parlinfo/download/library/prspub/R5SR6/upload_binary/r5sr60.pdf;fileType%3Dapplication%2Fpdf)>, viewed 15th June 2013.
- 12) National Health and Medical Research Council, *Organ and tissue donation after death, for transplantation : Guidelines for ethical practice for health professionals'*, 15th March 2007, Canberra, Australian Government Publishing Services, <http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/e75.pdf>, viewed, 15th June 2013.
- 13) Opdam, HI and Silvester, W : Potential for organ donation in Victoria : An audit of hospital deaths, *Medical Journal of Australia* 185(5) : 250—254, 2006.
- 14) Rodrigue, JR, Cornell, DL and Howard, RJ : Does family disagreement affect donation decision by next of kin?', *Progress in Transplantation* 18(3) : 179—184, 2008.
- 15) Rodriguez-Arias, D, Wright, L and Paredes, D : Success factors and ethical challenges of the Spanish Model of organ donation, *The Lancet* 376 (9746) : 1109—1112, 2010.
- 16) Marck, CH, Jelinek, GA, Neate, SL, Dwyer, BM, Hickey, BB and Weiland, TJ : Resource barriers to the facilitation of organ and tissue donation reported by Australian emergency clinicians, *Australian Health Review* 37(1) : 60—65, 2012.

