Culture, brain death, and transplantation

From the social sciences, we know the space between life and death is historically and culturally constructed, fluid and open to dispute. The definition of death has cultural, legal, and political dimensions. As healthcare becomes more culturally diverse, the interface between culture and the delivery of healthcare will increase. In our increasingly pluralistic, interdependent society, there is a growing demand to integrate healthcare, including transplantation, into a broader context that respects both individual and cultural diversity. It is important that we first consider and explore what elements of Western healthcare practices including definitions and advances, such as brain death and organ donation, are culturally influenced. This article highlights some of the cultural influences on brain death by focusing on Western and Japanese perspectives on the permissibility of organ procurement from brain-dead persons. It also offers 4 recommendations for healthcare workers working cross-culturally. (*Progress in Transplantation.* 2003;13:211-217)

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Notice to CE enrollees:
A closed-book, multiple-choice examination following this article tests your ability to accomplish the following objectives:

1. Identify how culture influences healthcare practice
2. Differentiate Western and Japanese perspectives on organ procurement in brain death
3. Discuss strategies for healthcare workers working cross-culturally with transplantation in brain death

Culture profoundly affects attitudes toward organ procurement from brain-dead persons. Tales about the ambiguity between life and death have deep cultural roots in many societies. Such tales appear in mythology and folklore from the middle ages.[1] In contemporary society, new criteria of death have been evolving in industrialized Western nations over the past 30 years. The clinical definition of brain death and its concomitant legal status as constituting death are at the center of this evolution. In general, Western cultures have been far more accepting of the concept of brain death than Eastern cultures.[2-4]

Cross-culturally, the question of brain death evokes strong reactions. Recognizing these deep-rooted concerns is critical to developing policies and practices that are respectful of the diverse, pluralistic societies we value and live within. In this article, we attempt to demonstrate how powerful a factor culture can be by comparing cultural influences on Western and Japanese notions of brain death. We then provide practical recommendations for working cross-culturally in this area.

Background

Although as healthcare workers we often acknowledge the medical and ethical complexities of brain death and organ procurement, we have barely begun to acknowledge the sociocultural complexities. In the past, death was a more frequent, home-based experience. In both the East and West, decisions related to the end of life were minimal and usually remained within the realm of families and small communities. This has changed because of burgeoning medical technology, changing demographics and social roles, and the introduction of life-sustaining technologies.

Attitudes about end-of-life decision making are ingrained in the cultural roots of a society.[4] Cultures are maps of meaning through which people understand the world and interpret the things around them.[5] Attitudes toward concepts and procedures such as brain death and organ procurement may be highly influenced by cultural perspectives that are rarely acknowledged. Differences in cultural perception may lead to impressions that patients on whom organ retrievals are performed are not really dead, or that patients have been prematurely withdrawn from ventilators so that organs can be procured.

Even within Western cultures, there is a small but growing concern about the circumstances of organ procurement.[6,7] This concern may be triggered by a decline of people's faith in the healthcare system and a cultural movement to look at health and illness in a

broader context.[8] Some feel the deeper ethical question of whether people who meet the clinical criteria for brain death are dead or alive has been supplanted by an unspoken consensus that they are good as dead, and can therefore be considered dead.[8] This ought to be of great concern for the field of transplantation. For even slight suspicion that our enthusiasm for organ donation affects our clinical judgment may damage the fragile trust between patients and healthcare workers, and the public's trust in organ donation.[9]

Japanese Culture and Brain Death

In 1967, the first heart transplantation in the world was performed in the Republic of South Africa. The next year, in 1968, a similar heart transplantation was performed in Japan. The recipient lived for 83 days after transplantation; however, a citizens group accused the surgeon of illegal human experimentation, and of exercising dubious judgment with respect to his determination of the donor's death.[10,11] After this incident, heart transplantation became a highly controversial and emotionally charged issue. Fifteen years later, it remained a contentious issue in Japan.

The Japanese Ministry of Health and Welfare established an ad hoc committee on brain death, and in 1985 the committee announced national criteria for brain death.[11] In 1987, the Japanese Medical Association declared brain death equivalent to death of the human being. Five years later, in 1992, the Prime Minister's Special Committee on Brain Death and Transplantation presented its final report.[12] The committee reviewed the brain death debates of the 1980s, and concluded that brain death is death of the human being and that a donor's prior intention to donate organs is necessary for organ removal. But the report also contained a minority opinion that concluded that brain death is not death of the human being.[11]

National objections to brain death were stronger than had been anticipated. In 1994, an organ transplantation bill was presented to enable organ removal from brain-dead patients if family consent was obtained, but it did not pass. In 1997, 2 organ transplantation bills reflecting starkly opposing views of brain death were presented simultaneously. One stated that brain death is equivalent to human death. The other stated that a brain-dead patient is still alive but organs can be legally removed if 2 conditions are met: the donor has made a prior declaration of a desire to donate organs, and the family consents to organ removal. An unpleasant debate began, and the second bill was rejected. The first bill was greatly revised, and was passed.[12] What is noteworthy is that the law did not provide a uniform solution to the question, "What is human death?" In 1999, 31 years after Japan's first transplantation from a brain-dead donor, the second heart transplantation was performed. By late 2001, there had been 14 transplantations from brain-dead donors.

On the surface, Western and Japanese healthcare are comprehensive, evidenced based, and technologically advanced. Yet cultural differences between the West and Japan are significant. One significant difference is that Japanese society does not perceive or value autonomy as the intellectual and moral foundation of healthcare. For many Japanese, focusing on individuality overlooks the social and moral meanings behind personal interconnectedness.

Exploring Japanese cultural and religious beliefs may help explain the aversion of some Japanese to organ procurement from brain-dead persons. Shinto, Buddhism, and Confucianism have helped shape Japanese culture. A recent study suggests that the powerful influences of Shinto and Buddhism in Japanese society strongly support "natural" processes and approaches to dying.[13] From a traditional Japanese perspective, a human being is the integration of body, mind, and spirit. After death, they remain as an integrated whole. The metaphorical center of the body, *kokoro,* has traditionally been located in the chest.[14] Removal of an organ from a brain-dead human, especially from the chest, may be perceived as disturbing this integrated unit.[15]

A noted Japanese anthropologist theorizes that the Japanese tend to find in every part of a deceased person's body a fragment of the deceased's mind and spirit.[16] In 1985, 520 people died when a Japanese jumbo jet crashed into a mountainside. Emiko Namihira, a cultural anthropologist, investigated how the victims' family members behaved toward their dead loved ones. She found that bereaved families were eager to confirm their dead family members' corpses with their own eyes, and tried to gather all parts of the victims' bodies. She concluded that the Japanese believe a dead person goes to the next world as a soul. This soul has its own body, senses, and feelings similar to a living person. The dead body must remain whole. If some parts are missing, the soul becomes unhappy in the next world.[17]

Such latent yet formative cultural views are not specific to the Japanese. A similar worldview is shared at least in East Asian countries where Confucianism once flourished; the Japanese view of the dead body can be closely linked to Confucist perspectives that existed throughout East Asia in ancient times.[18]

Furthermore, according to the Buddhist teaching of arayashiki, one's personal or collective identity is not exclusively located in the brain; thus, loss of brain function does not imply loss of the person. This may add to the explanation of why Buddhists may not consider brain death as death of the person.[19-25] Death as understood by many Buddhists is death of the entire body.[26] In summary, historical, cultural, philosophical,

and religious influences appear to have shaped Japanese attitudes toward brain death.

Western Culture and Brain Death

Within Western culture, death is generally considered a unitary phenomenon,[22] a universal and ultimately inevitable occurrence. However, in most Western nations there are 2 sets of medically and legally legitimate criteria for determining and pronouncing death. (1) An individual may be diagnosed and pronounced dead on the basis of the cessation of heartbeat and breathing—of circulatory and respiratory functions. These are long-standing, traditional indicators that the medical profession has used as definitive signs of death. (2) A person may also be "defined" as dead on the basis of the irreversible cessation of all functions of the brain, including the brain stem (whole brain).

These are the contemporary criteria for determining brain death—ones that were given substantive, symbolic, and legal impetus by the publication in 1968 of the report of a committee of Harvard Medical School[23] that set forth the criteria for brain death:

> ...those comatose individuals who have no discernible central nervous system activity… [and where it is possible to determine] the characteristics of a permanently nonfunctioning [entire] brain [including subcortical-thalamic and basal ganglion function].

The committee's recommendations were premised that the coma was irreversible and care was futile. "Brain death" did not supplant heart-lung–based death. The 2 coexist equally. The incentive to develop and apply the concept of brain death was given strength by at least 2 major medical technological advances: the development of intensive care, mechanical support systems that can artificially maintain respiration and circulation in patients whose brains have irretrievably ceased functioning; and the advent of organ transplantation for which viable and intact organs are needed. Although the West's conclusions on brain death were based on medical and not philosophical grounds, the inclusion of brain death as meeting the criteria of human death did not provoke any significant public concern.

Although it is based on scientific, rational, and objective principles, Western medicine is as much a cultural construction as any non-Western belief system.[24] The tendency to plan for and control major life events is a prominent feature of contemporary Western societies,[25] and appears to be strongest in anglophone countries.[8] This trend has extended itself to a growing demand for control over the timing and nature of dying. In combination with the increasing institutionalization of death,[26] this brings many people in the West to expect medical solutions at the end of life. Death is increasingly perceived as a failure of medical care. Organ donation is often perceived not only as a means of improving health but also as a means of extending life or evading death. With a growing number of people who meet clinical criteria for organ donation, the demand for such treatments can be powerful. Why has the West willingly accepted brain death and organ transplantation? What are the cultural, historical, philosophical, and religious influences that have made them permissible in the West?

In the West, human beings have often been perceived as syntheses of body and soul. Christianity has shaped the West as Buddhism, Shinto, and Confucianism have shaped Japan. In Christianity, one must respect the body even after death, as it was an essential part of the person during life; however, a body without a soul is no longer a person. With regard to organ procurement, Christians perceive the donation of one's organs as an act of love and generosity.[27] The spiritual value of nonreciprocal giving is central to Christian belief. This may, in part, contribute to the fairly large social acceptance of organ donation. Bodies and body parts in ancient Christianity were imbued with profound meaning and often considered capable of resurrection.[28-30] As well, communion—the symbolic giving of "the body and blood of Christ"—may have also contributed to Western cultural acceptance of organ donation.

Seventeenth century thinkers Bacon and Descartes have been perceived by some as responsible for placing the "locus of the person" in the mind and for relegating the body to a secondary role.[31] Symbolized by "I think therefore I am," this perception imbued the mind with social and ethical meaning but may have also devalued the body. The brain is the temporary home of the rational and autonomous mind. And at death, the mind leaves the body. From this perspective, once the house of the mind—the brain—dies, the synthesis between mind and body ends. With this separation of body and mind comes death of the human being.[32] Thus, organ procurement from brain-dead patients is perceived by many Westerners as solidly ethical.

We have described some of the cultural foundations of brain death in Japan and the West. We realize, however, that as healthcare workers we face the challenge of working in a pluralistic society in which brain death and organ transplantation are generally accepted and enshrined in law. Based on extensive end-of-life clinical experience we make the following recommendations.

Recommendations for Practice

How Are Decisions Made in the Family?

When considering views of organ donation cross-culturally, it is important to consider that autonomy is at the heart of Western moral reasoning and has pro-

foundly shaped our views on what constitutes good, effective, and ethical decisions. Autonomy reflects a belief in the importance, uniqueness, dignity, and sovereignty of each person, and the sanctity of each individual life. Accordingly, every person is entitled to self-determination. This stands in contrast to non-Western cultures in which interdependence is often valued over independence; profound social and moral meaning rests in these interrelations. Views of autonomy effect how we feel about the diagnosis of brain death and organ donation. For example, some families may focus far more on family or collective decision making than on individual wishes and preferences. Ask, "How are decisions made by your family?" and "What is most important when making a decision like this?"

The Recognition and Negotiation of Cultures

One of the greatest limitations to effective work cross-culturally in healthcare is the "them-and-us" approach, that is, our knowledge versus their beliefs. We must recognize that Western healthcare is representative of a culture with beliefs and values that may be foreign to others. Once we recognize this, we will be in a good position to negotiate differences. The first step is to understand the perspectives of our patients and their families, especially their understandings of illness and views on the nature and meaning of death, organ donation, and transplantation.[33] Do they believe in a Western biomedical view of illness or do they hold an alternative, or blended view of illness? The next step is to identify plans that are acceptable to patients and their families, and the healthcare team. The most effective way to address cultural difference is through open and balanced communication. The clinical situation is perhaps best conceptualized as a negotiation. When healthcare workers are unsure of how a patient or family perceives a situation, it is best to simply ask. The mere acknowledgement of cultural differences frequently leads to improved communication.

In the end, patients' families may not consent to organ procurement. Even in these situations, knowledge of the patients and families' beliefs and values may help healthcare workers avoid conflict over misunderstandings stemming from cultural differences.

Negotiate the Timing of Organ Procurement

For some people and cultures, death is not only a medical event but also a social and familial one. Furthermore, some Buddhists believe that the dying process takes several hours after a person appears clinically dead.[34] The patient's family may want only a few hours to pass after the declaration of brain death before they are willing to allow organs to be procured. If a family is amenable, negotiate how long the family needs before the team may begin organ procurement and obtain the organs after that period has passed.[35]

Negotiate Which Organs May Be Procured

Even if the team allows a significant amount of time to pass after the declaration of brain death, some families may still not be comfortable with organ procurement. Despite the passage of time after death, for some people, the soul, mind, and body remain an integrated unit. Although they may not be willing to donate vital organs such as the heart, which may be latently perceived as the locus of life and imbued with spiritual and cultural meaning, they may be willing to allow organ procurement of other organs and tissue such as the kidneys, skin, or corneas.

Need for More Cultural Research

Cultural influences are difficult to ascertain in medical practice. Deep-rooted cultural perspectives require in-depth qualitative research methods, something uncommon or often unaccepted in medical culture. Sometimes in developed nations there is resistance to exploring the remnants of ancient traditions and cultural beliefs, which may be influencing healthcare. More pragmatic explanations for differences in attitude tend to prevail such as the calibration of research design, the organization of medical care or the relationship between the healthcare system and the public. Because of this deficiency of cross-cultural research in healthcare we may form an unfounded impression that culture is not a significant determinant of health and views on end of life.

Conclusions

This article highlights some of the cultural influences on brain death by focusing on Western and Japanese perspectives on the permissibility of organ procurement from brain-dead persons. It also offers 4 recommendations for healthcare workers working cross-culturally.

From the social sciences, we know the space between life and death is historically and culturally constructed, fluid, and open to dispute. We suggest that death cannot merely be understood as a biological event. The definition of death has cultural, legal, and political dimensions. As healthcare becomes more culturally diverse the interface between culture and the delivery of healthcare will increase. It is important that we first consider and explore what elements of Western healthcare practices including definitions and advances, such as brain death and organ donation, are culturally influenced. By understanding our own culture, we are in a better position to begin to understand our interactions with other cultures.

Further development of refined sociocultural research in transplantation would be an excellent means to enable us to better meet the deeper needs and values of our patients. In our increasingly pluralistic, interdependent society, there is a growing demand to

integrate healthcare, including transplantation, into a broader context that respects both individual and cultural diversity.

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Culture, brain death, and transplantation

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1. Identify how culture influences healthcare practice
2. Differentiate Western and Japanese perspectives on organ procurement in brain death
3. Discuss strategies for healthcare workers working cross-culturally with transplantation in brain death

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❑c	❑c	❑c	❑c	❑c	❑c	❑c	❑c	❑c	❑c
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CE Test Questions

Culture, brain death, and transplantation

1. To what degree are attitudes toward brain death and organ procurement influenced by cultural perspectives?
   a. Highly
   b. Somewhat
   c. Rarely
   d. Not at all

2. When was the first heart transplantation performed?
   a. 1960
   b. 1967
   c. 1970
   d. 1976

3. When was the first transplantation from a brain-dead donor performed in Japan?
   a. 1968
   b. 1987
   c. 1994
   d. 1997

4. In Japanese culture, what is considered the metaphorical center of the body, or *kokoro*?
   a. Brain
   b. Chest
   c. Stomach
   d. Liver

5. According to Buddhist teaching, what is considered death of the person?
   a. Brain death
   b. Death of the entire body
   c. Myocardial death
   d. Cessation of breathing

6. Based on Buddhists beliefs, when does the dying process occur?
   a. Immediately upon death
   b. Several hours after clinical death
   c. The process is transformed into another life
   d. With brain death

7. In Western nations, how many sets of medically and legally legitimate criteria for death exist?
   a. 2
   b. 3
   c. 4
   d. 5

8. What ethical principle is the center of Western moral reasoning?
   a. Beneficience
   b. Nonmalificience
   c. Autonomy
   d. Trust

9. Families may be reluctant to allow procurement of which of the following organs?
   a. Heart
   b. Skin
   c. Corneas
   d. Kidneys

10. What is the most effective way to address cultural difference?
    a. Acknowledgment
    b. Negotiation
    c. Communication
    d. Recognition