

Living and Working with the New Medical Technologies

Intersections of Inquiry

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11 On dying twice: culture, technology and the determination of death

Margaret Lock

The enterprise of organ transplantation is like no other among biomedical technologies in that the rapid conversion of the technologically managed death of one patient is transformed into the "gift of life" for a second dying patient. By far the majority of solid organ¹ transplants make use of what is known as a "brain dead donor." A three-year-old is hit by the neighbor's car as it swings into the driveway; a sixteen-year-old hangs himself when his girlfriend tells him she does not want to see him any more; a stray bullet lodges itself in the brain of an innocent passer-by at a bank robbery; a middle-aged woman falls unconscious with a massive brain hemorrhage – patients such as these are placed on the artificial ventilator, permitting them to breathe even though they have lost the spontaneous capacity to do so, and are subjected to a battery of tests, scans and clinical examinations. Certain of these individuals will make a partial or complete recovery, but the hearts of others will stop beating, or their blood pressure will drop irrevocably, and they will then die in spite of the ventilator.

There is a third class of patients, those who neither recover nor die but become brain dead. For these patients, resuscitative measures are only a "partial success" (Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Death 1968) so that with the assistance of the ventilator, the heart and lungs of such patients continue to function, but the entire brain is irreversibly damaged. Brain dead patients exist betwixt and between, both alive and dead; breathing with technological assistance, but unconscious. Without the artificial ventilator the brain dead would not exist, and even with it, such patients survive for only a few hours, days or weeks, or very occasionally for months. Despite intensive care, the heart gives up, or the blood pressure cannot be sustained. Recently, however, with increased knowledge and experience, survival rates have lengthened, and one or two exceptional cases have been reported of over a year's duration (Shewmon, forthcoming), but there are no documented cases of anyone recovering from this state, *if* it has been accurately diagnosed.

"Accidental" deaths are untimely; senseless. In North America, even before the diagnosis is confirmed, patients are usually considered as potential organ donors. Once brain death is declared, if the patient's wish to donate is known, and with the consent of close relatives (although this is not legally required), the technologically maintained organs of brain dead patients can be used to "save the lives" of other patients whom the trauma victims never knew – patients whose hearts, livers, lungs, and/or kidneys have deteriorated beyond repair, and who have been selected as recipients by committees designated to allocate without prejudice the scarce supply of human organs. Aside from the benefit donation may bring to organ recipients, it is believed by many people who work in emergency medicine and by many families whose relatives have died of brain trauma, that the altruistic act of organ donation permits meaning to be created out of sudden death.

Becoming the recipient of an organ is a highly competitive endeavor, for we in Euro/America suffer from what is repeatedly characterized as a "shortage of organs." This shortage has been described as a "public health crisis" (Randall 1991). People whose work is associated with transplant technology are reminded repeatedly how many thousands of patients die each year waiting for an organ. In the United States, for example, roughly 30,000 potential recipients were waiting for transplants in 1993, and "every day six of these patients die prior to receiving a heart or liver transplant," while those who need kidneys continue on dialysis (Arnold et al. 1995: 1).

This shortage is exacerbated because people are more conscientious than formerly about buckling up seat belts and, over the past ten years, the number of automobile accidents has been reduced (Statistical Abstract of the United States 1997). At the same time, the "success rate" in obtaining agreement from patients and families to donate organs has remained unchanged (Caplan 1988; Prottas 1994). This is so even though the law demands "required request" of families in most parts of the United States, Canada and Europe. In certain European countries, including Spain and Belgium, "presumed consent" is legally recognized, that is, in theory permission is not needed from either donor or family in order to procure organs which will take place unless the family specifically "opts out." In practice, however, if families appear hesitant or are in opposition, no organs are taken routinely in any location in Europe or North America. Donation is not, therefore, based on individual autonomy, but on familial decisions, although surveys indicate that 90 percent of Americans, at least, claim that they will honor the wish of a relative to donate (Prottas 1994: 50).

An assumption is often made in North America and most of Europe

that procuring organs from a brain dead body is in effect similar to performing an autopsy on a corpse – a brain dead body is a biological entity, but no longer legally alive. The results of comparative research with intensivists in North America and Japan to be reported below show that even among specialists who routinely work with brain dead patients, such patients are not likened to corpses. Furthermore, culturally informed knowledge infuses clinical practice in both locations, having a profound effect on the diagnosis of brain death, the time of signing of the death certificate, the procurement of organs, and the transplant enterprise, in both these locations. Even though brain dead bodies are not assumed to be biologically dead in either clinical space, organs are nevertheless taken from such patients routinely in North America, in contrast to Japan, where, over the past thirty years, very few organs indeed have been recovered, and then under duress.

Unstable Boundaries and the Moral Order

Death has become increasingly visible in recent years as a subject for media attention, whether it be a discussion about the moral status of euthanasia, or a lament at the increasing number of violent deaths that we are exposed to each day. Whatever form death takes, it conjures up that margin between culture and nature where mortality must be confronted.

The conceptualization of nature, including the specification of its relationship to human society and culture is, of course, contingent, and thus meanings attributed to it change through time and space. Latour (1993 [1991]) has discussed the way in which we “moderns” have placed nature “out there,” in an ontological zone distinct from that of society and social relations. Conceptualized as neutral, nature is made into a domain entirely independent of the moral order. As a result it was possible to pass the Anatomy Act of 1832 in England, for example, so that dissections and autopsies of corpses could be legally carried out. In theory from that time on a corpse was reconceptualized as part of nature, no longer having social worth, and therefore available for scientific commodification. In practice, as Richardson (1989) has shown, corpses were not so easily divested of their meaning for families and social life. It is evident that nature continues to serve, as it did prior to the Enlightenment, as a hybrid² – a moral touchstone, the effects of which are especially apparent when we grapple with assigning the status of life or death to various entities (Lock 1995).

It is at sites of rupture and transition, of conversion from culture to nature, and life to death, or the reverse, where disputes often take place,

and it is at these sites that a toehold can be found for critical and reflexive analyses about the development and application of technoscience in contemporary societies. Moralizing runs amok where efforts at purification (in Latour's idiom) – that is, claims about the epistemologically neutral status of nature – the non-human – and its rigorous separation from society – the human – are rigorously challenged. Examination of assertions at disputed sites about what is “natural” and what is “cultural” often reveals concerns about a destabilization of the moral order due to technological innovation.

Thus, while it is important to establish how any given technology is perceived to “enable” everyday life, it is equally important, as Strathern (1992) has shown, to monitor the flurry of voiced opposition that surrounds the introduction of many of the new biomedical technologies, for example. When widely accepted ontological statuses, such as those taken to constitute life and death, or basic human bonds, including those thought to be appropriate between parents and their children, come to be seen as under threat by the legitimization of technologically aided biomedical procedures, the resulting disputes provide a rich source of data for anthropological analyses. Such data are invaluable when attempting to understand what is believed to constitute social order and affiliation in contemporary life.

Moral disputes of this kind occur in so-called rational, secular, scientific societies, and in societies where other forms of cosmological order are in theory dominant. Where the process of purification takes place relatively smoothly – where silence resounds about any given innovation – this too is fertile ground for social scientists. In this instance, the initial task is, of course, to name the hybrid, for it will usually be camouflaged as though it is a natural entity.

Culture and Heterogeneity

Brain dead patients/cadavers clearly represent a “coupling between organism and machine, each conceived of as coded devices” (Haraway 1991: 150). The “boundary transgressions” exhibited by such cyborgs³ present “dangerous possibilities” in part, suggests Haraway, because their development is related to an authoritarian need for control and universal domination. At the same time, she argues, cyborgs invite us to reconsider our relationship with and construction of the natural and mechanical worlds.

A comparative ethnography of technoscience (and I increasingly think comparison is a fruitful way to take on this daunting subject) must immediately confront the question of why in specific locales certain

cyborgs raise little concern, while in others they create havoc. North Americans have been forced to engage with what it is about the manipulation of the fetus that triggers fury and violence. In many other locations this hybrid remains dormant, safely obscure, and in yet other situations, although recognized as a living, or potentially living entity, it causes little debate. As does a fetus, a brain dead patient/cadaver lurks on the margins of life and death, but in most of Euro/America a remarkable silence persists in connection with this new death, whereas turmoil has erupted in Japan over the past thirty years in connection with brain death and its associated technologies. It was only in the fall of 1997 that brain death was legally recognized in Japan as human death, and even then only for those patients who had made it clear that they wished to be organ donors, and whose families were in agreement. Where no prior wish to donate has been made, a brain dead body is legally alive.

So here we are, back in anthropology's favorite stamping ground of difference, seeking to understand why the Japanese, technologically sophisticated as they are, find themselves unable to recognize brain death as the end of life; why brain death and organ transplants, so dependent upon the recognition of brain death as the end of human life, signal danger, loud and clear, to many Japanese. This perceived danger has stimulated widespread public self-reflection over the past thirty years including in which disputes about the relationship of Japan to the West, tradition to modernity, and culture to technology all loom large. These disputes reveal the ambivalence certain Japanese experience in connection with technologies that radically intrude into what is taken to be the "natural order," together with a concern about the mixing of "self" and "other." But other issues are regularly voiced, including grave doubts about the integrity of the medical profession; concerns because informed consent is not formally institutionalized in Japan; worries that organ transplants are inherently non-egalitarian; and confusion about the status of dying patients, dead bodies, and their relationship to the living – all of which topics radiate out from the centrifugal trigger of brain dead entities (Lock 1995, 1996, 1997; Lock, forthcoming).

Of equal interest as an inquiry into the Japanese national debate is, I believe, to ask why the majority of Euro/Americans *apparently* sense so little danger emanating from this technological intrusion into death. Why has the focus in most of Euro/America been almost exclusively on the heroics of organ transplants and the gift of life, while deleting, it seems, almost all anxiety about the source of organs? This selective blindness has ensured that the second part of the equation only – the self/non-self hybrid of the organ recipient – has fully captivated public attention. In Japan, in contrast to the majority of Euro/American count-

ries,⁴ it has proved impossible from the time the new technologically mediated death was first discussed by the medical world in the late 1960s, to objectify brain dead patients as cadaver-like. Both the subjectivity and the social status of dying patients remain intact following a diagnosis of brain death, making it very difficult for families and many health care professionals alike to accept that this diagnosis represents the end of life.

Alan Feldman, following Adorno, argues for the possibility of “cultural anesthesia” – a condition produced by the objectification of certain individuals that increases the social capacity to inflict pain, while at the same time rendering that pain inadmissible to public discourse and cultural reflection (Feldman 1994: 406). While my argument is not that someone who is brain dead feels pain (such patients are deeply unconscious), a form of cultural anesthesia is apparently present in Euro/America such that public reflection has not taken place to any extent, nor has the pain and ambivalence in connection with the donation of organs experienced by almost all relatives of brain dead patients, and by many health care professionals, been recognized. This pain is well masked by the persuasive metaphors about saving lives associated with the transplant industry (Sharp 1995). This is not to suggest that organ transplants are not very effective in many cases, and increasingly so with improved drug technology. However, this success comes at a price, the death of the donor, a death that is rendered invisible, and then rapidly remade as the gift of life.

I agree with Haraway that the very existence of cyborgs, products of technological innovation, in this instance those entities diagnosed as brain dead and on ventilators, invites us to reconsider the way in which the fluid boundaries between nature and culture are created and defended, but I would qualify this assertion: The process of construction of such boundaries and the meanings attributed to them must be empirically established in light of the practices prevalent in specific historical and geographical locations if we are to understand why certain hybrids, the cause of endless trouble in some sites, go unrecognized in other times and places. Moreover, such boundaries, even when apparently agreed upon and beyond dispute, may become fluid once again within the space of months or years – the result of “second thoughts” after extensive experience with the technology, or alternatively of further technological modifications and concomitant changes in representations. Given the heterogeneity of contemporary societies, it is unlikely that such disputes can ever be considered as settled once and for all.

Clearly the meanings attributed to death vary depending upon whether one is close to death but still conscious, a close relative of a

patient who is diagnosed as brain dead, a neurologist trying to subvert death, a transplant surgeon "in need" of organs, a cultural commentator writing for the media, someone who is devoutly religious or alternatively aggressively secular, an "average" Japanese or an "average" American, or some combination of the above. This chapter will show that heterogeneous constructions about the brain dead are created, as Casper (1994) suggests with reference to fetuses, through work practices. But they are also constructed in large part through culturally informed responses of individuals when confronted with brain death, whether as clients, patients, relatives or clinicians. Ultimately the treatment of brain dead bodies is dependent upon work practices in clinical practice, but work practices are not independent of culturally informed knowledge and values. In this chapter, attention will be focused on clinician conceptualizations and practices, and how their sensitivity to families in shock influences, in culturally informed ways, what is done to brain dead patients.

Pinning Death Down

Without the machine – the artificial ventilator – the condition of brain death would never have been marked, except on occasion as a brief period of time prior to cardio-pulmonary arrest, signaling the condition that most people living in the urbanized world intuitively understand as the end of life. Without the ventilator, then, brain death could not have been made into either a recognizable diagnosis or a construct for social analysis. The immediate precursor of the ventilator was the iron lung, invented in Denmark in the 1940s to assist polio patients, whose lungs had collapsed, to breathe. Created in the late 1950s, the artificial ventilator, with its delivery of oxygen under pressure was a great improvement on the iron lung, but polio was by then all but "conquered." One must meander through a veritable Latourian network of entanglements to tell the story of the ventilator. This particular network includes the emergence of the car as the prime mode of transport, and of fast roads, together with an accelerating number of automobile accidents, coupled, particularly in America, with escalating numbers (in absolute terms) of gunshot wounds, leading to increased incidents of traumatic injuries and deaths. These changes stimulated in part the development of emergency medicine as a specialty, and the institutionalization of intensive care units with specialized staff who work under pressure to get patients out of such units as speedily as possible, alive or dead. This is just one trajectory of the ventilator network; one must enter another domain to chart the emergence of an increasingly sophisticated immunology

throughout the 1950s, permitting kidney transplants from both live donors and cadavers, and then follow the grandiose fancies of certain surgeons as they experimented on animals with liver and heart transplants. This technology took the world by storm, when the flamboyant South African surgeon Christiaan Barnard carried out what was announced in 1967 as the world's first heart transplant.

It was evident by the late 1950s that patient/ventilator entities were causing disquiet. For one thing, it was not clear what to call them: "living cadavers," "ventilator brain," and "heart-lung preparations" were just a few of the terms bandied about. In a 1966 CIBA Foundation symposium, the focus of which was on organ transplants, a certain impatience, characteristic of many professionals associated with the transplant world in connection with these new entities was apparent:

[F]or how long should "life" be maintained in a person with irrevocable damage of the brain? . . . [W]hen does death occur in an unconscious patient dependent on artificial aids to circulation and respiration? [A]re there ever circumstances where death may be mercifully advanced? . . . [D]oes the law permit operations which "mutilate" the donor for the advantage of another person? (Wolstenholme and O'Connor 1966: vii-viii)

The thrust of such questions becomes, in effect, a desire to know when individual patients whose organs have potential value for others, can be counted as dead enough to be transformed into commodified objects. After the Barnard heart transplant, it was clear that such questions needed answering urgently, particularly because more than one transplant surgeon was shortly thereafter summarily charged with murder for removal of a beating heart from a patient. In one case, in Texas, the charge was dropped when it was decided by the medical examiner that the donor had been murdered by an assailant when his head was smashed in, and not several hours later by the transplant surgeon (*Newsweek* 1968). In Japan a surgeon was also charged with murder. The case was dropped two years later, but it was clear that the doctor had lied at the hearing, and that the donor probably was able to breathe independently when his heart was removed (Nakajima 1985). This scandal contributed enormously to the fact that brain death has only recently been recognized in Japan, and then only for organ donors.

In May 1968 an Editorial appeared in the *Journal of the American Medical Association* (*JAMA*) in which the dilemma posed by vital organ transplants was clearly voiced: "It is obvious that if . . . organs [such as the liver and heart] are taken long after death, their chance of survival

in another person is minimized. On the other hand, if they are removed before death can be said to have occurred by the strictest criteria that one can employ, murder has been done." The Editorial went on to state that it is therefore "mandatory that the moment of death be defined as precisely as possible" and concluded: "When all is said and done, it seems ironic that the end point of existence, which ought to be as clear and sharp as in a chemical titration, should so defy the power of words to describe it and the power of men to say with certainty, 'It is here'." (*JAMA* Editorial 1968: 220).

One month later, in August 1968, an Ad Hoc Committee composed primarily of physicians called together by the Harvard Medical School, published the findings of their meetings in the *JAMA*. The committee agreed that " 'irreversible coma' must be substituted for 'cessation of vital functions' as the criterion for death." Two principal reasons were given as to why there was a need for this new definition: improvements in resuscitative and supportive measures had led to increased efforts to save those who are desperately injured, sometimes with only partial success, so that someone with irreversible brain damage might continue to have a beating heart. It was argued that the burden of such patients was great on families, hospitals, and those in need of beds. A second reason given was that "obsolete criteria for the definition of death can lead to controversy in obtaining organs for transplantation" (Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Death 1968: 337). The report noted that the first problem for the committee was to determine the "characteristics of a *permanently* nonfunctioning brain." It was emphasized that a decision to declare irreversible coma must be made only by the physician-in-charge, in consultation with one or more physicians directly involved with the case (implying that transplant surgeons should not be involved). The report continued, "it is unsound and undesirable to force the family to make the decision."

A legal commentary which followed this statement corroborated that judgement of death must be solely a medical issue, and that the patient be declared dead before any effort is made to take "him off a respirator," otherwise the physicians would be "turning off the respirator on a person who is, under the present strict, technical application of law, still alive" (Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Death 1968: 86). The article also noted that Pope Pius XII had, in 1957, stated that it is "not within the competence of the Church" to determine death in cases where there is overwhelming brain damage, and that verification of death can be determined "if at all" only by a physician (*JAMA*, 1968: 362). In what seems to be, in

retrospect, a surprising oversight, the impression was left by the Ad Hoc Committee that from now on *all* death would be determined by the condition of the brain; this position was modified when the Uniform Determination of Death Act was passed in America in 1981.

Standardized criteria for determining brain death in both Europe and North America have been in existence for nearly two decades (although they vary in small but significant ways from one country to another). A battery of clinical tests (which also vary within and among countries) are used to make the diagnosis. Guidelines recommend that two specialists perform the tests independently of each other, that transplant surgeons are not involved with making the diagnosis, and that a confirmatory set of tests be carried out between six and twenty-four hours after the first diagnosis.⁵ However, when making clinical decisions on behalf of brain dead patients, this diagnosis provides little information that will incite any changes in the therapeutic regime, for nothing can be done, given our current state of knowledge, to reverse the situation once the brain stem is extensively damaged.

When an elderly or a very sick person on a ventilator starts to show signs of irreversible brain damage, very often no special effort is made to diagnose brain death. There is no pressure to bring about resolution to the situation. It is only for that relatively small number of patients who may become organ donors that a precision diagnosis is called for. Once it is confirmed that a donor has been located, then the assertive force of transplant technology comes into play, and attention is turned from the living cadaver to the condition of their organs (see also Hogle, 1999).

When Bodies Outlive Persons

It is striking that despite legal recognition of whole brain death as the end of life (or alternatively brain stem death in the United Kingdom and other locales), and the publication and distribution of recognized standardized guidelines for its determination by the various medical associations and hospitals, these guidelines are rarely referred to by the thirty-two intensivists⁶ and eight nurses in ICUs whom I interviewed in 1997 and 1998 in Canada and the United States. Usually, intensivists are simply taught what to do at the bedside without referral to written guidelines and today, in contrast to the situation twenty years ago, there is a high degree of standardization (although not complete) across hospitals with respect to clinical tests (there is much less agreement about the value of certain confirmatory procedures such as use of the electroencephalograph).

All the intensive care specialists who were interviewed agree that the clinical examination for brain death is straightforward. The tests are described as "robust," "simple" and "solid" and, together with the apnea test which confirms whether or not the patient can breathe independently of the ventilator, they inform physicians about the condition of the lower brain – about the brain stem. If there is no response to this battery of tests, then whole brain death is diagnosed provisionally. Once the tests have been repeated for a second time, the diagnosis is confirmed (in practice, if the trauma is very severe, a second set of tests is dispensed with), the death certificate is signed, and the ventilator is turned off unless the patient is to become an organ donor.

Complete agreement exists among the intensivists interviewed that the clinical criteria for whole brain death (or brain stem death) are infallible *if* the tests are performed correctly. There is also agreement that whole brain death, properly diagnosed, is an irreversible state, from which no one in the experience of the informants has ever recovered, although five of those interviewed have been involved with cases where "errors" have occurred. However, although the physicians I talked to agree that a brain death diagnosis is robust, it does not follow that they believe that patients are biologically dead when sent for organ retrieval.

Not one thinks that a diagnosis of brain death signals the end of biological life, despite the presence of irreversible damage, and knowledge that this condition will lead, usually sooner rather than later, to complete biological death. As one intensivist puts it, "It's not death, but it is an irreversible diagnosis, which I accept." Despite massive technological intervention, a diagnosis of whole brain death indicates that the brain cannot continue to function as the site for the integration of biological activities in other parts of the body. At the same time a unanimous sentiment exists that the organs and cells of the body, including small portions of the brain, remain alive, thanks to the artificial brain stem created by the ventilator. Indeed, if organs are to be transplanted, then they *must* be kept alive and functioning as close to "normal" as is possible; as Youngner et al. note, "maintaining organs for transplantation actually necessitates treating dead patients in many respects as if they were alive" (Youngner, et al. 1985: 321).

The majority of intensivists are aware that infants have been delivered from brain dead bodies. It is not possible for them to disregard the fact that the brain dead are warm and usually retain a good color, that digestion, metabolism and excretion continues, and some know that the hair and nails continue to grow. Further, clusters of cells in the brain often remain active after brain death has been declared, and endocrine and other types of physiological activity continue for some time.

For almost all of those intensivists interviewed, although a brain dead patient is not biologically dead, the diagnosis indicates that the patient has entered into a *second* irreversible state, in that the "person" and/or "spirit" is no longer present in the body. The patient has, therefore, assumed a hybrid status – that of a dead-person-in-a-living-body. However, rather than dwell on ambiguities or engage in extended discussion about conceptual ideas about death, clinical practitioners are, not surprisingly, interested first and foremost in biological accuracy and certainty. In order to convey this certainty, namely that an irreversible biological condition has set in, in addition to explaining about tests and examinations to families, they emphasize that the "person" is no longer present in the body, even though the appearance of the entity lying in front of them does not give visual support to this argument.

Intensivists stated that they say things to families at the bedside such as: "the things that make her her are not there any more," or, "he's not going to recover. Death is inevitable." One doctor, who in common with many of his colleagues, chooses not to say simply that the patient is dead, because for him personally this is not the case, tells the family firmly that the patient is "*brain dead*" but that there is "absolutely no doubt but that things will get worse." A young physician doing a fellowship in intensive care pointed out that it is difficult to assess what is best to say to the family, because in most cases one does not know if the family has religious feelings or not:

I believe that a "humanistic" death happens at the same time as brain death. If I didn't believe this, then I couldn't take care of these patients and permit them to become organ donors. For me the child has gone to heaven or wherever, and I'm dealing with an organism, respectfully, of course, but that child's soul, or whatever you want to call it, is no longer there. I don't know, of course, whether the family believes in souls or not, although sometimes I can make a good guess. So I simply have to say that "Johnny," is no longer here.

Another intensivist thinks of the brain dead body as a vessel, and tells the family that what is left of their relative is only an empty container, because the "person has gone." For a doctor born in Latin America, the "essence" of the patient has gone, and this is what he tells the family. With only one exception, for all the intensivists, the absence of the person is evident *because* the brain is irreversibly damaged, thus ensuring a permanent lack of consciousness, no awareness, and no sensation of pain. In other words, a sensate, suffering, individual has ceased to exist.

More than one physician intimated that it is essential that the doctor takes control "a bit" when discussing brain death, both when it is imminent, and after the fact. As one of them put it, "families often find it

difficult to accept that there is no possibility of reversibility, and this is where the doctor cannot afford to appear diffident or equivocating.” Another insisted that “you can’t go back to the family and say that their relative is brain dead, you’ve *got* to say that they are dead – you could be arrested for messing up on this.” This intensivist recalled that during his training he had described a patient as “basically dead” to his supervisor, who had responded abruptly by insisting: “He’s dead, that’s what you mean, basically.” The task for intensivists then is to convince the family that, even though their relative appears to be sleeping, they are in fact no longer *essentially* alive; what remains is an organism or vessel that has suffered a mortal blow.

Doubts Among the Certainty

It is clear that the intensivists have few second thoughts about reversibility, but it is also evident that many of them nevertheless harbor some doubts about the condition of a patient recently declared brain dead, and it is often those with the longest clinical experience who exhibit the most misgivings. An intensivist with over fifteen years of experience working in ICUs said that he often lies in bed at night after sending a brain dead body for organ procurement and asks himself, “Was that patient *really* dead? It is irreversible – I know that, and the clinical tests are infallible. My rational mind is sure, but some nagging, irrational doubt seeps in.” This doctor, and the majority of other intensivists interviewed, take some consolation from their belief that to remain in a severely vegetative state is much worse than to be dead. *If* a mistake is made, and a patient is diagnosed prematurely, or treated as though brain dead when this is not the case, then it is assumed that either the patient would have become brain dead shortly thereafter, or permanent unconsciousness would have been their lot. But doubts continue to fester away at some people.

One intensivist, who came to North America from India as an immigrant when a child, stated that for him a brain dead body is “an in-between thing. It’s neither a cadaver, nor a person, but then again, there is still somebody’s precious child in front of me. The child is legally brain dead, has no awareness or connection with the world around him, but he’s still a child, deserving of respect. I know the child is dead and feels no pain, is no longer suffering, that what’s left is essentially a shell. I’ve done my tests, but there’s still a child there.” When asked by families, as he often is, if the patient has any consciousness, or feels pain, this intensivist has no difficulty in reassuring them that their child is dead, and is no longer suffering. He noted that it is especially hard for

relatives when they take the hand of their child and sometimes the hand seems to respond and grasp back. This reflex response was noted by several of the intensivists and nurses as very disconcerting for families, especially when one is trying to convince them that the patient is dead.

One doctor professed to a belief in a spirit or soul that takes leave of the body at death. For her, if brain damage is involved, this moment happens when the patient's brain is irreversibly damaged, at the moment of trauma or shortly thereafter, that is, before the brain death diagnosis. Another intensivist insisted at first, as did many of the people interviewed, that he had no difficulty with the idea of brain death: "it seems pretty straightforward to me. Do the tests, allow a certain amount of time; a flat EEG and you're dead." Then, ten minutes later this doctor said: "I guess I equate the death of a person with the death of the spirit because I don't really know about anything else, like a hereafter. I'm not sure anyway, if a hereafter makes a difference or not." When asked what he meant by the word "spirit," this doctor replied: "I guess one would have to take it as meaning that part of a person which is different, sort of not in the physical realm. Outside the physical realm. It's not just the brain, or the mind, but something more than that. I don't really know. But anyway, a brain dead patient, someone's loved one, won't ever be the person they used to know. Sure their nails can grow and their hair can grow, but that's not the essence."

Another senior physician, struggling to express his feelings, imbued the physical body with a will: "the body *wants* to die, you can sense that when it becomes difficult to keep the blood pressure stable and so on." This intensivist, although he accepts that brain death is the end of meaningful life, revealed considerable confusion in going on to talk about the procurement of organs: "we don't want this patient to expire before we can harvest the organs, so it's important to keep them stable and alive, and that's why we keep up the same treatment after brain death." Yet another informant acknowledged that the "real" death happens when the heart stops: "the patient dies two deaths."

For these doctors, because there can be no argument about the liveliness of the principal body organs, aside from the brain, an organ donor is by definition biologically alive, or at least "partially" biologically alive when sent to the operating room for organ retrieval. Perhaps most pertinent of all is that, in addition to the confusion and occasional doubts expressed in connection with the status of a brain dead individual, among the thirty-two doctors interviewed, only six had signed their donor cards or left other forms of advanced directives, and one other wasn't sure whether he had done so or not. When I pressed for reasons for this hesitation, no one gave me very convincing answers. Some

intensivists said that their family would know what to do, or else that they just didn't feel quite right about donating organs, or, alternatively, that they supposed they should get it sorted out.

Nursing the Brain Dead

Among the eight nurses I interviewed, all of them assume that brain death is a reliable, irreversible diagnosis, and claim that they have no difficulties in understanding what it signifies. When the first set of clinical tests indicate brain death, nurses think of their patients as "pretty much dead," because none of them have ever witnessed a reversal of the diagnosis when the second set of confirmatory tests are performed. However, they do not change their care or behavior towards a patient until after the second and final confirmation of brain death, and even then very little if the patient is to be an organ donor.

While carrying out their work between the two sets of diagnostic tests, nurses continue to talk to their patients and, in addition to keeping their eyes on the monitors, they pay careful attention, as they would with any patient, to the comfort and cleanliness of the body. Two nurses stated that they are acutely aware of the family at this time, and deliberately make their behavior around the patient as "normal" as possible, for the sake of the family. More often than not it is the nurse to whom the family has been putting their urgent questions, asking above all about the prognosis. In many cases nurses sense that patients are brain dead before the first set of tests are actually done, for they have been checking the pupils of the eyes regularly, looking for reflexes, and noting that the patient no longer responded to pain stimulation, nor shows any response when tubes are threaded into or taken out of their bodies.

Once whole brain death is confirmed, if the patient is going to be an organ donor, ongoing procedures do not change, except that the focus of attention is on the condition of individual organs, and not on the patient as a whole. The majority of the nurses now regard the patient in front of them as no longer fully human: "a brain dead body can't give you anything back; there's only an envelope of a person left, the machines are doing all the work." Some nurses continue to talk to brain dead bodies as they "care" for the organs, "out of habit," "just in case a soul is still there," or "because the soul is probably still in the room" (Youngner et al. 1985; see also Wolf 1991).

In common with the physicians interviewed, the majority of nurses think that "it is what goes on in your head that makes you a person." One nurse insisted that the idea that nails grow after brain death does not make her at all uncomfortable. Confusion is apparent, as we saw

among some physicians, in the way in which nurses talk about the brain dead: "Once the patient has been declared brain dead you still keep them on all of the monitors and the ventilator, for two reasons: first of all, the family wants to go in and see the patient *still alive* and second, soon after, a few minutes after, we'll be asking them to consider organ donation" (emphasis added). One nurse insisted that brain death is not death, and that patients remain alive until the heart stops beating, which, if organs are to be procured, takes place in the operating room when the ventilator is finally turned off. Despite these ambiguities, the ICU nurses with whom I talked are more conscientious than are the physicians about signing their donor cards – all but one senior nurse had done so.

One group of medical specialists, anesthesiologists who are also intensivists, sometimes find themselves in disturbing circumstances in connection with organ procurement. As one woman who works in a children's hospital put it:

Occasionally there is a patient who I've been looking after over the weekend in the ICU, working with closely, hoping that things will improve. The following week I will be having my turn on anesthesiology, and so I don't go to the ICU, and I look up and see them wheeling in the child so as we can procure organs from him. The child has taken a turn for the worse and become brain dead in the day or so after I went off the ICU. For me, this is the most ghastly job that I have to do. (see also Youngner et al. 1985)

This same doctor added:

Procurements are not a pretty sight. I always get the hell out of the operating room as soon as I possibly can. As soon as they've got the heart out. Everyone starts to scrabble at that point. It's ghastly, absolutely ghastly. I sort of have to sit down by the machines and just keep checking the dials every couple of minutes so as I don't have to watch what's going on. It's ghoulish, but you just have to try and focus on the fact that those organs are going to do some good. In a way I *have* to think of them still as a patient because they are under my care, and I guess the most important thing is that they are treated with respect, which isn't normally a problem at all. But with procurements, there's this conflict between the whole body and the organs. I can't really let myself think of it as a person any more. On the other hand, certainly if I've had contact with the patient before, and have been caring for them, then it's really hard for me to just accept that that process has ended. There really is a conflict. So I have to think of the body as a vessel, partly because I'm trying to protect myself. It's a really unpleasant emotion, especially because often there's no external trauma, so it's really hard to realize that this young person is dead.

In summary, none of the clinicians whom I interviewed, physicians and nurses, were opposed in principle to the idea of organ transplants, and all of them believe that it is appropriate for individuals who have

given prior consent to donate organs. Intensivists are more ambivalent than many of them care to admit, however, about the status of a living cadaver. While everyone agrees that brain death is irreversible, no one believes that brain dead individuals are biologically dead. Nevertheless, because they are convinced that no sentient being continues to exist once brain death is declared, they find themselves in good conscience able to send brain dead individuals off for organ procurement. Persons are clearly located in brains, that is, in minds.

In addition to ambiguous feelings about the ontological status of brain dead organ donors as alive or dead, are the more mundane but terrifying anxieties created by the possibility of errors, cases of which all the intensivists had heard about, and with which some have been directly associated. Among the intensivists interviewed, five of them had been involved with cases where there was confusion in connection with the apnea test, the test that confirms whether or not a patient can breathe independently of the ventilator. In one case, when the intensivist was still a resident, he had been part of a team that was trying to establish brain death very quickly:

I suppose we were working under pressure to procure organs for transplant. We did the apnea test for half a minute [a much shorter time than usual] and the patient didn't breathe. Then we sent the patient to the OR as a donor, and when they stopped the respirator, the patient started breathing. They brought him back to the ICU, and we kept supporting the patient. He finally died about two months later, but it was a complete nightmare. There were no excuses for that, but it was at the time before clear guidelines had been established for brain death – in the early 70s. I always tell my residents about this case, and I always teach people that they must *never* be in a hurry with this diagnosis.

One or two North American physicians have been actively opposed to the concept of brain death from the time it was first formulated in the late 1960s. In a review article Byrne and Nilges conclude that the requirement of the Uniform Determination of Death Act that “all functions of the entire brain” should have ceased before brain death can be declared, is not in fact met in clinical practice, and therefore “dying is confused with death.” For these authors, “imminent” death is not sufficient or satisfactory as a criterion for organ donation. They also note that protocols put out by transplant coordinators and transplant surgeons emphasize the “*rapid acquisition of physiologically sound organs,*” something that these authors insist “puts the donor at risk” (Byrne and Nilges 1993, emphasis in original).

On the basis of their review these authors claim that they are forced to bring up the “haunting question” of whether the “brain dead” really have an absence of all functions of the brain. Byrne and Nilges conclude

that we should reverse our usual orientation, and that we should search not for signs of brain death but for signs of brain life. They are convinced that if this approach had been taken at the outset thirty years ago then greater efforts would have been made to save patients with major brain trauma:

Gunshot wounds of the brain have not been treated aggressively in the past twenty-five years. Pessimism as to outcome has led to withholding of adequate neurosurgical care (Kaufman 1990). We would suggest that to salvage some benefit out of such tragedies and to salve the consciences of those rendering care, these unfortunate patients (who are usually young and in previous good health) are used as organ donors without being given the benefit of at least an attempt at neurosurgical debridement. The period of lack of improvement in the care of gunshot wounds of the brain almost coincides with the rise of transplant surgery. (Byrne and Nilges 1993: 21)

During the interviews, several intensivists made their own anxieties quite clear about equivocal outcomes from severe brain trauma. They have all witnessed many patients who neither progress to brain death nor recover, but remain in a persistent vegetative state, and they themselves would rather be dead than in such a condition. While aggressive therapy may lead to something approaching a full recovery, the likelihood of this being so is very small. The experience of most intensivists is that partial recovery is the best that one should hope for. Some families want aggressive treatment, but many refuse this option, often on the grounds that they do not want to cause any more suffering for their dying relative. Today, a good number of intensivists and involved families alike believe that organ donation is the best way to create meaning out of sudden tragedy. Although I have no evidence for this, there is a possibility that a certain amount of collusion takes place at times between intensivists, nurses, transplant coordinators and families, so that slippage is made a little too quickly from being a patient for whom everything is being done, to becoming an organ donor. In Japan, it is just this kind of fear, that patients are being made into organ donors before they have died, that has created what is known nationally as the "brain death problem" (*nôshi no mondai*).

The Brain Death "Problem"

Tomoko Abe, a Japanese pediatrician employed for many years in a hospital that specializes in neurological disorders, has spent considerable energy during the past decade working with the grassroots movement in Japan against the legalization of brain death as the end of life. In discussing her position with me at one of our several meetings, she

emphasized that the concept of brain death was created primarily for the purpose of facilitating organ transplants. She is emphatic that when a dying person is understood as the focus of both a concerned family and a caring medical team, then it is difficult to interpret brain death as the demise of an individual. Her opinion is derived, Abe states, from reflection on her own subjective feelings as a pediatrician: "The point is not whether the patient is conscious or unconscious, but whether one *intuitively* understands that the patient is dead. Someone whose color is good, who is still warm, bleeds when cut, and urinates and defecates, is not dead as far as I am concerned. Of course I know that cardiac arrest will follow some hours later – but I think even more significant is the transformation of the warm body into something that is cold and hard – only then do the Japanese really accept death." When asked why this is so, Abe replies that "it's something to do with Buddhism, I suppose, I'm not really a Buddhist but it's part of our tradition." Abe is completely opposed to organ transplants that are dependent on brain dead donors, and also has strong reservations about living related organ donations.

In 1985, the Japanese Ministry of Health and Welfare published guidelines for the diagnosis of brain death (*Kôseishô* 1985). The Ministry report is explicit, however, that "death cannot be judged by brain death" and it makes no claims to having any legal clout. Nevertheless, the diagnosis is frequently applied, and by 1987, 70 percent of the larger hospitals and university centers in Japan were making use of it, although patients were almost without exception maintained on ventilation even after the diagnosis "because relatives cannot accept the reality and medical personnel fear legal repercussions if they insist on discontinuing cardiopulmonary care" (Takeuchi et al. 1987: 98).

The three decades of debate and confusion about brain death in Japan *apparently* reached closure on 17 June 1997 when the Japanese government passed a bill just moments before parliament was dissolved for the year end recess. The bill, which became law in October 1997, is a compromise, however, and the long dispute over whether brain death represents human death remains unresolved because ambiguity is built into the wording of the new law. This states that organs may be retrieved from a patient diagnosed as brain dead provided that the patient (at least fifteen years of age) has left written consent to be a donor, and that the family does not overrule the declared wish of the patient. Consent should be obtained from *all* relatives who lived with the deceased, including grandparents and grandchildren, if appropriate. Caution is advised with patients who are mentally handicapped. If no advanced directives exist, then a brain dead patient will continue to receive

medical care after such a diagnosis is made, until such time as the family and medical team agree to terminate treatment and turn off the ventilator, often several days after brain death is diagnosed.

In other words, brain death is legally recognized only for those patients who have made it clear that they wish to donate organs. For potential organ donors, the legal time of death is when brain death is confirmed. For all other patients, brain dead or not, it is when the heart stops beating. If organs are removed from the body, then this must be noted on the death certificate. The Act also stipulates that medical expenses for patients who continue to be ventilated after a diagnosis of brain death will be reimbursed through the health insurance system, "for the time being." The current law is subject to revision after three years. The law has been described as a "typically confusing Japanese compromise" by many commentators in Japan (Hirano: 1997). Under the new bill, physicians are not required by law to make routine requests for organs from the relatives of brain dead patients, nor can they be required by hospital administrators to do so. Initiation of inquiries about donation is thus left entirely up to the family.

Over the past thirty years, charges of murder have been laid against more than twenty doctors for procuring organs from brain dead, or purportedly brain dead patients. These charges were for the most part made by citizen activist groups, some of them led by physicians such as Tomoko Abe. Earlier this year all outstanding legal cases were dropped, and the assumption is that these decisions will facilitate the institutionalization of organ transplants using brain dead donors. However, despite the new law, to date not a single transplant has been performed making use of a brain dead donor. There have, however, been several "near misses." What might have been the first case of donation after the law was passed, by a man in his 50s, was brought to a halt because he had made a small error in filling out his donor card. The nation remains poised, still waiting for the first legal heart or liver transplant from a brain dead donor to be performed.⁷

A vast literature exists, mostly in Japanese, commenting on why there has been so much resistance to the recognition of brain death in Japan. There is no consensus, and explanations range from historical prohibitions about the dissection of human bodies, concerns about the souls of the dead, corruption in the Japanese medical system, to a lack of trust in doctors in tertiary care institutions, caused especially because the idea of informed consent is not fully recognized in Japan. All of these arguments have some validity, but Japan is a complex, pluralistic society about which sweeping generalizations cannot be made (even though many commentators are tempted to do so). Despite the thirty-year

impasse about brain death, public opinion polls have shown for several years now that approximately 50 percent of people in Japan think of brain death as the end of human life, a figure that is not very different from those obtained from polls in North America (Nudeshima 1991).

Among the fifteen Japanese intensivists whom I interviewed, the majority of whom were neurosurgeons, I did not find anyone who took such an extreme position as Abe, although her sentiments and those of others who think as she does (including many physicians), are well known among the Japanese public because they have made numerous television appearances and published widely on the subject. Like the North American intensivists, all of the physicians with whom I talked believe that brain death is an irreversible condition, provided that no errors have been made, but that a brain dead body is not dead. They are not opposed to organ transplants, unlike Tomoko Abe, but none of them has ever actually been involved with procurement of organs for donation.

Although I conducted interviews in the year before the law was implemented, I would be surprised if the neurosurgeons working in departments of emergency medicine in Japan have changed their practices very much.⁸ Their position, even though they are not in principle in opposition to organ donation, is that it is inappropriate to declare brain death and then abruptly ask the family about donation. If the family does not raise the question of donation independently, as they rarely do (although this is changing a little since the passing of the new law), then the matter will not be discussed. There is, therefore, no haste, no pressure, and no need for an accurate diagnosis. This situation remains even after the enactment of the law in most clinical settings because, aside from a relatively small number of designated, university hospitals, other hospitals are still not legally able to procure organs, and thus far a lack of cooperation among hospitals continues to be the usual state of affairs (Ikegami: 1989). Given the discursive background and the history of legal suits in connection with brain death in Japan, it might be assumed that doctors would tend to practice "defensive medicine" and that this would therefore account for their reluctance to approach families about donation. While there is some validity to such an interpretation, it is grossly oversimplified in my opinion, and underestimates to what extent doctors are active participants in their own cultural milieu.

Among the neurosurgeons interviewed, they all agree that they "more or less" follow the Takeuchi Criteria, that is, the standards set out by the Ministry of Health and Welfare in 1985 for determining brain death. However, several of them added comments to the effect, "we don't always make the diagnosis, even when we suspect brain death. We often

guess, which is much easier for the patient and the family.” What is implied is that, in severe cases, the attending neurosurgeon will do one or more clinical tests, on the basis of which he comes to the conclusion that the patient is either brain dead or very close to it. He then informs the family that their relative is *hobo nôshi no jotai* (almost brain dead), or alternatively that the situation looks *zetsubôteki* (hopeless). Despite the prognosis, the ventilator is not turned off until the family requests it, often several days after the diagnosis.

One physician commented, “perhaps this is unique to Japan, but we believe that it is best to tell the family that we are continuing to do our best for their relative even though brain death is ‘approaching,’ rather than to say as they do in America, ‘the patient is brain dead, here are the test results, we are going to terminate all care.’ ” This same neurosurgeon went on to state that usually, once he is convinced of brain death, he will “gradually reduce the treatment,” meaning that no more medications are administered, and that the amount of oxygen being delivered from the ventilator is reduced. In his own mind nothing more can be done for the patient, but this neurosurgeon continues catering to what he believes are legitimate family desires.

Another neurosurgeon commenting on the actions of his colleagues said that “brain death is a kind of ‘end stage,’ in other words, there is nothing more that we can do for the patient, but we are ambivalent because brain death is not human death. There was a case I had a while ago where a child stayed alive for six or seven days even when the ventilator had been turned down. If the family had said early on that they wanted to donate organs I would have stopped the ventilator at once, but there was no suggestion of this. As far as they were concerned, I would have been killing their child if I had turned off the ventilator – and in a way they are right. After all, we don’t sign the death certificate until the heart stops beating.”

A neurosurgeon with more than fifteen years of clinical experience said that he would never approach a family about donation, nor does he turn off the ventilator until the family requests it. This doctor reminded me that an extended family is often involved, and that if even one distantly related uncle telephones to say that he does not want the ventilator stopped, then it remains in place. In his experience the family usually waits for three or four days after they have been told that things look hopeless when, having come to terms with the situation, the ventilator is removed “and the patient dies.” Like his colleagues, this neurosurgeon reduces the oxygen from the ventilator once he is convinced in his own mind that the patient is brain dead: “we do the basics and leave the rest to nature, we always leave room for a miracle, just in case some-

one comes back." This same doctor insists that he has recently been getting firmer with families who stubbornly refuse to accept that the situation is hopeless. However, he never tells families that their relative is dead, simply that their condition is irreversible, and that they can no longer breathe on their own. Among those specialists who were interviewed, only one emergency medicine doctor, a man who had worked for several years in America, believes that families should be told firmly that their relative is dead once brain death is diagnosed.

Of the four Japanese nurses whom I interviewed, in common with the neurosurgeons, none of them evinced any difficulty with turning down the supply of oxygen from the ventilator once it was clear to the medical staff that brain death was close. Nevertheless, as one nurse insisted, for the family a brain dead relative always remains alive. Like several of the doctors, the nurses insisted that "life" and "death" are not fully medical matters, and family sentiments must be considered. Further, they argued that although moral and ethical issues in connection with the brain dead are not the same as for the living, brain dead patients remain in a "micro world" of their own where "something continues to exist."

In complete contrast to the responses given in North America by medical professionals, although there is an acute sensitivity about the ambiguous nature of a living cadaver, no one in Japan described the shell of a body remaining once the person or the soul departs. There are three reasons for this, I think. One is that clinicians do not think it is appropriate to persuade families that their relative is no longer alive; second, although many of the doctors stated clearly that for them once consciousness is permanently lost a patient is as good as dead, they do not believe that most families think as they do. "Traditional" medical knowledge in Japan holds that life is diffused throughout the body in the substance of *ki* (*ch'i*, in Chinese), and it is assumed as a result that most Japanese are not willing to equate a permanent loss of consciousness with death; third, surveys have shown that in Japan a good number of families remain concerned about tampering with the newly deceased who will eventually attain immortality as ancestors, and therefore deserving of special respect. A small number of doctors participate in these sentiments, and those who are non-believers are reluctant to override families when they express some hesitation about donation; fourth, of most importance, perhaps, the idea of the person is not usually understood as an autonomous entity firmly encased inside a brain.

Japanese have never been overly concerned by something resembling a Cartesian dichotomy, nor is the concept of unique, clearly bounded individuals in whom rights are unequivocally invested part of their recent heritage, although both these topics are extensively debated in

Japan today. Among fifty Japanese I have talked to, only one-third locate the "center" of their bodies in the brain; the others, of varying ages, selected *kokoro* as the center, a very old metaphorical concept that represents a region in the thorax where "true" feelings are located.

The idea of individual rights is currently gaining a serious foothold in Japan, but has to battle against the still powerful flow of tradition in which an individual is conceptualized as residing at the center of a network of obligations, so that personhood is constructed out-of-mind, beyond body, in the space of ongoing human relationships. "Person" in Japan remains, for perhaps the majority, a dialogical creation, and what one does with and what is done to one's body are by no means limited to individual wishes. Moreover, self-determination is often thought of as essentially selfish (Lock 1998). In this climate, in which doctors themselves self-consciously participate to a greater or lesser degree, they are unlikely to impose their interests on families of dying patients, particularly when in the recent past the law has intruded with such force into medical practice.

Cultures of Technoscience

In North America, for intensivists, a brain dead body is alive, but no longer a person, whereas in Japan, such an entity is both living and a person, at least for several days after a declaration of brain death. Because, in the Japanese case, the social identity of brain dead patients remains intact, a brain dead body cannot be easily made into an object and commodified, but continues to be invested with "human rights." In North America, in contrast, a brain dead body takes on a cadaver-like status, deserving of the respect given to the dead, and, with family cooperation, is available for commodification, on the assumption that the procured organs will be transformed into the "gift of life." While these differing discursive backgrounds do not determine what happens in clinical settings, they nevertheless contribute profoundly to the way in which clinical signs and symptoms are interpreted and then acted upon. It must be emphasized that these are the dominant positions in these two geographical areas, and that in both locations ambiguities persist and are contested and resisted, particularly in Japan.

In North America a cultural anesthesia has prevailed, the dominant position was institutionalized with little trouble by powerful mediators in the medical world, backed up by the law, and given the stamp of approval of the Catholic Church. What few disputes arose were refocused by medicine and the media onto the heroics of organ transplants, an act deemed to promote social affiliation. In Japan, the medical world

blundered. The infamous case of 1969 that resulted in a murder charge being laid against the physician, and others similar to it that followed, exposed corruption in medicine. Japanese lawyers were immediately opposed to recognition of brain death, religious bodies remained virtually silent, and the media for the most part participated in a campaign to bring down the profession they have repeatedly described as arrogant. Culturally shared ideas about dying and the importance of family involvement in the determination of death have been mobilized in Japan and put to use for political ends in creating these arguments (Lock, forthcoming), but these same ideas are also acted out at the clinical level, where preservation of family affiliation is usually given precedence over any promotion of the donation of organs to unknown others.

One other major difference between Japan and North America is that in North America those individuals who choose not to cooperate with the donation of the organs of their relatives tend to be thought of as aberrant. Organ donation is thoroughly normalized and, aside from the perennial concern about sales of organs, it is assumed that organ procurement and transplants should be promoted worldwide. In Japan, by contrast, there is a reflexivity and caution about these practices, caused not simply by the internal national difficulties that have arisen with these procedures, but also by an awareness that ideas about altruism, human relations and human solidarity, personhood, and autonomy are cultural constructs. It is believed in Japan that "Western" forms of these constructs function positively in connection with the donation and receiving of organs, and that this particular technology is not easily transportable to the cultural setting of Japan where ideas about human affiliation are on the whole different.

The Slippery Slope of Truth

Although the public is almost oblivious, in North America and Europe doubts persist among professional commentators on brain death, as they do in Japan, as to what actually constitutes human death (Arnold and Youngner 1993; Veatch 1993). Although it is frequently reiterated that debates about the concept of death must be kept entirely separate from the organ procurement enterprise, it is evident that in reality this has not been possible. The crisis created by the "shortage" of organs has caused the transplant world to cast around looking for other sources of organs. The question of redefining death once again, as the cessation of upper brain function alone, looms large as a result. Such a definition would permit patients in persistent vegetative state and possibly anencephalic infants (who lack part of the brain) to be counted as dead, or at

least as dead enough to become organ donors if their relatives see fit. One effect of this re-examination of death, perhaps unforeseen, has been to cause a number of neurologists and associated specialists to reconsider the original brain death concept.

Robert Truog, a pediatric neurologist, argues that "despite its familiarity and widespread acceptance, the concept of 'brain death' remains incoherent in theory and confused in practice. Moreover, the only purpose served by the concept is to facilitate the procurement of transplantable organs" (Truog 1997: 29). Truog insists that it behooves us to maintain a "clear and simple distinction between the living and the dead" (Truog 1997: 34) and therefore we should return to the "traditional" cardio-respiratory standard but also permit retrieval of organs from those patients who have indicated their willingness in advanced directives, or have the permission of a recognized surrogate, when "no harm" will be done to the donor. This would include, according to Truog, those individuals who are permanently and irreversibly unconscious (but whose hearts still function either independently or through assistance from a respirator) and those who are imminently and irreversibly dying.

Robert Taylor, also a neurologist, comes to similar conclusions using an entirely different argument. He is emphatic that "death is a biological phenomenon, not a social construct." For Taylor a separation of nature from culture is complete, and must remain so for purposes of clarity. He continues, "the proper biological definition of death is 'the event that separates the process of dying from the process of disintegration' and the *proper* criterion of death in human beings is the "permanent cessation of the circulation of blood" (Taylor, forthcoming, emphasis added). Taylor, like Truog and others, finds the brain death definition of death unconvincing. However, together with Truog, he does not wish to undermine the transplant industry, and so he suggests that, similarly to "legal blindness" (a social construct designed to provide assistance to those who are not fully biologically blind), we could maintain brain death as a social construct and as a legal definition of a condition that, once entered, means that an individual, though living, could become an organ donor provided consent has been established.

Alan Shewmon, a pediatric neurologist from Los Angeles, in a letter circulated to certain participants of the Second International Conference on Brain Death that took place in Havana in February 1996, summed up the points of dispute that arose at the conference which struck him as most critical. His impression was that the majority of individuals who presented papers on various aspects of clinical diagnostics lacked a "coherent and universally accepted conceptual basis for why brain death should be equated with death." Shewmon is of the

opinion that by the end of the conference there appeared to be virtually unanimous agreement that loss of all brain function is not equivalent to loss of biological life of the body as a whole, although obviously brain destruction is a fatal injury. The brain should be understood, therefore, as the organ critical to "consciousness and personhood." The question of its role in the "somatic integrative unity" of the body remains unsettled but, in any case, this should not be crucial in making a diagnosis of brain death. By extension Shewmon argues, as did at least one other conference participant, the philosopher Karen Gervais, that "if the brain dead patient is dead, then so is the PVS [persistent vegetative state] patient," because the only *coherent* argument that brain death is death [a lack of consciousness] logically applies to PVS as well" (emphasis in the original, unpublished letter). Shewmon argues that "we [society] tacitly adopted a new concept of human death, namely that human death is the permanent absence of consciousness" when we adopted the brain death criterion as signifying the end of life, even though this had been repeatedly denied in the medical literature. Shewmon is of the opinion that beyond that point, conference participants were seriously divided in their opinions because no agreement could be reached on the concept of "personhood" (personal communication, March 1996).

Truog, Taylor and Shewmon, together with an increasing number of their colleagues in neurology and related subjects, suggest that we should abandon what has informally been accepted as the axiom for organ donation: "the dead donor rule." However, they agree that organ donation will be severely curtailed if we can no longer obtain organs from brain dead donors, and hence these neurologists argue that individuals, with their prior consent, should be permitted to become donors while still alive, when it is clear that no chance exists for recovery. This position is not unlike that now legally recognized in Japan, except that in Japan families and not individuals have the last word. The debate continues, the transplant enterprise frets, and the hybrid of the brain dead body remains suspended, betwixt and between.

NOTES

1. By "solid organ" is meant those internal organs including the heart, liver, kidneys and lungs that have an obvious anatomical boundary in contrast to blood, bone marrow and so on.
2. The term "hybrid" is liberally used in contemporary cultural studies and cultural anthropology to signify the mixing and inversion of what are taken to be fundamental divisions and categories in society. When objects, languages and signifying practices recognized as coming from separate

domains are fused in practice then hybridity has occurred (Werbner and Madood 1997). In this paper I am following Latour (1993 [1991]), Strathern (1996) and others who have given particular emphasis to two things in connection with hybridity, namely that the dualistic categories of nature/culture, society/individual, subject/object and so on, characteristic of Euro/American thinking, are false dichotomies, cultural constructions that in practice cannot be readily divorced from one another. Second, a division between human and non-human cannot be specified because humans are materially constituted by objects, and objects of all kinds are prosthetic extensions of humans – thus the world is inhabited by hybrids, and heterogeneity is commonplace.

3. Haraway conceptualizes cyborgs as creatures that are both “organism and machine,” entities that appear in science fiction but also populate the everyday world. She argues that cyborgs are ubiquitous, at once mythological and real. The cyborg is inevitably a politicized entity, in contrast to Latour’s conception of a hybrid, and its recognition assists us in questioning that which is taken as “natural” and “normal” in hierarchic social relations (1990: 149). I make use of both hybrids and cyborgs in this paper when discussing bodies diagnosed as brain dead. Although these concepts come from different theoretical agendas I in effect use them interchangeably in the present discussion.
4. In Sweden, Denmark and Germany public debates about the recognition of brain death have taken place at various times over the past thirty years, setting these countries apart from the rest of Europe and North America.
5. The recommended time for waiting before confirming a brain death diagnosis varies depending upon local guidelines, and upon the cause of the brain trauma. With cases of hypothermia, for example, great caution is usually taken, and the wait may be up to 48 hours before brain death is confirmed.
6. The clinical tests to establish brain death inform one about the condition of the lower brain, or brain stem. In Great Britain, brain stem death is assumed to be equivalent to brain death because if the brain stem no longer functions then the upper brain must inevitably cease to function as well. In North America, France, Japan and other countries, confirmatory tests are often done to reveal the condition of the upper brain, and the diagnosis of brain death in these countries is understood as “whole brain death.”
7. As of October 1999, four procurements have now taken place in Japan from brain dead donors.
8. I was told repeatedly while doing this research that the facilities in Japan for emergency medical care are not as up to date nor as efficient as those in America. Virtually no facilities have trauma units, accident victims are taken to general emergency medicine departments and centers. When a patient with a brain injury is brought in to such a unit a neurosurgeon, if not already on duty, will be called to assess the case. The specialty of intensive care is not highly developed, and very few physicians indeed describe themselves as intensivists.

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