



# Twice Dead: Organ Transplants and the Reinvention of Death

*Margaret M. Lock*

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Tales about organ transplants appear in mythology and folk stories, and surface in documents from medieval times, but only during the past twenty years has medical knowledge and technology been sufficiently advanced for surgeons to perform thousands of transplants each year. In the majority of cases individuals diagnosed as "brain dead" are the source of the organs without which transplants could not take place. In this compelling and provocative examination, Margaret Lock traces the discourse over the past thirty years that contributed to the locating of a new criterion of death in the brain, and its routinization in clinical practice in North America. She compares this situation with that in Japan where, despite the availability of the necessary technology and expertise, brain death was legally recognized only in 1997, and then under limited and contested circumstances. *Twice Dead* explores the cultural, historical, political, and clinical reasons for the ready acceptance of the new criterion of death in North America and its rejection, until recently, in Japan, with the result that organ transplantation has been severely restricted in that country. This incisive and timely discussion demonstrates that death is not self-evident, that the space between life and death is historically and culturally constructed, fluid, multiple, and open to dispute.

In addition to an analysis of that professional literature on and popular representations of the subject, Lock draws on extensive interviews conducted over ten years with physicians working in intensive care units, transplant surgeons, organ recipients, donor families, members of the general public in both Japan and North America, and political activists in Japan opposed to the recognition of brain death. By showing that death can never be understood merely as a biological event, and that cultural, medical, legal, and political dimensions are inevitably implicated in the invention of brain death, *Twice Dead* confronts one of the most troubling questions of our era.

## Twice Dead: Organ Transplants and the Reinvention of Death Details

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# From Reader Review Twice Dead: Organ Transplants and the Reinvention of Death for online ebook

## M. Benesh says

Lock is the go-to source on the topic of donation and brain death. I highly recommend this book if you're interested in either topic.

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## Qihua says

### PREAMBLE: ACCIDENTAL DEATH

- Institutionalization and legitimization of brain death as end of human life.
  - oAssigning death to a scientifically deducible and verifiable moment, thus making it at once indisputable in medicine and recognizable in law.
    - oIf there is no possibility for cognitive function in an individual because of irreversible damage to the upper brain, then that person can be pronounced as no longer having any “individual interest.”
    - ?Not clinically or legally brain-dead because the lower brain remains intact.
  - Japan:
    - oDying is understood as a process, and cannot be isolated as a moment.
    - oDeath is more than the extinction of individual bodies: it is a familial and social occasion. Even when medically determined, death becomes final only when the family accepts it as such.
    - Clinically, several concepts and values must coexist to facilitate organ transplants from brain-dead bodies.
      - oA dead body must be recognized as “alienable” (legally available for transfer or sale), and thus can be handed over or acquired for dismemberment for medical purposes.
      - oUtilitarian concern about use of medical resources and money. Ventilator support of a brain-dead patient is interpreted as a “waste” and continued care deemed futile, declaration of legally dead and therefore alienable could be put to good medical use.
    - In modern society, “accidents” have no satisfactory explanation and are particularly disturbing because they represent a loss of control. Through the “gift of life” – the ultimate act of altruism – control is to some extent reasserted and the disruption created by the accident is partly corrected, making nameless strangers into heroes.
    - oJapan: Gift-giving is deeply embedded in an economy of reciprocal exchange, thus the idea of giving objects of value to complete strangers with whom one has had no personal contact appears strange to many.

### THE PROCUREMENT

“Watching the delicacy with which the surgeon handles the kidneys and the way an arriving surgeon goes straight over to admire these newly procured mulberry-colored organs glistening with health, I am reminded that throughout this entire process it has been the organs, and not the donor, on which everyone has been concentrating. The donor is merely a container that must be handled with care.”

### BOUNDARY TRANSGRESSIONS AND MORAL UNCERTAINTY

- Biological death is recognized in society and in law by the standards of medical science, but what exactly constitutes death of a body, and what does this death signify with respect to death of the person?
- In recent years, some have argued that irreversible brain damage should not be thought of as biological death, but that it nevertheless represents the end of meaningful life.

### MORAL ECONOMIES OF SCIENCE AND STYLES OF REASONING

“Modern world” – nature, including the human body in life and death, functions according to scientific laws and is, therefore, autonomous and independent of social context and the moral order.

- Nature must be “reworked” on the basis of intellectual and technological innovation, but nevertheless functions according to laws that ensure its continued autonomy from culture.

“Moral economy” of science

- The ideal of scientific objectivity insists on the “existence and impenetrability” of boundaries between facts and values, between emotions and rationality, but this ideal is based on an illusion.

- “Moral economy” – a web of affect-saturated values that stand and function in well-defined relationship to one another.

- Even though moral economies in science “draw routinely and liberally upon the values and affects of ambient culture, the reworking that results usually become the peculiar property of scientists.”

In hospitals and other medical settings, individual death was stripped of much of its social significance and remade as a biological event.

- Doctors acquired the authority to pronounce death because lay people did not have the required expertise or objectivity.

Crucial questions:

- What is a person?

- What is the relationship of person to body?

- Does the person cease to exist when the physical body dies?

- What exactly is death – physical, personal, and social?

### THE AMBIGUITIES OF BLURRED BOUNDARIES

Hesitation about commodification of dead bodies and their use for medical purposes arose less from a concern about the moment of the departure of the soul than from reservations about desecrating the human body. Only when corpses could be conceptualized as neutral biological objects, as part of nature and therefore autonomous and without cultural baggage, was it possible (for medical men, at least), to divest them of social, moral, and religious worth; commodification for the benefit of scientific advancement then became not only legal but laudable.

- For involved families the bodies of their relatives were not so easily divested of social meanings.

Technology: Brain-dead patient-cadaver hybrid of human and machine

- It is the hybrid and not the machine itself that incites moral dispute, doubts, and angst. The existence of the technology does not determine anything.

- Technologies are usually understood as “enabling” scientific progress in addition to fulfilling human “needs.”

### THE USES OF CULTURE

Kiuchi: “I feel that I was supposed to be killed by Japan, by the Japanese government, Japanese tradition, Japanese culture. If I had stayed there I would have died.”

Secularization and modernization trajectories in Japan and North America

- North America

o Hegemony: Legitimization of brain death as the end of human life has rarely been contested either by medical professionals or by the public.

o Arguments about death are usually assumed to lie fully in the medical domain and therefore to be objective.

- Japan

o No naturalization of brain death. Death is not readily located in the brain, nor is the essence or identity of the person; and commodification of bodies, dead or alive, creates angst. Medicine has not been able to claim hegemony over the new death.

### COMMODIFICATION OF HUMAN BODY PARTS

Clearly, in their original function, body parts are not commodities, but they may become commodified. It is important, therefore, to consider how and under what conditions body parts accrue value, at times monetary value, and what local resistance there may be to the alienation of body parts.

This depersonalization constitutes a form of “euphemized violence” – a form of exploitation in which vital

human organs are assessed as invaluable until the moment that culture intrudes, in the form of a skilled transplant surgeon. Organs are then transformed into precious commodities.

Marx – how commodities are transformed into money under capitalism

- “Fetishism of commodities” – items come to be thought of as having inherent value, as they might have weight or color. The commodity/object is decontextualized in a capitalist system, and consumers know little or nothing about the social relations of production or of exchange.

- Human organs – social history is erased, value assessed solely in terms of their quality as organs for transplant.

#### ETHNOGRAPHIC INVESTIGATION OF BIOMEDICAL TECHNOLOGIES

- In North America, the focus has been almost exclusively on the heroics of organ transplants and the “gift of life,” so little public reflection has taken place about the accompanying new death or on the ambivalence about donation so often manifested by relatives of brain-dead patients.

- In Japan, it is the suffering of the people who wait for organ transplants that is overlooked.

The martyrdom of the intensive care unit has begun ... the man in the bed is to be ventilated, dosed, defibrillated, probed, suctioned, and infused. Most of his bodily functions will be taken over. No longer need he swallow, chew, inhale, or exhale, cough, urinate, defecate, clear his throat, maintain acid-base balance, cogitate, remember, sigh, weep, laugh, desire. Richard Selzer.

#### TECHNOLOGY IN EXTREMIS

##### ARTIFICIAL RESUSCITATION AND PREMATURE BURIAL

- Europe – fear of being buried alive since the 14th century.

- Japan – both cremation and burial.

##### LOCATING BIOLOGICAL DEATH

- Where is death located?

o Heart? 18th, 19th centuries, a powerful counter-philosophy of decentralism held that the vital principles were distributed throughout the body.

o 18th century physiologist Marie Francois Xavier Bichat – vital organs: heart, lungs, kidneys

- Is death an event or process?

o One-organ “centralists” usually argue for death as an event.

o Decentralists argue that because different parts of the body stop functioning and die at different times, death must be a process.

- In contemporary medicine the concept of futility – permitting the discontinuation of treatment when nothing more can be done therapeutically – combined with an economically driven vigilance about use of scarce medical resources, creates space for doubts about medically managed deaths.

##### LOCATING THE MOMENT OF DEATH

The existence of ventilator-dependent patients raised 2 concerns:

1. The fear of being counted dead before one’s time and overhastily designated an organ donor
2. The fear of being kept alive too long, as a “vegetable,” with severe, irreversible brain damage, but not technically brain dead.

##### QUICKENING THE NEW DEATH

For how long should “life” be maintained in a person with irrevocable damage of the brain? Does a parent always have the right to accept or refuse treatment of his child? What special protection might be given to minors, people of low intelligence, or prisoners, in regard to clinical trials or donation of tissues? When does death occur in an unconscious patient dependent on artificial aids to circulation and respiration? Are there ever circumstances where death may be mercifully advanced? Does the law permit operations which “mutilate” the donor for the advantage of another person?

“Soul-body dualism” of Enlightenment philosophy

In its new apparition, the dualism of the brain and body holds that the true human person rests in (or is represented by) the brain, of which the rest of the body is a mere subservient tool. Thus when the brain dies, it is as when the soul departed: what is left are “mortal remains.” Now nobody will deny that the cerebral

aspect is decisive for the human quality of life of the organism. The position I advance acknowledges just this... but the extracerebral body has its share of the identity of the person. The body is uniquely the body of this brain and no other, as the brain is uniquely the brain of this body and no other. What is under the brain's central control, the bodily total, is as individual, as much "myself," as singular to my identity (fingerprints!), as noninterchangeable, as the controlling (and reciprocally controlled) brain itself. My identity is the identity of the whole organism, even if the higher functions of personhood are seated in the brain.

#### MAKING THE NEW DEATH UNIFORM

Doctor's dilemma: Prolonging life when nothing can be done for a patient reflects no credit on the attending doctor. Such patients should never be hooked up to life support in the first place: "It would be unfortunate if the time came when no patient in the hospital could decently die without the last rite of modern medicine – a statutory period on the ventilator."

#### CLOSING THE LOOPHOLES

4 distinct questions should be kept separate:

1. What are the best technical measures of the destruction of the brain?
2. What is it that is so essential to our concept of human life that its loss should lead us to treat the individual as dead?
3. When should our laws and our courts regard a person as dead?
4. When should a medical professional be authorized to pronounce death?

4 concepts of death:

1. Irreversible loss of the soul
2. Irreversible cessation of the flow of "vital" fluids, of which the blood is the most obvious
3. Irreversible loss of bodily integration, including spontaneous breathing, bodily reflexes, responses to stimuli, etc.
4. Irreversible loss of consciousness or a "capacity for special interaction."

"Neurological disintegration" – when what remains is no longer a functional or organic unity, but merely a mechanical complex.

#### BIOLOGICAL DETERMINISM AND PHILOSOPHICAL ESSENTIALISM

1. Death can be assessed solely on the basis of biological measurements, permanent cessation of functioning of the organism as a whole

a. Complex interaction of organ systems regulated primarily by the brain.

2. Once an irreversible loss of consciousness is medically established, supporters of this position assume that the person is dead.

#### TECHNOLOGY AS OTHER

#### JAPANESE MODERNITY AND TECHNOLOGY

Perhaps the dominant theme in the Japanese cultural debate over the past 40 years has been the extent to which it is possible or appropriate to continue to cultivate uniqueness.

The specters of individualism, utilitarianism, and super-rationalism – values closely associated with the West – push some Japanese toward a rhetoric of difference, even though they are not always enamored of its nationalistic and essentialist associations. Cultivation of an idyllic recollection of rural Japan reveals anxiety and a sense of loss.

#### SOCIAL DEATH AND SITUATED DEPARTURES

Because they are socially transcendent, the dying are made into the "moral architects of the living world."

Two contradictory strategies deployed simultaneously by contemporary society to combat the void of death.

- The modern strategy is to "deconstruct" mortality by battling disease and other threats to life.
- The postmodern strategy works to deconstruct immortality entirely, to transform life into an unstoppable, daily rehearsal of the universal mortality of things, to move from the horror of death to a seeking-out of "death-risks."

#### WHEN BODIES OUTLIVE PERSONS

#### DETERMINING THE END OF LIFE

- Brain death ≠ end of biological life, but will lead to complete biological death.
- A doctor must take control a bit when discussing brain death. Families often find it difficult to accept that there is no possibility of recovery, and the doctor cannot afford to appear diffident or equivocating. The task is to convince the family that even though their relative appears to be sleeping, the person is no longer essentially alive; what remains is an organism or vessel that has suffered a mortal blow.

#### DOUBTS AMONG THE CERTAINTY

- Brain-dead body as an “in-between” thing. Neither a cadaver nor a person, but then again, there is still somebody’s precious child in front of me.

#### NURSING THE BRAIN-DEAD

- Patients don’t look dead until the heart stops beating, but can tell even before measurable clinical signs appear.

#### MEDICAL OPPOSITION TO BRAIN DEATH

#### THE SOCIAL LIFE OF HUMAN ORGANS

Marcel Mauss, 1990 – gifts, like commodities, must be understood as part of an economy of exchange. All gifts carry reciprocal expectations, and gift exchange is a means of establishing lifelong commitments that create the structure of social institutions and their hierarchies. Individuals in effect give away a modicum of themselves with a gift, an animated “essence” that should, therefore, be returned in kind.

#### AN ECONOMY OF GIFTS

- Give to strangers – contemporary society is strengthened when individuals exercise the moral choice to give to strangers in nonmonetary form
- Charity
  - o Modern sense of charity – the “needy” often resent being turned into recipients of charity. Many are well aware that their marginalized position is the direct result of exploitation by institutions and individuals related to those that are praised for their life-saving donations.
  - o Biblical sense of charity – more along the lines of organ donation

#### ORGANS AS THINGS

- Medical language insists that human body parts are material entities, devoid of identity whether located in donors or recipients.
- Donations language are animated with a life force, and donor families are encouraged to think of their relatives as “living on” in the bodies of recipients.
- o Create meaning out of a senseless, horrifying death – “a technological path to transcendence.”
- No chance of creating human ties, though because letters are anonymously delivered through the local transplant coordination service with all identifying features deleted.
- o Reciprocity is reduced to an act of imagination, and donors must be content with the thought that should they or their families ever need an organ, then perhaps another family will be willing to donate to them.
- “Tyranny of gift”

#### LINGERING ANIMISM

- Should death-row inmates be allowed to donate their organs?
- Many organ recipients worry about the gender, ethnicity, skin color, personality, and social status of their donors. Even some surgeons also think this way! Fetishism at work.
- Marx: the fetishism of commodified objects – their objectification as things-in-themselves – disguises the relations among individuals involved in the production and consumption of those commodities. This is theoretically how anonymous donations are supposed to work.
- Fetishism in its original sense – the animation of objects with magical or religious power – what Mauss suggests happens with gift exchange – happens as well. Body parts remain infused with life and even personality.

#### TIES THAT BIND: GIFT GIVING AND RECIPROCITY

- “Gift of life” doesn’t work in Japan because it’s not reciprocal – doesn’t fit into an economy of exchange.

- Charity doesn't work either in Japan, because it connotes pity, and is associated with inequalities, cold relations, and anonymity.

### THE TYRANNY OF THE GIFT

- In fact, Japanese recipients do not always suffer from frustration over an inability to reciprocate.

### CONCLUSION

- Is the price we pay for anonymity too high? Is the shortage of organs perhaps exacerbated by an insistence on anonymity? Could anonymity be a matter of choice, carefully mediated by coordinators, but left up to donors and recipients rather than an imposition?

### REVISITING VIVISECTION IN A WORLD SHORT OF ORGANS

- Arguments about "maximizing" the availability of organs are grounded in the utilitarian assumption that organs must be made available for the greatest good of all.

- o Xenotransplants – from animals into humans

- o Permitting the sale of organs

- o Whether the category of patients counted as good-as-dead can be expanded, in order that we may harvest their organs.

- Futility – often deployed as an ethical trump card that overrules patient autonomy and can be used to justify denial of treatment.

### SENTIENCE DOES NOT MAKE A PERSON

- Current theory holds that consciousness is activated by the lower brain – neurological experts cannot be certain that loss of higher brain function ensures no consciousness or awareness. Neocortical death is not biological death, and must be interpreted as death of the person, or the "unmaking" of the person.

### ANENCEPHALIC INFANTS AND THE ORGAN SHORTAGE

- The first surgeons justified organ procurement/donation from infants in several ways:

- o They were persuaded into organ procurement by parents wishing to create a meaning for their infant's existence.

- Life of the infant is dismissed as without meaning because it has no capacity for consciousness or mental functioning and its prognosis is uniformly terminal.

- How to reach consensus

- o Act first, talk later

- o Seek social approval and consensus prospectively

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### Amy Rutherford says

Brain death and the commodification of organs.

Although at times a read requiring more concentration (especially the first few chapters) it was highly enjoyable and informing. It was something I hadn't had an interest in until a friend recommended it.

The book summarizes and compares the modern history of organ transplants in different countries, how laws and opinions change, and how the different cultures react and adapt.

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### Victor Gonzalez says

What is death? Is it a process or a moment? But the most important question is , when are you dead? Death has different meaning depending on culture and religion and it has had different ways of being defined

throughout history, which has changed based on the needs and advancements of medicine.

I believe death, as well as birth, is a moment; at one moment you are living and at another you are not, but for others death is a process. If death is a process then we are all in the process of dying and they wouldn't be much use of our existence.

In the book 'Twice Dead' by Margaret Lock she studies the world of organ transplant and make a comparison of that industry in North America (and to some extend Europe) and Japan. The main theme of the book is not to treat the positive and negative aspects of organ transplant, but how the concept of death has changed so that the technology of organ transplant can be improved. Lock makes a comparison of how in the US and Canada the concept of brain death has not had many public discussion but in Japan it has been the contrary. Lock examine how Japan has come to cope with the development of the concept and what has prevented it to deeply penetrate into the believes of the Japanese.

Brain death occurs when there is no longer any brain activity. For some people this is not death, death come when the heart stops beating. The problem with brain death is the accuracy of determining it. Lock illustrate on her book how different people have targeted this issue, she mentions Tachibana Takashi (a Japanese award winning journalist) who has made his mission to inform the people of Japan the medical accuracy on determining brain death and the life that remains in the people who suffers it (152). Lock also summaries how confident intensivists are on the clinical criteria for determining brain death if the test are perform correctly (242), but the problem lies in there. The tests can be performed badly and human error can be an issue. Another concern is how much we know of the people suffering brain death, how can the doctor know 100% if they are not experiencing any pain.

Brain death is a legal death that was created so that doctors could be covered (legally speaking) from homicide on the moment they were procuring organs. In my opinion the most reasonable aspect of recognizing brain death as the death of a person, from a legal perspective, is represented in a second bill introduced in Japan in 1994 that states that brain death is not the end of life but those people who are willing to donate their organs if they are declare brain dead can do so, a prior will indicating this is needed. In my opinion this is the best way support all the different believes towards death.

The needs for organs is what has taken this problem regarding death, because for transplant of organs like the heart and the liver you need them to be working and without a lack of oxygen to be able to secure a higher success rate for transplant. A heart that has stop beating is no good for use after. But this need for organs have shifted the care that brain dead should have, and has transformed them from patients to living cadavers that are kept alive just to maintain the health of their organs. Why isn't there more care of the brain dead, why there is not willing ness to keep investigating how to bring them back or how other organs are still working when the controlling organ of the body (the brain) is dead.

Death can be considered a mystery and what is considered to be death can be interpreted differently.

Margaret Lock presents the controversy involved on what death is and how the development of organ transplant has changed the definition of it in some countries and how a lack of education and public discussion on this subject has affected the US and Canada. The books would be interesting for people working on ethics especially those working in hospitals and related institutions, also people related to organ procurement and transplant. People who are interested in donating organs, and those needing organs can also benefit from Lock's book since it can provide and inside on the world of organ transplant and how organs are procured.

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## **Tom Quinn says**

Three words: Itty. Bitty. Font.

This is a very interesting topic, but I like my non-fiction more accessible. Think Mary Roach, think Carl

Sagan. This author sure is knowledgeable but she focuses on her own experiences in Japan too often for my tastes. It sort of drew me out of the narrative.

Still, it's thorough and contemporary -- a very up-to-date discussion of the medical, ethical, and legal quagmires that exist in the world of brain death and live organ transplants.

3 stars out of 5.

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