CRITERIA FOR DEATH:
SELF-DETERMINATION AND PUBLIC POLICY

ABSTRACT. 'Whole brain death' criteria have found support in Western cultures in regard to post-mortem organ donation and the termination of care for patients meeting these strict criteria. But they are of minimal use in Asian cultures and in the ethics of caring for the persistent vegetative patient. This paper introduces a formula for a global Uniform Determination of Death statute, based on the 'entire brain including brain stem' criteria as a default position, but allowing competent adults by means of advance directives to choose other criteria for determining death during the process of dying.

Key Words: euthanasia, brain death criteria, higher brain death criteria, individual choice, multicultural society, self-determination

DUALISTIC ANTHROPOLOGIES AND BRAIN-BASED CRITERIA FOR DEATH

Two decades ago, an Ad Hoc Committee of the Harvard Medical School with great success proposed new criteria for declaring death, 'the irreversible cessation of all functions of the entire brain, including the brain stem' (Beecher, 1968). These criteria have since been accepted, with technical refinements, in most, but not all, Western countries (Bundesarztekammer, 1982; US President's Commission, 1981). The new formula represents a medical-ethical response to increased capabilities of intensive care medicine to keep patients alive on respirators over long periods of time and to post-mortem organ transplantation, providing morally 'safe' criteria for determining bioethically acceptable criteria for the biotechnical determination of death. The relatively smooth and widely accepted shift from cardio-pulmonary death to whole-brain death was made possible by dormant values and principles in Western tradition, supported by humanist Greco-Roman as well as religious Judeo-Christian dualistic traditions of differen-
tiating between the mortal body and the immortal soul and by the interpretation of the ontological 'nature' of humans based in the *differentia specifica* of reasoning, communicating and self-communicating.

The Old Testament describes the creation of Adam after God's own image. God, in blowing his own breath (*ruach Jahwe*), into his creature after basic gestation, made him corresponding, responsible and communicative to the creator, different from the rest of creation (Genesis, 2, 7). The general pattern of the image of God, the special relationship of the creator with his image is reaffirmed and deepened in Christian belief in Jesus as the son of God, his suffering and resurrection and the eternal kingdom of heaven, as being something spiritual, not biological. Consequently, the Christian doctrine that teaches the departure of the soul from the body at the moment of death strongly supports brain related criteria for the determination of death (Sass, 1991). In 1957, Pope Pius XII, based on the century old tradition of the theory of animation, declared that in cases of 'prolonged coma' the soul might already have left the body and no 'extraordinary means' would be required to support the life of such patients any longer and that the technical determination of death should be left to the physicians (Pius XII, 1957, 1027–1033). The Christian tradition that differentiated between inanimate or non-ensouled and animate or ensouled fetuses could easily differentiate between postanimate somatic life and animate somatic life at its end (Sass, 1989). Summarizing the President's Commission: 'a statute incorporating a brain-based standard is accepted by theologians of all background' (1981, p. 42).

Non-European religious traditions of similar dualistic anthropological concepts based on animation or re-incarnation, such as Farsi or Buddhist and Hindu positions, believe that at one time the body will become ensouled and that at an other time the 'soul' will leave the body. The Indian concept of reincarnation denies individual death as strongly as Christian traditions and theoretically is as well prepared to accept brain based criteria.

**HOLISTIC ANTHROPOLOGIES AND WHOLE PERSON DEATH CRITERIA**

But Judeo-Christian anthropology does not always support brain based criteria. Jonas, in a strongly worded rejection of the Harvard formula, accuses the Committee of defining 'not death, the ul-
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An ultimate state, itself, but a criterion for permitting it to take place unopposed, i.e., by turning off the respirator. He strongly believes, that ‘we do not know the borderline between life and death, and a definition cannot substitute for knowledge’ (Jonas, 1969). Twenty years after the first proposal of the Harvard criteria, the Danish Council of Ethics (in 1987) stated that a change in criteria for death is ‘an event of such significance that it should not be permitted without a major public debate on the ethical questions involved’ (Rix, 1990, 233). The council is now initiating such a debate, which has not yet resulted in legal changes in Denmark. It has been argued that the new criterion is ‘shocking, not merely because it is unfamiliar, but also because its implications are morally repugnant’ (Evans, 1990, 221) as it would not exclude the ‘cremation of the ‘living heart cadaver’’ (230).

While Jonas, Evans and the Danish Council argue from within the European anthropological tradition, Asian holistic anthropological concepts such as Taoist, Confucian, Zen-Buddhist and Shinto positions, stress the wholeness and essential integratedness of body and mind; they have even greater difficulties in replacing ‘whole person death’ criteria with ‘whole brain death’ criteria. However, a recent survey in Japan, undertaken by the Japanese Prime Minister’s office in July 1987, showed that of 61% respondents 24% favored criteria based on cessation of heart activity, 24% accepted brain death criteria, and 37% would favor criteria based on the patient’s or his or her family’s will (Sass, 1991).

The controversy between those supporting brain related criteria and those with a ‘plea for the heart’ (Evans, 1990) reflects not only emotions and cultural attitudes influenced by a relatively rapid shift in parameters of great cultural and ethical relevance, but also a difference in the concept of death: the permanent loss of integrated functions of the entire body, body death, versus the loss of something which is the differentia specifica of human individuals, brain death (Downie, 1990).

MORAL ADVANTAGES AND DISADVANTAGES OF THE HARVARD FORMULA

The Harvard criteria provide the following four ethical-medical advantages: (1) Human life that meets the strict and well defined biomedical criteria of whole brain death does not require further
intensive and heroic measures for its prolongation. (2) Moral, emotional, cultural, social and economic costs that would have been associated with the artificial extension of 'brain dead' life can be saved. (3) Organs become available for patients who otherwise would die or face severe suffering, hardship or inconvenience. (4) One single biomedical criterion serves as a correlate for a bioethical consensus on the difference between animate and inanimate life: 'cessation of all functions of the entire brain'. The disadvantages of the Harvard formula include: (1) Forms of comatose or vegetative human life, including the irreversible cessation of neocortical functions only, are not covered. (2) Anencephalic unborns or newborns not meeting the brain stem death criteria are not covered, either. (3) Holistic anthropological positions have problems accepting the formula. (4) They do not allow for competent adults having different belief systems and attitudes toward death and dying to make individual choices and exercise self-determination via self-definition of criteria for their individual death.

Now, increasing numbers of patients in long-term persistent vegetative state, over 25,000 in the US (Shapiro, 1990, 440), have again opened the debate over deficiencies associated with the Harvard criteria (Brody, 1988; Colby, 1990; Shapiro, 1990) and call for ethical reflections 'beyond whole-brain criteria' (Zaner, 1988).

Four different lines of argument can be developed for establishing a morally more acceptable treatment of PVS patients: (1) developing criteria for euthanasia (Welie, in this issue) (2) proposing a special PVS treatment statute (Shapiro, 1990), (3) introducing higher brain criteria only (Veatch, 1988), (4) allowing competent adults to make educated choices among a limited set of criteria by means of advance directives.

VEGETATIVE HUMAN LIFE AND THE EUTHANASIA DEBATE

The recent euthanasia debate in Germany comes with strong emotional undertones, which is of no surprise given the Nazi past in Germany. At the same time the practice of patient oriented and patient directed euthanasia in the Netherlands seems to find support (as Welie describes in this issue). The euthanasia discussion in the US can be highlighted in a controversy between Rhoden (1988) and Dresser (1990). Rhoden favors family discretion in decisionmaking for incapacitated patients. She argues
against involvement of lawyers and courts as “courts have deferred to the medical status quo, which is strongly pro-treatment and thus anti-family in cases of conflict”, while “the preferences of most individuals, and our society’s history and values, lend far more support to family decision making than to the medical predominance inherent in our medical and legal status quo” (Rhoden, 1988, p. 436 and p. 446). Dresser takes issue with that position as it seems not to meet “our moral obligations to protect incompetent patients” (Dresser, 1990, 425). She calls for an “objective treatment standard” (427ff) and declares that, instead of giving presumptive authority to living wills and family decision making processes, “decisions should rest on observer’s systematic evaluation of the patient’s present capacities and experiences, because they are the only thing that now matter to this individual” (437). Both positions, whether based on family decision or on medical observation of the actual state, do not rate high with the moral and political principle of self-determination, allowing citizens to make their own quality of life decisions, in which the *ars moriendi* is an essential part of the *ars vivendi*.

**PERSONAL DEATH AND HIGHER-BRAIN CRITERIA**

Philosophical and religious tradition in the Western world suggest higher-brain criteria rather than whole-brain criteria, as the former offers better “conceptual clarity” (Sorenson, 1989, 246). Veatch, a supporter of higher-brain-based criteria, writes: “What we are really interested in is not the presence of neocortical activity, but the presence of certain functions that, for want of a better term, we often refer to as higher-brain functions. Exactly what those functions are is open to much further debate, but they would seem to include capacity to be conscious, to think, feel, and to be aware of other people” (Veatch, 1988). Smith in referring to routinely made decisions to withhold specific intervention, such as antibiotics from long-term patients in vegetative stage, argues that the current legal treatment of brain death has a double standard: “It upholds surrogate decisions to terminate life-support systems and nourishment when incompetent patients irreversibly lose all consciousness and cognitive functions, yet it fails to recognize neocortical death”. He suggests, to “treat the irreversible loss of higher-brain function as legal death, reserving the right of the patient or the patient’s family to maintain biological existence”,
thus making the neocortical criteria the uniform standard, but allowing for opting out by special request from the patient or the family (Zaner, 1988, p. 133).

In 1981, the President's Commission had based its decision for the "entire brain including brain stem" definition in part on the argument, that 'it is not known which portions of the brain are responsible for cognition and consciousness" (US, President's Commission, 1981, p. 40). The authors of the Harvard formula therefore “opted for a philosophical view which identifies 'human life' with strictly organic, bodily conditions": the "moment at which the body’s physiological system ceases to constitute an integrated whole” (Zaner, 1988, p. 6). For these technical reasons the Harvard formula is not yet an adequate translation of the Western bioethical concept of personal death into the criteria of biomedical technical determination of irreversible cessation of the relevant parts of the brain. Gervais concludes that "whole brain theorists appeal only to the brain’s integrative role, and not to its role in consciousness" and that, in effect, they employ "a lower-brain concept of death, and not a whole-brain concept" (Gervais, 1989, p. 12). The President's Commission deliberately did not include in its definition those "who have lost only cognitive functions but are still able to breathe spontaneously" as this "would radically change the meaning of death. Furthermore, in language as well as content, any legislation ought to make personal sense to lay people and to reflect scientific knowledge and clinical reality"; therefore it recommended a 'minimum' change in the law in order to address only the "cases of coma with respirator assistance" (President's Commission, 1981, p. 7).

Given technical improvements in diagnostic certainty in many, not in all, cases of determining PVS, Shapiro proposes to replace the Harvard formula by a model Permanent Vegetative State Treatment statute: "Upon a medical determination of permanent vegetative state, there is a presumption that treatment will be terminated. If the individual has not expressed a desire to be maintained on artificial life-support systems in the event of permanent vegetative state, all artificial life-support systems, including the provision of artificial nutrition and hydration, will be withheld or withdrawn" (Shapiro, 1990, p. 449). According to this formula, higher-brain criteria would serve as the default position for determining personal death except in cases where patients have opted otherwise.
SELF-DETERMINATION, ARS MORIENDI AND PUBLIC POLICY

Existing statutes do not allow for self-determination, only the euthanasia policy that the Netherlands seems to allow for making decisions in regard to the 'quality of the dying process'. Given the enormous technical capabilities of supporting marginal life at its end over very long periods, and the multicultural set of different expressions of the *ars vivendi* within multicultural societies, the quest for self-determination in matters of death and dying is not just one among other secondary principles in medical ethics and in public policy; rather it is a *prime value*, but it has yet to be recognized as such.

In order to respect and to support the principle of self-determination in matters of death and dying, legal and medical paternalism has to be reduced and the right and the responsibility of the citizen to make educated choices has to be affirmed. The ethics of public policy in multicultural societies and respect for individual value-based self-determination call for one ethically safe and medically strict model as a general default position in determining death, but which includes a number of alternative criteria, which competent adults may choose in reference to their individual system of belief or quality of life and dying. This window of opportunity has been mentioned previously (Zaner, 1988; Veatch, 1988; Gervais, 1989; Shapiro, 1990) in the academic literature, but recently it has been widely opened by a landmark court decision. In the *Cruzan versus Director, Missouri Department of Health* (Colby, 1990), the court upheld the strict whole brain formula in the case of Nancy Cruzan, a patient in PVS since 1983, but affirmed the right of a competent person to make explicit advance directives based on his or her belief system. With similar argumentation Hoerster (1989, p. 295) has proposed a reformulation of the German Penal Code, exempting a physician from persecution if euthanasia has been provided on the clear and documented request of a terminally ill patient.

Neither the medical establishment, the judicial-political establishment, nor the citizen as a prospective patient and dying person seem to be prepared to fully accept individual responsibility for the *ars moriendi*. A massive effort in education for individual moral and cultural risk management is required, as the Danish Committee for Ethics correctly recognizes. But education should be directed toward self-management of lifestyle and death
related personal and moral risk rather than towards accepting a new heteronomous governmental or medical formula. Instruments for improving health based individual cultures of the *ars vivendi* and the *ars moriendi* have yet to be developed. Early successes in establishing the patient’s *value history* seem to be most promising (Gibson, 1990; Sass, 1990); further progress will allow for an improvement in trust-based physician-patient cooperation, for self-determination of the patient in matters of death and dying, and for the termination of state sponsored paternalism in matters of death and dying.

Public policy as well as good patient oriented medical ethics require either the introduction of a *conscience clause* into existing statutes (President’s Commission, 1981; Beecher, 1968; Bundesärztekammer, 1982) or a new *global model statute* reconfirming existing whole-brain death criteria as a uniform default position for determining human death while respecting and encouraging self-determination and allowing competent individuals to opt for other criteria based on their system of belief. A universal Determination of Death statute could read as follows:

An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, or (3) irreversible cessation of higher-brain functions is dead. Competent adults, using advance directives may opt for either one of these criteria; proxy decisionmaking is not accepted, except in cases of parents deciding for their minor children. In the absence of advance directives, the irreversible cessation of all functions of the entire brain, including the brain stem, will signify death. Given global cultural diversity and different legal and religious traditions, states in promoting their interest in protecting the life and dignity of their citizens in accordance with widely held values within their constituency may, as a matter of public policy, define different death criteria, such as those based on cessation of functions of the entire body or the heart, but should provide a conscience clause for individual choice. A determination of death must be made in accordance with accepted medical standards.

The proposed statute provides a number of advantages over existing formulas in different parts of the world: (1) Given wide differences in worldview, culture and moral priorities in multicultural societies and in a world of diverse cultural traditions, only a conscience clause respects and supports individual self-determination and religious and cultural tolerance. (2) Legislation and regulation provide safe ethical and legal parameters for the full
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protection of life for those who do not wish to make their own choices regarding death and dying. (3) Competent adults will not be sentenced by legal statutes to a slow dying process through various stages of vegetative life. (4) Health care professionals will not be called upon to prolong vegetative human life against their own system of belief, but will not be allowed to take the life of a PVS patient without specific directives by the patient. (5) Whole-brain death criteria will become even more robust and stable, probably becoming even more widely accepted, morally and legally, when they become the uniform default position; the fact, that some intelligent people choose less strict criteria for the determination of their death, signals that the default position might be too strict, but definitely not too loose or too liberal. (6) Principles of self-determination incorporating the self-definition of individual criteria of death will improve individual and societal trust in and support of the medical system, particularly intensive care intervention. (7) The strictness of the default position might facilitate greater public support for post-mortem organ donation by increasing trust and personal choice; however, more liberal criteria should never become legal for the purpose of obtaining an increasing number of organs for transplantation (Wolffslast, 1989). (8) Personnel and funds spent to exclusively support a single set of state-sponsored criteria for death in a multicultural society will be utilized for better and less paternalistic use. (9) 'Homogenization' of ethical decisions by 'institutionalized morality' (Bayertz, in this issue) will be replaced by principles of choice and self-determination. (10) While theologians, philosophers, neurologists and physicians of different expertise and worldview might disagree about what dying and death really mean, death and dying again should become a very personal matter, free from governmental or medical paternalism in defining other people's death.

REFERENCES