Dying as a social relationship: A sociological review of debates on the determination of death

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Abstract

The research literature about ‘brain death’ is largely characterized by biomedical, bioethical and legal writing. This has led to overlooking wider but no less pertinent social, historical and cultural understandings about death. By ignoring the work of other social and clinical colleagues in the study of dying, the literature on the determination of death has become unnecessarily abstract and socially disconnected from parallel concerns about death and dying. This has led, and continues to lead to, incomplete suggestions and narrow discussions about the nature of death as well as an ongoing misunderstanding of general public and health care staff responses to brain death criteria. This paper provides a sociological outline of these problems through a review of the key literature on the determination of death.

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Introduction

The scientific determination of death continues to be characterized by controversy, confusion and criticism. Much of this professional turmoil can be traced to philosophical and biomedical objections to the definition of brain death, its criteria, or tests to establish them. To worsen matters, the dominance of philosophical perspectives has emphasized asocial ideas of personhood that do not reflect the cultural and interpersonal realities at the deathbed. Failure to accept clinical definitions of brain death in all its different versions, by the general public or families, is often attributed to their ‘confusion’ about what death actually ‘looks’ like.

Resistance to the very idea of brain death, and not only simply by countries such as Japan, but also in the USA, Britain and other European nations, is constantly explained in terms of religious differences, ignorance or a matter of conscience. During this time, there has been little or no evidence of a dialogue between students of dying in cognate areas such as hospice, euthanasia, aged care or grief studies, and those researchers in the determination of death field. There is minimal recognition too, that these problems are not simply bioethical or biomedical in nature but fundamentally shaped and driven by a series of important sociological influences.

The aim of this review is to draw attention to this seriously overlooked set of influences and to demonstrate that sociological perspectives about dying and the determination of death are crucial, not only for understanding current and past patterns of dissent, but also for...
devising more inclusive health policies in the future. This paper is a contribution toward restoring balance to past neurobiological and bioethical emphasis in the research and literature on the determination of death. I will argue that by overlooking one simple sociological fact — dying as a social relationship — we also overlook the single most important reason why biomedical and philosophical formulations of brain death are incomplete and therefore subject to resistance and dissent.

In the first part of this paper, I will briefly review the history of the debate about brain death drawing attention to the diversity of their clinical, philosophical and sociological objections. The second half of the paper will provide a critical outline of the asocial image of the dying person so commonly witnessed at the core of contemporary determination of death discussions and research. I will demonstrate the sociological basis for so-called ‘public confusion’ toward concepts of brain death, drawing attention to the sharp contrast between publicly held social ideas about dying and the loner view of dying so commonly assumed by mainstream academic literature on the determination of death.

Determining death: a brief history

For most of human history, determining death for human beings was no different from determining death in animals — a living thing fell down and did not move again. The differences between the moment of insensibility and the moment of death blurred because determination was based on observed behaviour (slacken mouth, movement cessation, etc.) and not an assessment of physiological states (Knudsen, 2005). After a person ‘fell down’ death was determined gradually (Lock, 1996: 579), observers looking for tell-tale signs such as rigor mortis (stiffening of the body), livor mortis (discolouring of the body) or algor mortis (changes to the eyes). Eventually putrefaction or the invasion of maggots occurred (Gorman, 1985).

In recent times, cardiovascular failure and cessation of breathing was judged equally reliable and a quicker criteria for adjudicating about the onset of death. The older signs were more time-consuming and less than pleasant for family members to watch. Until the 1960s, observations of cessation of cardiovascular and respiratory functions were the main way to diagnose death (Waisel & Truog, 1997: 683) and remain largely the cardinal signs even today outside hospital situations (Crimmins, 1993; Knudsen, 2005: 43; Poppe & Bottinger, 2006; Robinson, Murphy, & Jacobs, 2003). Despite these long-standing criteria, the interest in determining death through employment of brain death criteria has grown steadily over the last few centuries.

The first person to advocate the idea of brain death appears to be Moses Maimonides (1135—1204), who theorized upon the jerking movements in decapitated humans. He argued that these movements did not represent ‘life’ or ‘centralized control’ (Laureys, 2005). Later, 19th century theories about brain death were derived from theories about intracranial pressure and its apparent causal relationship to respiratory arrest (Settergren, 2003). In 1959, French neurologists Mollaret and Goulon identified a particularly deep and apparently irreversible coma that they described as ‘coma depasse’ (Laureys, 2005: 899). In 1968, a combination of developments in intensive care technology and the rapid rise and interest in human organ transplant surgery prompted the Harvard medical school to convene an ad hoc committee to develop a new criteria for death that matched the complexity and biological implications of those developments (Giacomini, 1997). These Harvard deliberations were historically significant because the formulation of brain death developed by their ad hoc committee established the basic criteria from which all subsequent revisions and debates have derived.

Since that time there have been other legislative and professional changes that have advocated one of two definitions of brain death. In the USA, the President’s Commission Report (1981) on ‘Defining Death’ and the Uniform Determination of Death Act settled on a ‘whole brain’ definition of death (Truog & Fletcher, 1990). In the UK, the Conference of Medical Royal Colleges and their Faculties settled on a ‘brain stem’ definition of death (Sundin-Huard & Fahy, 2004). Over 80 countries have now adopted one or the other of these definitions of brain death (Bernat, 2005b).

The clinical pathway to determination of brain death begins with a state of coma. Depending on the cause of the coma and the extent of brain damage patients may develop locked-in syndrome, a vegetative state, chronic coma or brain death (Laureys, Owen, & Schiff, 2004). Brain damage begins a few minutes after cessation of cerebral blood flow (see Bernat, 2004: 163) with global destruction of brain cells after 20—30 min. Brain cell death leads to diffuse cerebral oedema with a resultant increase in intracranial volume (and therefore pressure). As pressure builds in the rigid skull vault, intracranial pressure exceeds the pressure of blood flowing to the brain and circulation ceases. The contents of the brain then start to partially herniate into the brain stem.

During these physiological changes, further changes at the cellular and molecular level occur (in the rostral
ventrolateral medulla) that create a deteriorating conflict between ‘pro-life’ and ‘pro-death’ neural programs, with ‘pro-death’ programs becoming dominant (Chan, Chang, & Chan, 2005). These processes in their turn accelerate a programmed cell death both as a response to interruption of vital metabolic nutrients and vicariously from stress (Vaux, 2002; Vaux & Korsmeyer, 1999). ‘Whole brain’ death originally included the cerebral hemispheres, brain stem, cerebellum, and spinal cord, but the spinal cord was dropped from the definition when it was discovered that most ‘dead’ people retained or regained reflexes from this area after a short time (Truog & Fletcher, 1990: 204).

Determining whole brain death or brain stem death follows the same clinical principles: assessment of state of coma, establishment of sustained apnea, and assessment of brain stem reflexes (Plum, 1999). Confirmatory tests are also helpful. These tests include EEG [recording of the usual spontaneous electrical signals of the brain], cerebral angiography [injecting contrast dye to display cerebral blood flow], transcranial Doppler ultrasonography [ultrasound imaging], somatosensory evoked potentials [recording of ‘evoked’ or ‘stimulated’ signals in a brain] and scintigraphy [nuclear imaging] (Sundin-Huard & Fahy, 2004). The general criteria for death are irreversible cessation of circulation and respiration or irreversible brain function (whole brain, that is, cerebral hemispheres and brain stem; or brain stem alone). These criteria are not reliable in the newborn period (Diamond, 1998).

There is still a wide variability in the brain death criteria that is academically advocated around the world and these include the whole central nervous system, whole brain, brain stem, and the neocortical area/cerebral hemisphere (higher brain) (Facco & Machado, 2004). Initially, the development of intensive care technology led to an increase in survival of acute brain damaged patients (Laureys et al., 2004) but the incidence of these kinds of patients is decreasing or stabilizing due to advances in neurocritical care and falling incidence of road accidents in the developed world (Doig & Rocker, 2003).

There has been significant debate about why brain death was chosen as the main criteria for death itself. These reasons include a desire to relieve financial costs to families (Schlotzhauer & Liang, 2002), the social pressure to bring psychological relief to families of the sick, freeing up beds or respirators in intensive care units (ICU) (Pernick, 1999), and removing grounds for objections to organ harvesting (Karakatsanis & Tsanakas, 2002). The increasing demand for organs has been regularly implicated in discussions about motives for brain-based determinations of death (Bos, 2005; Doig & Rocker, 2003; Truog, 1997). Against this view, Diamond (1998) rejects any suggestion that support for concepts of brain death are a result of a conspiracy of ‘body-snatchers’, ‘grave robbers’ and transplant lobbies. However Giacomini (1997), in an extended document analysis of the 1968 files of the Harvard ad hoc committee, has persuasively demonstrated the powerful influence exerted by the transplant lobbies within the medical community at that time.

Clinical, philosophical and sociological objections

During the 40 years or so since the deliberations of the Harvard committee, objections to the concept of brain death came in thick and fast with no recent indication of a slow down (see Machado & Shewmon, 2004; Youngner, Arnold, & Schapiro, 1999). Some authors have argued that organic definitions of brain death will never replace cultural and social definitions of death (Gervais, 1989; Jones, 1998; Sass, 1992), and besides, consciousness cannot be checked by any medical test so the diagnosis of brain death remains an unproved hypothesis (Karakatsanis & Tsanakas, 2002: 140). Creating a sharp division between life and death has also been argued to be artificial since no such distinction actually exists in nature itself (Halevy & Brody, 1993).

Bernat (2004) and Laureys (2005) assert their dis- taste for the phrase ‘brain death’ on the grounds that it implies that there are other kinds of death or that it is only the brain that is dead in these cases. Bernat (2004: 370) further asserts that death is ‘fundamentally’ a biological phenomenon, all other uses being merely ‘metaphorical’. People ‘must be’ dead or alive because no-one can reside in both. Their assertions fly in the face of a diversity of findings about both biological AND social understandings about death.

For example, many authors have questioned the veracity of brain death even when the criteria have all been met. The question, ‘is the brain really dead?’, seems to have plenty of evidence for a decisive ‘no’ (Banasiak & Lister, 2003; Karakatsanis & Tsanakas, 2002; Truog, 1997; Waisel & Truog, 1997; Zamperetti, Bellomo, Defanti, & Latronico, 2004). The work of Vaux (2002) and Vaux and Korsmeyer (1999) ably demonstrates the co-existence of both live and dead and living and dying cells in all multi-cell organisms including humans. Furthermore, Waisel and Truog (1997: 684) point out that many so-called brain dead patients are capable of reproduction, a criterion that many biologists would regard as the “sine qua non of life”.

Several researchers have observed how both health care workers and families hold ideas about life and death in co-existent and situationally contingent ways (Kaufman, 2005; Lock, 1996; Sundin-Huard & Fahy, 2004; Veatch, 2005). This complements the very longstanding work by medical and social science colleagues, outside the determination of death field, that death and dying are viewed as social and not simply biological experiences (see Blauner, 1966; Cassell, 1974; Charmaz, 1980; Guthrie, 1971; Hartland, 1954; Kalish, 1968; Leming, Vernon, & Gray, 1977; Michalowski, 1976; Vernon, 1970; Vollman, Ganzert, Picher, & Williams, 1971). Kalish (1968), for example, has argued that concepts of organic, clinical, and social perceptions of death are commonly fluid ideas and may co-exist and change for carers and the dying person. Cassell (1974) has argued that both death and dying — for clinical staff and families — are not simply viewed as bodily processes alone but are personal and social experiences. Categories of ‘death’ or ‘dying’ are not so simply characterized in real life situations as ‘living’ or ‘dead’ or as ‘metaphorical’.

Other objections include the tendency for absence of evidence about consciousness to be construed as evidence of absence of consciousness (Diamond, 1998); the tendency for brain shock (ischaemia penumbria) to mimic brain death and obscure possible recovery (Sundin-Huard & Fahy, 2004); and vague and imprecise use of the concept overall (Shewmon, Capron, Peacock, & Schulman, 1989; Truog & Fletcher, 1990). Many others have also questioned the problem with phrases and terms such as ‘futility of treatment’ or ‘irreversibility’ of brain function. These have been questioned conceptually (Bernat, 2005a; Cohen-Almagor, 2000; Cole, 1992) and clinically and statistically (Shewmon, 1987).

Finally, there has been widespread concern about how well understood the concept is among clinicians, including those who work in transplantation and intensive care (Conrad & Sinha, 2003; Winkler & Weisbard, 1989; Youngner, Landfield, Coulton, Juknialis, & Leary, 1989), not to mention that many places do not have experienced neurologists available to help with any of this uncertainty (Bernat, 2005b). In some developing countries, the number of neurologists per capita of population is estimated at one in three million people (Baumgartner & Gerstenbrand, 2002). There are further concerns, in more affluent countries, about the wide variation in experience and qualifications of doctors involved in brain death determination (Sundin-Huard & Fahy, 2004: 69).

And the problems do not stop here. Although according to Gervais (1989: 9) we ‘normally’ proceed from theory to criteria to tests, not only have we got this process out of order by beginning with criteria but also the tests themselves are not entirely compatible with those criteria (Waizel & Truog, 1997: 684). Tests for brain death have been subject to equal criticism and scepticism. As Bernat (2004: 161) reminds us, making the claim of irreversibility of brain death is one thing but proving it is quite another. The tests for brain death are about as good as the operators in charge of the tests and the people interpreting them (Conrad & Sinha, 2003; Young & Lee, 2004).

Tests in cerebral angiography are invasive and technically difficult to perform (Young & Lee, 2004: 503) and may have deleterious impacts on other clinical signs (Sundin-Huard & Fahy, 2004: 69). Sonography and CT scans (three dimensional X-rays) also have major problems with false positives, and MRIs (magnetic or radio wave scans) are insufficient tests on their own (Young & Lee, 2004: 503). EEGs cannot diagnose brain death though they may help confirm it (Moshe, 1989; Schneider, 1989) and anyway do not supply information about brain stem function (Facco & Machado, 2004). Scintigraphy — the use of a nuclear tracer chemical to assess blood flow — is apparently an excellent test, but much depends on how well the test is actually performed. Therefore, given this rather common problem, even this test can only provide conditional support rather than replace clinical assessment (Conrad & Sinha, 2003: 313; Laureys et al., 2004: 537, 543). This is an ironic, final observation given that the tests are frequently looked for as confirmatory of the clinical assessments and not the reverse.

In concluding this summary of objections to the concept of brain death it should also be observed that regular reviews of the recent debate about the determination of death have been singularly incestuous in academic terms. In other words, most of the deliberations about brain death have been relatively closed conversations between medical, philosophical and legal communities and seldom ones that include the social sciences. How the determination of death by the medical or legal profession is itself a social and cultural activity is rarely acknowledged. Important social studies of dying have not been consulted to understand congruence or dissonance between biomedical and social ideas of death and dying. Why such definitions are resisted or supported by wider communities has witnessed few attempts (see Pernick, 1996, 1999; Veatch & Tai, 1980, for important exceptions) to check and examine the parallel history of how understandings of death have changed or evolved in human cultures in general.

Some authors have argued that the early Harvard committee and President’s Commission displayed a distrust of non-medical, outside opinion about
determination of death, especially suspicion of those from law, philosophy and ‘thanatology’ (Pernick, 1999: 13–18). However, it is also true that seminal histories about our changing understandings of death by the French historian Philippe Aries (1974, 1975, 1981) were too late for the Harvard ad hoc committee (1968) (but not for the 1981 President’s Commission).

In the President’s Commission (1981) report only two historical references were noted by the commission — Michel Vöffel’s (1980) article on the ‘rediscovery of death since 1960’ and a fictional reference to Edgar Allan Poe’s ‘Fall of the House of Usher’ (President’s Commission, 1981: 4, 82). On the other hand, other important related work did exist at that time, and was ignored, and unfortunately these did have important historical bearing for that committee’s work (for examples, Borkenau, 1965; Freud, 1915; Moore, 1946; Sudnow, 1967; Toynbee, 1968; Van Gennep, 1908/1969; Williams, 1966).

Williams (1966), for example, surveyed 30 years of psychological abstracts to assess changing attitudes to death during this period, primarily in the USA. Sudnow (1967) studied 200 hospital deaths, most of them comatose before their death, and made careful observations of staff reactions. He argued that social meanings of death are drawn from particular professional practices of a situation. Van Gennep (1908/1969) is a classic anthropological work that provides important insights into how dying and death is commonly divided up by onlookers into social stages of transition. This process rarely results in an idea of death as annihilation but rather transformation — a crucial insight in explaining why modern peoples might not easily go along with a definition of death they cannot actually see for themselves. Had even the most basic findings and insights of these early works been highlighted or incorporated into deliberations about brain death in the late 1960s both interpretations of staff and family behaviour and/or the policy recommendations might have looked substantially different.

The concept of brain death has suffered a litany of clinical and philosophical objections but these objections themselves have overlooked a broader, and arguably more important, epistemological problem with the ascendant definition of brain death. Definitions of brain death have ignored the historical and sociological basis of human understanding of death itself. By ignoring the parallel literature on the history of death and dying, and sociological studies of how death and dying is commonly perceived in social settings, determination of death literature has become idiosyncratically technical and de-contextual. The evidence for this problem is further demonstrated by an examination of how the debate about determination of death persistently views the dying person — not as a social being — but rather as a lone and psychologically isolated entity.

**The dying person as loner**

On rare occasions it is possible to read authors in the determination of death literature that accept that definitions of death must be viewed not only philosophically and biologically but also as a social and cultural matter (Jones, 1998; Veatch, 2005). However in other literature, more often than not, when the definition of death is debated in these social and cultural terms it is in relation to discussions about foreign cultures, particularly the Japanese and their long resistance to concepts of brain death (Bowman & Richard, 2003; Brannigan, 1992; Doig & Rocker, 2003; Kimura, 1991; Kita et al., 2000).

With the exception of some Christian Fundamentalists (Campbell, 1999) and Jewish groups (Rosner, 1999), Western ideas about death are assumed to be less resistant to medical definitions of death and that the general public is more willing to accept this kind of leadership. In this way, dissent or resistance is attributed to ‘religious or ethnic difference’ and not to a wider and deeper schism in public understanding between the nature of death and the end of identity. Dissent or resistance is too commonly localised in minority or foreign groups. Indeed, the (US) President’s Commission Report of 1981, entitled “Defining Death”, indicated that it would be a definition identified by medical and legal institutions and their professions and not individuals (Gervais, 1989).

Recently, Laureys (2005) and Machado and Shewmon (2004) conducted reviews of the determination of death debates and claimed a broad ambit for their reviews but this turned out to be limited to medical, philosophical, legal and ethical issues — the same narrow factors considered important by the Harvard ad hoc committee 37 years earlier (Ad hoc committee, 1968: 337). Unfortunately then as now, there is no mention of the social and cultural factors in America or elsewhere that are essential to a national understanding, less acceptance, of brain death criteria. Furthermore, Laureys (2005: 907) concludes, rather unsurprisingly that, after all, death is a biological phenomenon.

Lizza (1993, 1999), an advocate for the ‘higher brain’ definition of death, argues that ‘death’ of the human being should really be viewed, not purely in biological terms, but in terms of the criteria we create for what it means to be human. In an early paper, Lizza
(1993) argued that all philosophers agree on the necessary conditions for what being a person means. It transpires that, rather unsurprisingly for philosophy and philosophers, ‘being human’ means a capacity to think. As the sociologist C. Wright Mills (1959: 19) remarked when referring to the epistemological bias in different disciplines, “every cobbler thinks leather is the only thing”.

Personhood, according to Lizza (1999: 441, 442), may express itself in three possible ways. First, a person may be a member of a species (whether dead or alive) such as the human race. Secondly, a person may be psychological or characterological; that is, a presence behind the organic/biological appearance. Finally, a person may be a unique personality. The ‘philosophical’ problem for Lizza is which of these categories of explanation best accounts for what we want to say about, for examples, death, permanent vegetative states, or anencephalics. There are two obvious social problems with these clean categories of ‘personhood’.

First, many people hold these categories simultaneously and changeably. People become attached to others (both living and inert objects) because of their social relationship to those persons or objects. The idea of ‘personality’ or the general character behind things as they appear are of secondary importance to the way in which others relate to that person or object. Person is not simply a ‘being’ but a ‘property or quality’ given/imposed on someone or something by others. To employ a philosophical term, person is not an ‘essentialist’ category for most people (a quality in and of itself divorced from the rest of the world) but one born from, and given meaning by, a perceived history of social reciprocity. Identity is created in the minds of others by a history of relationships to persons or things.

Secondly, technical definitions of personhood or brain death, if not inclusive of the people for whom it is designed (that is, ordinary everyday people), are merely academic categories that (1) are not likely to adequately explain death for people who are not involved in their formulation; and (2) are even less likely to explain attachment for most people — an important social factor in understanding family and staff resistance to a diagnosis of brain death. In other words, definitions of personhood that emphasize a lone and highly individualized view of dying as merely ‘thinking’ or ‘personality’ fail to understand dying as a social relationship. Not understanding the reciprocity inherent in both personhood and attachment leads Lizza (1993: 361) to some ironically impersonal conclusions:

“In the ordinary way of speaking’, ‘Paul Brophy’ (a fictitious example) refers to the person and the human being. However, after Brophy lost higher brain functions, ‘Paul Brophy’ no longer refers to ‘Paul Brophy’, the person, since Paul Brophy, the person, no longer exists. What lies in the hospital bed, what we refer to by Paul Brophy is only Paul Brophy the human being”.

Unsurprisingly, as a holder of this above view, Lizza (1993: 358) is somewhat bemused at the fact that the majority of people and family remain emotionally committed to people in a persistent vegetative state (PVS). Yet, Lizza displays no subsequent awareness that the asocial, academic view of personhood that he rehearses may be the main obstacle in his own understanding of bedside behaviour toward PVS patients.

This idea that a person is a lone quality separate for the relationships that create it, sustain it, and give it meanings, is widespread in the determination of death literature. Diamond (1998: 74) writes poetically about determining death as if this has nothing to do with social relationships and instead draws from medieval religious imagery that again focuses entirely on the lone individual: “What is being attempted by all conscientious attending physicians is to know the unknowable, that is, the point at which the soul leaves the body”.

Settergren (2003) quoting from Lachs (1988: 250, 251) continues this eulogy to the socially unconnected individual:

“When we unalterably lose the ability to will and to do, to think and to hope, to feel and to love, we have ceased existence as human beings. The only humane course then is to declare us dead and to treat us accordingly....once the human person is gone, in the faltering body there is no-one there”.

In this above view, human beings are NOT reciprocal beings, not people who share a common will and identity with family and friends; acting and hoping together, not only just giving but also receiving affirmation, feelings and love from others.

Once again, many of these recent views from medicine, bioethics and philosophy in general have emerged because they consistently fail to engage with parallel social and medical sciences discussions and data about the social nature of dying that are cognate to the determination of death literature. The past seminal work of sociologists studying death and dying like Blauner (1966), Glaser and Strauss (1965, 1968, 1971) or Charmaz (1980) or physicians Hinton (1967), Weisman (1972) or Witzel (1975) are no-where cited or integrated
into an understanding of the person-near-death in determination of death literature. More recent sociological and clinical work about dying from Davies (1997), Kellehear (1990), Lawton (2000), McNamara (2001), Seale (1998), or Young and Cullen (1996), to name only a few studies and reviews, make no appearance in the discussions about how people understand death and come to define it for themselves or others.

Recently, Kaufman (2005) has produced a lengthy and nuanced ethnographic study of how hospital treatments are interpreted and employed by those at the bedside, for family and staff, and this includes issues of life support. Kellehear (2007a) has recently published a social history of dying showing the symbiotic relationship between dying, death and community. This historical sociology shows how the concepts of ‘dying’ and ‘death’ have exchanged places several times in human history and how, contrary to some biotechnical thinking (Veatch, 2005: 360–362), life and death are rarely seen as opposites or absolutes. It remains to be seen whether these recent studies enjoy any more success in restoring a sociological balance to the loner view of dying than the equivalent but unused studies of the 1960s and 1970s.

Dying as a social relationship

Not all philosophical commentary has eschewed social concepts and arguments in discussions about determination of death. However, there are two problems with even this literature. First, the number of authors who attempt to argue the importance of social factors in the determination of death are very modest. Secondly, among those who do advance these insights, there is an unfortunate division between those who assert the need for more social understandings about death and those others who provide us with empirical indicators of this reality.

Among the theory-minded writers, Cohen-Almagor (2000: 267) argues that ‘people are social beings’. Medical language, such as ‘vegetative’ states, ‘irreversibility’ or ‘futility’, serve physician interests more than patients. He emphasizes what he calls the ‘reality-building’ nature of language and is not surprised at why many families do not share the language (and hence ‘reality’) of brain death, coma, or persistent vegetative state.

Jones (1998) wrote an intriguing paper comparing brain birth with brain death. Although he is quick to point out that concepts of development and degeneration are NOT interchangeable he is equally adamant that both brain birth and death are only partly biological, the characteristics of both owing much to social, religious and ethical values. This echoed the earlier views of both Sass (1992) and Veatch (1993) who argued that definitional issues about death will not settle the cultural ones. Zamperetti et al. (2004) in their review of the literature flatly declare a need for a more pragmatic social approach to determination of death. They argue that after 35 years we need to acknowledge that the biological evidence for brain death is always equivocal and advocates the need for a name change from ‘brain death’ to ‘Irreversible Apnoeic Coma’. This name change focuses the clinical and family discussion on the likelihood of recovery and not arguments about the nature of death itself. It is also easier to explain to the public because of this simplification and leaves more scope for involvement and participation of society in general and families, in particular.

Sassower and Grodin (1986), in a paper that comes closest to recognition of the crucial importance of dying as a social relationship, argue that it is ‘meaningless’ to provide an answer to the question, “Is the patient dead?” outside a specific context. We need to know who is asking the question and for what purpose and how certain you want to be about the answer. In other parts of the literature, often not citing this more conceptual material, exist support for these ideas from more empirical and clinically oriented authors.

Robinson et al. (2003) conducted a survey of determination of death by medical transport teams in the USA. With a 57% response rate from all available working teams in the USA (N = 190) they discovered that the key criteria for determination of death was simply unresponsiveness to advanced cardiac support. But more interesting is their finding that the key reason for NOT pronouncing or presuming death in their patients was ‘political reasons’ (71%). These political reasons included the ground crew’s level of comfort, the flight crew’s level of comfort, involvement in a crime scene, involvement of law enforcement officers, involvement of a child, and involvement in a humanitarian mission of some sort.

Against these kinds of circumstance-led determinations, where the decision to presume death, or not to presume it, are mediated by the relationships between the patient and those others around him/her, are the prevailing social ideas about reversibility of death. Cole (1992) argues that brain death is counterintuitive because it runs counter to people’s experience of medical rescue in the media — TV, films or newspapers. Of course, viewers commonly see ‘flat line’ images as suggestive of death but just as commonly (and perhaps more importantly) such images are demonstrated to be
reversible. Reversibility is not only witnessed in scenes of medical resuscitation but also the rebuilding of other seemingly destroyed objects and organizations such as engines, cities or houses. The very idea of irreversibility is both ahistorical and inconsistent with social experience. According to Cole, it simply doesn’t ‘make sense’.

The experience of medical staff and families working with ‘brain dead’ patients actually supports — not undermines — this sense of continuity. Brain dead patients look alive — they are pink and breathing (Truog & Fletcher, 1990); they sometimes respond to surgical incision with elevated blood pressure and respiration (Karakatsanis & Tsanakas, 2002: 129); they are capable of reproduction (Waissel & Truog, 1997); they develop bedsores and pneumonia, something that cadavers don’t do (Sundin-Huard & Fahy, 2004: 66); and they move in their beds, mimicking restlessness, and grasping at deliberate or accidental stimuli (Turmel, Roux, & Bojanowski, 1991). This is not ‘confusion’, ‘misapprehension’ or ‘misconceptions’ by the general public about those who are brain dead (Laureys, 2005: 899; Lizza, 1993; Siminoff & Bloch, 1999: 187). By most social criteria, the brain dead do appear alive.

Moreover, many of the brain dead resemble those asleep, a more familiar experience that often attracts similar attentions and supports (Aubert & White, 1959). People who sleep often require bedding and favourable environmental conditions, especially protection from unnecessary disturbances. Furthermore, people who are ill and sleeping commonly require or attract unobtrusive checking or monitoring. These are not the needs of corpses. Little wonder there is a widespread desire by carers of the unconscious to support them, in spite of whatever abstract medical reasons are offered for the poor-responsiveness of their charges. Indeed, ‘wonder’ is only possible if somehow dying is NOT viewed as a social relationship but merely as some abstract technical notion divorced from the everyday world of social life and its principles of interaction, reciprocity and meaning-making.

And even if death was declared and agreed by all — say, with widely observed onset of rigor mortis or even later with onset of putrefaction — this rarely ends a social relationship. In other words, it is not only dying that is a social relationship but also death. It is NOT the case that death kills identity whatever legal, financial and moral changes are prompted by these bodily changes (Veatch, 2005). Both the social commitments and emotional attachments rarely evaporate at death.

Instead, as a host of social and anthropological literature on death and dying ably demonstrates, relationships continue to evolve at the point of death (see for examples, Hartland, 1954; Hocart, 1953; Howarth, 2000; Kellehear, 2007b; Palgi & Abramovitch, 1984; Pardi, 1977; Riley, 1983). Relationships evolve in memorial practices in the home, roadside vigils at the place of death, or even in traditional graveyard visitation where ‘talking’ with one’s dead is historically and sociologically widespread. Furthermore, contemporary people widely report ‘interactions’ with their dead in visions of the bereaved, dreams, séances, consultation with mediums, or psychomanteums (see Howarth, 2000; Kellehear, 2007b; Picardie, 2000 for fuller details and examples). Such ‘interactions’ with the dead are believed to be ‘reciprocal’. This broader human context of dying and death as ongoing social relationships mean that ‘determination’ of death is more ‘determination’ of particular social and moral functions during bodily decline (Miles, 1999: 313).

Therefore, the emphasis cannot be on death — as we have seen, an inseparable symbiotic relationship between biology and culture — but on the irreversibility of biologic, social and financial (with obvious legal ramifications) decline. Since ‘irreversibility’ can only ever be subject to mere and fallible assessment, the legal and social challenge before us is not one of consent but consensus. This brings us firmly into the world of advanced directives, participatory medical decision-making, and civic law. These are debates about citizenship — legal and social discourses about rights, entitlements and obligations — not simply or solely discussions about biology or bioethics.

Death is not decided by appeals to biology but by a social mix of medical, legal and family consensus. As a spouse of someone with severe dementia once remarked: “That’s why I’m looking for a nursing home for her. I loved her dearly but she’s just not Mary anymore. No matter how hard I try, I can’t get myself to believe that she’s there anymore” (Gubrium, 2005: 314). People stay when their loved ones appear dead; others leave when those loved ones appear fit and alive but no longer reciprocate in recognizable ways. It is the strength of bonding, opportunities for ongoing reciprocity of the relationship, and the future sustainability of both, that are crucial for determining whether a relationship is finished and moving into a new phase, or whether it is possible and desirable to hold onto the old one.

Medical and ethical information is necessary and important, but commonly, to the surprise and chagrin of some, not decisive. That is often because the determination of death has historically been based on community criteria of death. You are dead when WE say so, and not simply when SOME of us say so, or even when your
doctor says so (Lock, 1996: 575). In other words, any criteria for death must draw on, or consult with wider cultural sources and ideas than merely those from the professions. Ignoring this fact about dying as a social relationship will indeed bring physicians, inevitably, predictably and unnecessarily, into conflict with families of comatose patients (Bernat, 2005a).

Conclusion

This review has made several sociological observations about past and recent literature on the determination of death. First, much of that research and literature is ahistorical. This has meant that research into concepts of death, and experiences of dying, have not been placed in a wider context of changing attitudes and behaviour. Surveys of attitudes or knowledge about ‘brain death’ tend to assess people’s understanding about death from the standpoint of the medical criteria for death. The identification of alternative, but wider sources of understanding about death and dying, located in their biographies or communities, is not an aim of much of this research (see for example, Siminoff & Bloch, 1999).

Secondly, omission of an historical dimension into death and dying has also led to a related inattention to the sociological and anthropological research into the everyday assumptions and knowledge that people use to construct their understandings of death and dying. Research into social attachment and disengagement (of staff, families or communities) toward the dead or dying person needs to be incorporated in all new reviews of the literature as well as empirical work on the determination of death.

Thirdly, much of the research about the determination of death has displayed an over-reliance on psychological and philosophical perspectives. While it is certainly true that ‘cobbler’s’ such as sociologists are no less likely than philosophers to commend their perspectives to any research area it is, nevertheless, true — in language, theory and methodology — that traditional work in the determination of death has been lop-sided. The dominant picture of dying that has emerged emphasizes cognition, will and consciousness over the social basis of attachment, meaning-making and identity. So-called ‘interdisciplinary work’ in this area requires greater collaborative effort in biomedical, bioethical and social sciences quarters of this field.

Some of the muted or absent calls for a social perspective on death and dying from biomedicine and bioethics may be due to their lack of willingness or interest in reviewing and evaluating the literature about dying in sociological ways. However, some of the problem here must also be attributed to the apparent lack of interest or willingness by sociology and anthropology to enter debates that may appear to them to be esoteric to neurology and ontology. Perhaps this is indicative of the ongoing ambivalence and tension between the social sciences and medicine in matters to do with the body. But whatever causes may be implicated in this bias toward favouring psychobiological structures over social structures we can say that this leads to one final observation.

Debates about the determination of death have encouraged an academic climate conducive to uncritical acceptance of biological criteria for death with an under-recognition of the crucial role of the social criteria for death. The reluctance to view death in both biological and social terms constitutes the single most important barrier to the general public’s confidence in these scientific, legal and ethical deliberations.

For future research, this means a need for more empirical work that fosters collaboration or dialogue with colleagues in the social sciences, especially in the comparative disciplines such as sociology and anthropology. Literature reviews will continue to cover biomedical and philosophical matters but they need to integrate the related clinical, behavioural and social research into death and dying in areas cognate, but directly relevant, to concerns about the determination of death. For future policy development, it will be important to include the communities that are directly affected by these concepts including other health care colleagues who must address the complexities of brain death with little or no neurological specialist support.

A wide remit for the determination of death is crucial to this field because the problem of death is not only simply a technical problem of the brain and its workings but also about how experiences of mortality are mediated by social understandings of death and dying. As in all sociological attempts to grapple with the human verities (Mills, 1959), including death, this means understanding death and dying at the place where biology and biography meet at their intersections with society and history.

References


