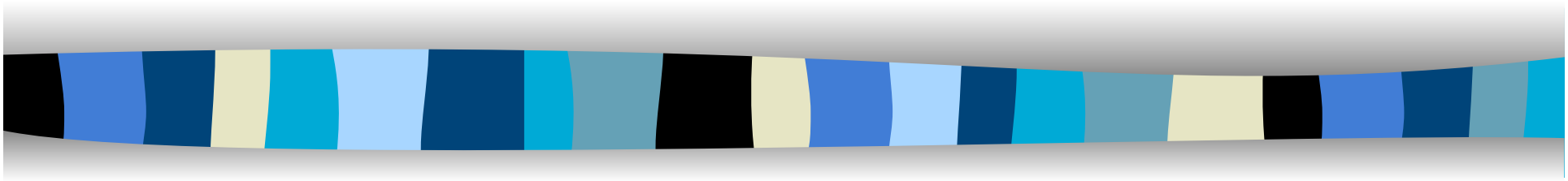
What is Dead?
A social view of a medical view



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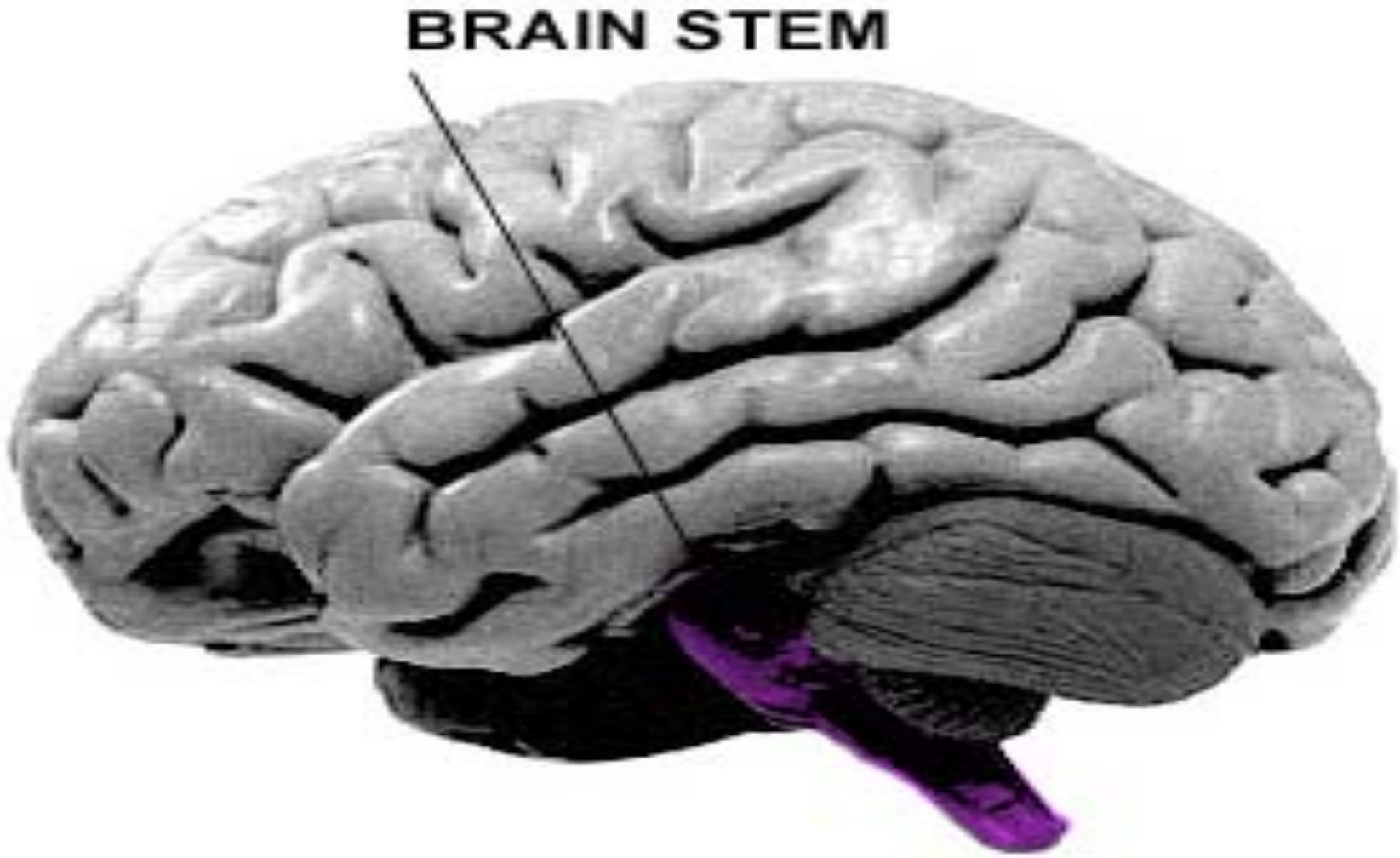
My friend the brain

My friend's friend the brain stem



The Scientific Determination of Death

a quick & dirty history

- Falling Down
- Slow signs - rigor, livor, algor mortis
- Putrafaction and invasion of maggots
- Cardiovascular failure & cessation of breathing
- Brain death
- CV & breathing failure OR Brain death

Who says you're dead?

a parallel history

- Anybody remotely experienced with death or with an intact sense of smell
- Anybody with a mirror or intact sense of hearing
- Anybody with basic medical and/or resuscitation knowledge
- Anybody with a neurology degree

Determining who is brain dead

- Not related to political party preferences, occupational group or degree obtained

- Medical criteria only
- Assessment of state of coma
- Establishment of sustained apnea
- Assessment of brain stem reflexes
- Tests - EEG, cerebral angiography, MRI, ultrasound, scintigraphy

Why the focus on the brain?

- Relieve financial costs to families
- Psychological relief for families
- Free up respirators and beds in ICUs
- Removing critical grounds for organ harvesting

- Increase demand for organs regularly implicated in discussions about MOTIVES

Continuing objections to brain death

- Ignores social and cultural criteria for death
- Consciousness cannot be reliably checked by medical tests
- Sharp division between life and death artificial
- Tho debatable some have recovered after meeting all medical criteria for brain death
- The brain dead capable of reproduction
- Absence of evidence of consciousness = evidence of absence of consciousness

Objections (continued)

- Brain shock (ischaemia penumbria) mimics brain death
- Vague & imprecise use of concept
- 'futility' and 'irreversibility' conceptually and statistically unsound
- Poorly understood among clinicians incl those who work in transplant medicine and intensive care
- Neurologists thin on the ground esp in developing countries where rates can be 1 for 3 million
- Wide variation in training, qualification and experience among those who 'should know'

Social problem - number 1

- Uncritical acceptance of biological criteria for death
- Esp conflation of 'brain' death for death

- This acceptance and conflation suggests a naïve materialist view of identity ie death of body = death of identity

Example

- Theorists and clinicians explain deathbed behaviour of relatives in terms of:

  ignorance

  misunderstanding

  confusion

About 'what death REALLY looks like'

- ...it 'looks' like Anatomy Lab 101

HOWEVER – from a social viewpoint

- So called 'brain dead' people:

1. Are pink and breathing
2. Respond to surgical incision with elevated blood pressure and respiration
3. Are capable of reproduction
4. Develop bedsores and pneumonia (things cadavers refuse to do)
5. Move in bed, mimick restlessness and grasp at noxious stimuli (from irritating intubation to the unwelcome appearance of Tories)

HOW 'IGNORANT' OR 'CONFUSED' CAN YOU GET?

Social problem - number 2

- Biomedical and bioethical views of the dying person are anti-social
- The dying person is commonly viewed as a Loner - a solitary being to be understood and valued for its independent existence and NOT for its inter-dependent, SOCIAL nature

Example

- Philosopher Lizza (1993, 1999) argues that ALL PHILOSOPHERS agree on the necessary conditions for being human
- 'Being Human' means 'a capacity to think'
- Not a surprising definition if you're a philosopher

Another example

- Settergren (2003); Lachs (1988) "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."

Yet another example (continued)

- Human beings not reciprocal beings
- Share common will, values, culture
- Acting and hoping TOGETHER
- Giving but also receiving affirmation of identity
- Embedded in group affiliations
- Identity PART owned by self and PART owned by others with vested emotional, social & political interest.

Similar errors of assuming the dying as loner

- Suicide - never fully appreciate the social destruction left behind
- Family and medical resistance to calls for assisted death by the dying
- Theories of bereavement that view grief as a private reaction to loss

Social problem - number 3

- Most discourses on determination of death based on medical, philosophical, legal and ethical literature (where's the social science?)
- Almost entirely self-referential and incestuous within these traditions
- Ignores community views about death or dying
- Furthermore, ignores the empirical and theoretical literature about dying (anyone for irony?)

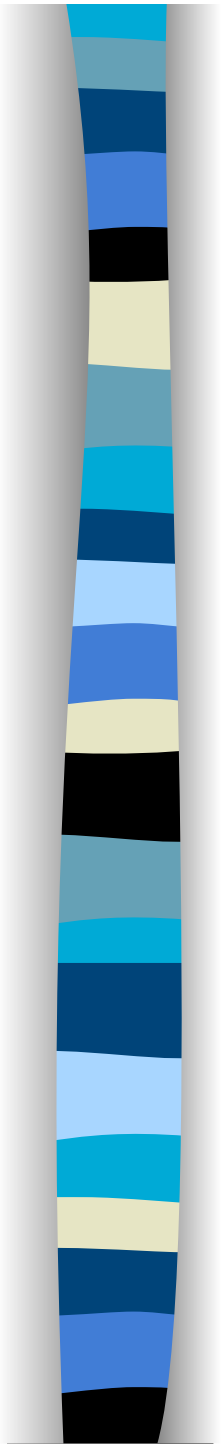
Examples

- Most surveys about community attitudes assess these against current medical understandings about brain death
- 'interdisciplinary' euphemism for medicine, law and philosophy since 1968 'til the present
- Few to no citations to any major studies of dying behavior
- Few sociologists or anthropologists as authors of major research or policy documents

Implications and future challenges

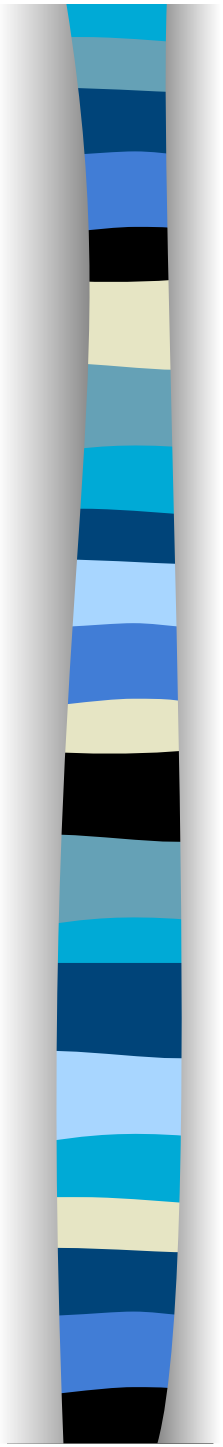
- For some time thoughtful men have been increasingly troubled by the present attitude in the medical profession: "You're dead when your doctor says you are"

Desmond Smith, The Nation, 1968



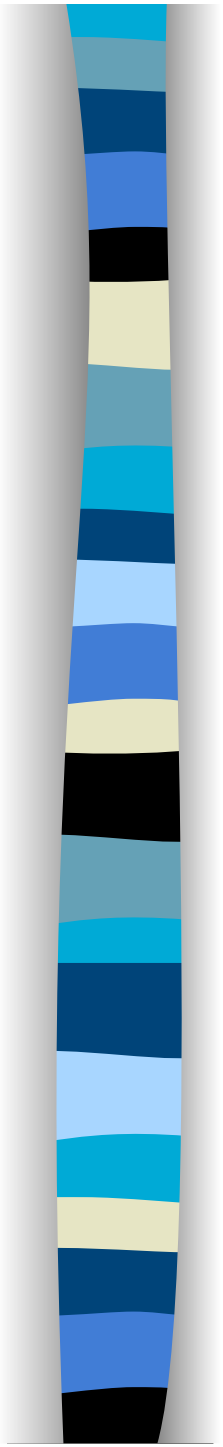
1. Lessons from a sociology of death & dying

- Communities have always argued that you are dead when WE say so, not when your doctor says so
- Current ideas about brain death are biomedically reductionist, unsettled and highly debatable.
- Current ideas about brain death may represent vested interests in organ transplantation rather than understanding mortality
- Current ideas about brain death may therefore have vested interests in reducing uncertainty and exaggerating certainty
- Current professional discourses about the nature of death are exclusion zones for social sciences



2. Lessons from public health theory & practice

- Technical definitions of death are unlikely to adequately explain death for those people not included in its formulation
- A biologically reductionist view of death is no more likely to gain support than a genetically driven view of health
- Technical definitions of death divorced from staff training, qualification and support will encourage irrelevance at best, incompetence and abuse at worst
- Recognition of HIV does not promote safe sex. Recognition of the link between tobacco use and cancer does not promote smoking cessation. Recognition of brain death criteria will not deliver public confidence in transplantation medicine



3. Lessons from policy studies

- The science of dying must be grounded in empirical research into its policy targets - an interdisciplinary study of dying
- Credible policies are derived from wide consultation - in the case of brain death - this is the general public, non-transplant clinicians, and the social sciences
- All biomedical and bioethical dilemmas are social and political dilemmas. These are questions about citizenship - questions about rights, obligations and entitlements
- Therefore, death is NOT decided by appeals to biology but by a social mix of medical, legal and family consensus

A Parting thought

- As a spouse with 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 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