

Vulnerability at End of Life: A Historical and Cultural Perspective

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Origins

- Vulnerable is derived from Latin *vulnerabilis* from Latin *vulnerare* (to wound) from *vulnus* (wound).
- The Canadian Oxford Dictionary (2001)

Dictionary Definition

- **Vulnerable:** 1. able to be physically or emotionally hurt 2. liable to damage or harm esp. from aggression or attack (a vulnerable position) 3. Exposed or susceptible to a destructive agent or influence (vulnerable to attack).
 - The Canadian Oxford Dictionary (2001).

- It is a stark and sobering reality that as humans we are all vulnerable.
- every person is vulnerable to a greater or lesser extent depending on their circumstances (within or beyond their control).
- can change over time...

Who is Vulnerable?

- Poor and homeless persons
- Children and adolescents
- Substance abusers
- Mentally Ill Individuals
- Migrant workers
- Immigrants, refugees
- Abused individuals
- prisoners
- Minority groups
- elderly, disabled
- Terminally ill

Vulnerability

- Individuals
- Populations or Social Groups

Predisposing Factors...

- Socioeconomic status
- age or gender related related causes
- health related causes
- life experiences
- Modifiable and non-modifiable risks

Vulnerability at end of Life

- Modifiable/non-modifiable factors (diagnosis, prognosis, place of death, pain management, treatment or no treatment, etc.)
- Social (family support, work/income, living situation (rural/urban as well as home, neighborhood, social group membership, history, social support networks)

Vulnerability at end of life

- Psychological (personal resilience, life experiences, coping skills)
- Physical (previous/current illness, prognosis, pain, mobility, genetics)
- Environmental (home, neighborhood, community, country)
- Other (justice, access to culturally competent care, knowledge of system)

When does end of life begin?

- There is no consensus on what constitutes “end of life” ...
(National Institutes of Health State-of-the-Science Conference Statement on Improving End-of-Life Care, 2004)
- Depends on our view of when death occurs (brain death, cardiac, spiritual death, etc.);
- Who defines end of life?

Death Defined...

- For example, the first edition of *Encyclopaedia Britannica* informed its readership that "DEATH is generally considered as the separation of the soul and body; in which sense it stands opposed to life, which consists in the union thereof" (1768, v. 2, p. 309).

Definitions of Death...

- whole-brain versus cerebral death.
- the cessation of life as determined by the absence of blood circulation, respiration, pulse, and other vital functions.
- Harvard Criteria: Flat EEG and lack of blood circulation in the brain.

Death...

- **Legal Definition:** An individual who has sustain either (1) irreversible cessation of circulator and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, are dead.
 - (Uniform Determination of Death Act)
- **Clinical Definition:** the cessation of life as indicated by the absence of circulating blood, respiration, pulse, and other vital functions.

History and Culture

- My argument:
 - vulnerability at end of life is a social construction, significantly influenced by social, cultural and religious values and shaped by our history;
 - Influenced by current social institutions (our deaths are a mirror of how we live in society)
 - Not everyone is vulnerable at end of life.

Culture and Death

- Individual knowledge and fears of death are conditioned by our social and cultural environment (Kearl, 1989)
- Culture influences how we understand and perceive such concepts as health, illness, pain, suffering and death.
- Social institutions help to frame concepts such as death;

- The more powerful the institution the greater influence it has on death ideology and our outlook on life.
- Modernity has overcome religion's monopoly on death – secularization of death

Influence of the state on our conception of death

- Decide why we die (declarations of war, controlling harmful substances in environment, destruction of environment)
- How we die (euthanasia laws, abortion laws, termination of life)
- Who dies (social injustices leading to inequities in access, oppression (A Black male)
- Where we die (support for nursing homes versus home care) (Kearl, 1989)

Medical Establishment

- Medical system's role in creating or ameliorating vulnerability at end of life
 - Forewarnings of death (diagnosis/prognosis)
 - Control over the process of living/dying is routine (medical treatment, diagnostics, pharmaceuticals, technology, hospitals)
 - Pronouncement of death

From Religion to Medical Model Conceptualization of Death

- “Within the huge secular cathedrals dedicated to battles against death, we find physicians, our culture’s high priests on matters of life and death, redefining the very boundaries of life and researching way individuals can survive with artificial hearts or transplanted kidneys.”
 - Kearl, 1989 (p. 13).

Culture Defined...

- “culture” refers to the collective beliefs and shared practices that people use to make sense of their reality and includes the concepts of ethnicity, language, religion etc..
 - (Helman, 2002)
- In this way culture acts as a set of guidelines – an inherited lens – through which people view society and informs people how to participate in society.

History of Death, Dying and End of Life

- Perceptions of death have been shaped by religious values and beliefs regarding an afterlife;
- Throughout history our views and beliefs regarding death have changed;
- Different cultures/religions view death differently;
- Prior to the “medical model” death was more accepted as “normal”
- More recently, we have witnessed a secularization of death;

Vulnerability and Dying

- Not everyone is vulnerable at end of life;
- Indeed, for some cultural and religious traditions vulnerability is a desired state as one approaches death.

Some unique situations

...at end of life

- Martyrdom;
- Soldiers;
- Death as a spiritual experience...(Hindus view death as the birth pangs of entering the next life...)
- Sudden death.
- Persistent vegetative states...
- A longed for death...
- Acceptance of inevitable death.

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Questions/Discussion?