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Disability Bioethics

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What is bioethics?

Bioethics examines the ethical issues raised by medicine, health and life sciences

Focuses on *advances* in life science that raise (or appear to raise) novel ethical dilemmas

New ethical issues can arise from

new biomedical technologies

impact of science and technology on how we think about e.g. human lives, subjectivity, values

- Traditionally bioethicists have had backgrounds in philosophy, medicine, law
- Tend to take abstract, decontextualized approach
- Increasing input from social science, empirical, feminist approaches, but only just beginning to engage with disability

Bioethics and disability

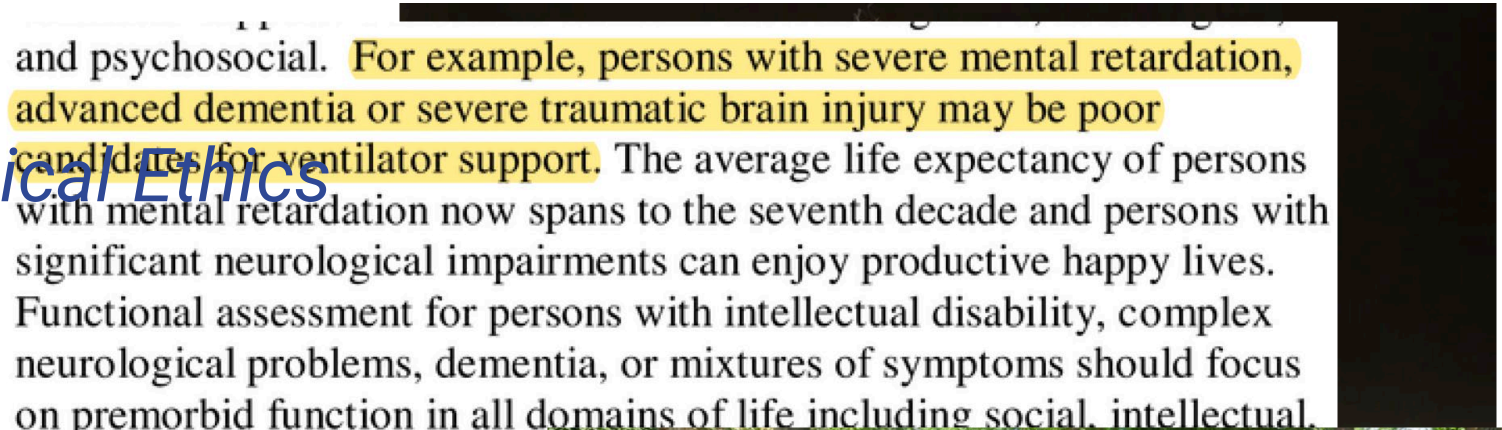
- Much of biomedicine = interventions to avoid, cure or ameliorate conditions that compromise health or are disabling
- Much of bioethics → evaluating ethical permissibility of interventions to avoid disability
- Ethically contentious at beginning and end of life
- "…the relationship between bioethics and disability has traditionally focused on killing" (Vehmas 2003, 146)

Bioethics and disability

…have had a tense relationship

Bioethics and disability activism

- Peter Singer, *Practical Ethics* (1979)
- Protests by disability activists
- Lack of engagement has been counterproductive



and psychosocial. For example, persons with severe mental retardation, advanced dementia or severe traumatic brain injury may be poor candidates for ventilator support. The average life expectancy of persons with mental retardation now spans to the seventh decade and persons with significant neurological impairments can enjoy productive happy lives. Functional assessment for persons with intellectual disability, complex neurological problems, dementia, or mixtures of symptoms should focus on premorbid function in all domains of life including social, intellectual, professional, etc. Persons wit

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Outline

Distinguish between bioethics of disability vs disability bioethics

Bioethics of disability = systematic thinking about morally good ways to behave towards people with disability

Disability bioethics = moral understandings and analyses generated through experience or knowledge of disability

Indicate where bioethics of disability is inadequate and disability bioethics can be better

…with some examples

Bioethics of disability

- Oversimplifying the meaning of disability
- Disability as problem to be solved
- Individual pathology
- Deviation from biomedical norm of physical or mental structure or function

Disability bioethics

- Uses a variety of models
- Social, relational, minority, human rights
- Relational and contextual approach
- Aware of effects of disablism and ableism

Bioethics of disability

- Epistemically limited
- Lack of empirical or experiential knowledge seen as irrelevant to ethics or easily overcome
- Problematic because evaluating permissibility of interventions often involves ‘quality of life’

Disability bioethics

- Epistemically grounded in empirical and experiential knowledge of disability
- Open to “what goes on in actual social and moral orders”
- Counters epistemic injustice
- Disability as personal identity, political identification, intersectionality

Bioethics of disability

- Tends to discuss ‘disability’
- Neglects diversity in
  - impairment
  - cultural attitudes
  - personal responses
  - social and material environment
  - inclusion
  - medical and social care provision

Disability bioethics

- Heterogeneity of impairment
- Diversity of social and individual responses
- Dynamic vs static
- Connects disability to embodied experience

Bioethics of disability

- Rooted in philosophical traditions (eg utilitarian) with particular view of persons and situations
- Decontextualized
- Disembodied
- Socially disembedded

Disability bioethics

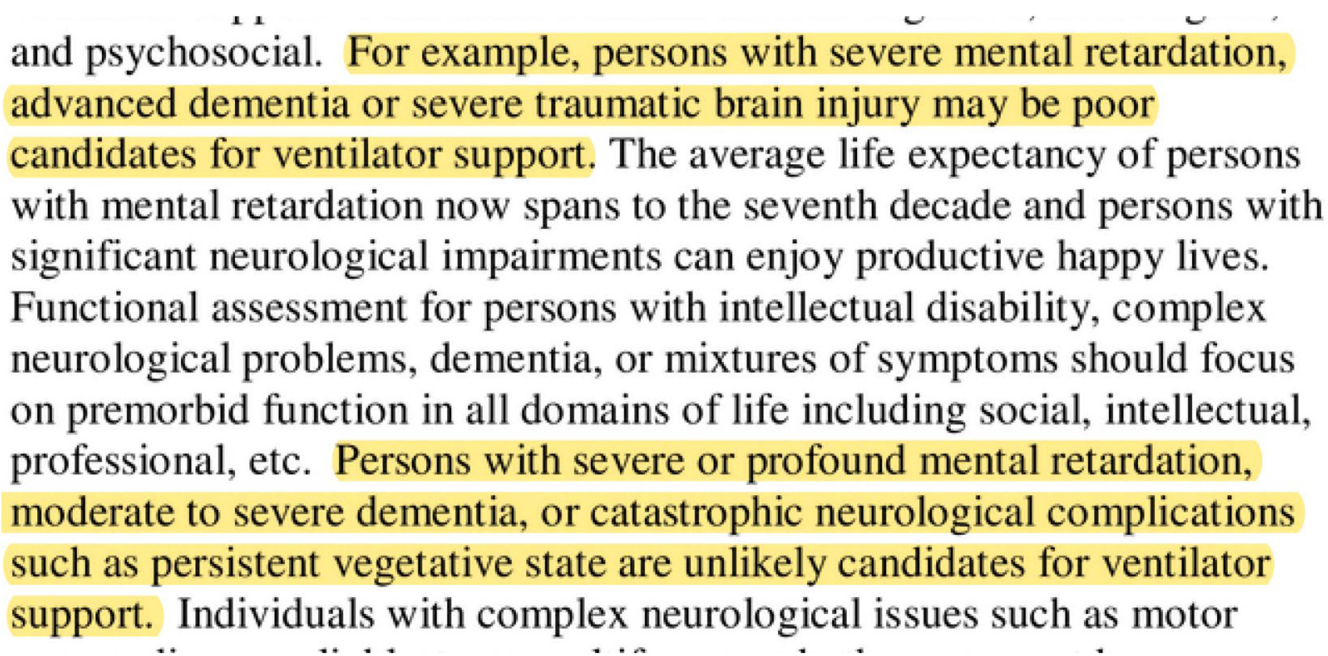
- Influenced by feminist bioethics
- Contextual
- Moral significance of the body and bodily difference
- Attuned to small and large-scale structural injustices
- More conscious of bioethics' broader responsibilities

"…it is ethically irresponsible to fail to consider the real-world consequences" (Kittay 2009, 139) of bioethical input in policy and practice, and public thinking on "normality"

COVID-19 and disability: pandemic triage

- In a pandemic (like COVID-19) or other emergency, unusual pressure on healthcare resources
- Concern over restricted access to critical care (ICU, ventilation), potential discrimination against people with disability
- Guidelines from Alabama, Tennessee, Utah, Pennsylvania, NICE guidelines UK)

- Aquino et al *(Health Care Analysis, 2021):* 21 local and national guidelines excl. USA, 9 specify disability as exclusion criterion, only 1 excludes disability



and psychosocial. For example, persons with severe mental retardation, advanced dementia or severe traumatic brain injury may be poor candidates for ventilator support. The average life expectancy of persons with mental retardation now spans to the seventh decade and persons with significant neurological impairments can enjoy productive happy lives. Functional assessment for persons with intellectual disability, complex neurological problems, dementia, or mixtures of symptoms should focus on premorbid function in all domains of life including social, intellectual, professional, etc. Persons with severe or profound mental retardation, moderate to severe dementia, or catastrophic neurological complications such as persistent vegetative state are unlikely candidates for ventilator support. Individuals with complex neurological issues such as motor

Principles of critical care allocation (“triage”)

- Bioethical debate fed into principles on which guidelines were based
- Saving maximum number of lives as measured by clinical outcome
- *How should disability be addressed?*

Issue of ‘underlying health conditions’

- Many people with disability, DPOs concerned that ‘underlying health conditions’ used to exclude from access to critical care
- Some underlying health conditions *are* relevant to clinical outcome
- → disability *may* be relevant, but only when a relevant health condition is involved
- So in principle no problem of unjust discrimination
- *Attention to perspectives of people with disability and empirical evidence + understanding of structural injustices → disablism*

Disablism

- “…practices and attitudes of contemporary society that result in exclusion, oppression, or discrimination against people with disability”
- In COVID-19, disablist assumptions that people with disability:
- inevitably have underlying *health* problems (they don’t)
- Inevitably have underlying relevant health problems (they don’t)
- are *naturally* more vulnerable (most aren’t)
- have poorer overall quality of life* (most don’t)
- are in some way of less value to/a burden on society*

Disability bioethics' analysis

- Disablist attitudes that influence interpretation of guidelines
- People with disability made disproportionately vulnerable by societal failures
- Expand debate, eg *is saving max number of lives best criterion*
- Responsibility on bioethicists to state clearly that
  - evaluations should ignore irrelevant health conditions, QOL, social utility
  - people with disability have equal right to care
  - including ongoing access to critical care, future treatment, vaccination

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