

# Inequalities and Inequities in End-of-Life Care

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# Outline

1. Justice, the liberal state, and end-of-life care
2. Justice and health inequalities
3. Utilitarian views of just health care
4. Daniels' theory of just health care
5. Do these theories apply: Peculiarities of end-of-life care
6. Inequalities in access, up-take, and consequences and their correlations with other factors

# End-of-life Care

- Palliative care given to individuals, regardless of age, who are judged to be dying and for whom no treatments to prolong life are available
- Neither preventative nor curative
- Exaggerated and idealized definition
- Not concerned with moral issues concerning when to discontinue care

# The Liberal State

- Representative government with guarantees of political rights
- Equality of citizens; impartial state action
- State neutrality with respect to ideals
- Individuals and the state share responsibility for outcomes. State is responsible for opportunity and a safety net -- a facilitator and insurer, not a nanny.

# Health and Justice

- Health depends heavily on choice and chance -- limited state responsibility
- Inequalities in health are very important
- Inequalities in health hard to measure
- What could health equality be?
- Health cannot be directly distributed
- Should the concern be with health inequalities or overall inequalities?
- Importance of correlations with other inequalities.

# Justice and Health Care

- Health care can be distributed
- But why focus on it, since it is less important to health than factors such as education or income?
- Two theories will be discussed here:
  - Norman Daniels' account
  - Utilitarianian account

# Utilitarianism

- Central claim: A policy is morally permissible if and only if no alternative results in more total (or average) happiness (or preference satisfaction).
- This describes four different theories
- What about justice?
- Naively applied appears to be an illiberal doctrine.

# Utilitarianism and Liberalism

- Mill's argument in On Liberty for limits on direct pursuit of maximum total well-being
- The utilitarian case for the liberal state:
  - Representative government and individual rights
  - Equality and impartiality
  - Neutrality
  - Individual freedom and responsibility

# Utilitarian Perspectives on Just State Health-Care Policy

- What effects do health care and its distribution have on total welfare?
  - Direct health effects (which are also welfare effects)
  - Other direct effects on patient and others (reassurance, evidence of concern, etc.)
  - Indirect effects, particularly of health effects
- What are the alternatives?

# Problems with Utilitarian Approaches

1. Implies that it is more important to cure those with high incomes than those with low incomes
2. Hard to measure the welfare benefits of health care
3. Implies that affluent countries are spending too much on health care

# Daniel's View of Just Health Care

- Rawls' two principles of justice:
  - First, each person is to have an equal right to the most extensive basic liberty compatible with a similar liberty for others. (1971, p. 60)
  - [Second] Social and economic inequalities are to be arranged so that they are both (a) to the greatest benefit of the least advantaged and (b) attached to offices and positions open to all under conditions of fair equality of opportunity (1971, p. 83).
- First principle has priority over the second
- Fair equality of opportunity has priority over 2a.

# Where Do Health and Health Care Fit?

- Include health among “social and economic inequalities”?
- Focus on the way that health determines “opportunity” (in an enlarged sense)
- Daniel’s principle: distribute health care so as to secure to everyone the species-typical functioning of people of that age and gender, insofar as that functioning depends on health care
- Focus on opportunity rather than welfare

# Justice and End-of-Life Care (I)

- Does Daniels' account apply? (What is the relevant notion of "opportunity"?)
- How different are the two approaches?
- The three objections to the utilitarian approach are less serious with respect to end-of-life care

# Justice and End-of-Life Care (II)

## Some Distinctions

- Individual variation vs. co-variation
- Three domains of inequality
  - Access or availability
  - Uptake
  - Consequences
- Seven co-varying factors:
  1. individual choice
  2. medical condition
  3. age
  4. gender
  5. geography
  6. culture, religion, ethnicity
  7. socioeconomic status

# Individual Choice

- If truly voluntary and not distorted by other injustices, then justifies inequalities in uptake and consequences
- Does not typically justify inequalities in availability
- No disagreement between utilitarians and Daniels

# Medical Condition

- Justifies differences in treatment and availability
- Inequalities in uptake due to the effects of medical condition on patient's capacities apparently unjust
- Straightforward utilitarian case; from Daniels' perspective, more needs to be said about "opportunity"

# Age, Gender, Geography

- All ought to be irrelevant to availability, uptake, and consequences (except insofar as they correlate with other factors)
- A caveat concerning geography, owing to issues of cost
- No disagreement between Daniels and the utilitarian

# Culture, Religion, and Ethnicity

- Differences in uptake, consequences and even availability that express ideals of cultural, religious, and ethnic groups may be just.
- But these ideals are subject to moral scrutiny and respecting them may treat individuals unjustly
- A presumption that the state should heed the wishes of religious, ethnic and cultural groups, which is limited by duty to apportion resources evenly and to avoid reinforcing other unjust inequalities.

# Socio-Economic Status

- Those who are better off are likely to gain advantages in care
- These inequalities are less worrying in end-of-life care if a high standard of care is offered to everybody
  - Things that money cannot buy are important
  - A universal high standard is feasible

# Conclusions

- A high standard of end-of-life care should be available to everybody. Few inequalities in availability are justified, and then mainly for practical reasons.
- There should be a defeasible presumption that inequalities in uptake and consequences due to individual choice, culture, religion, and ethnicity are just.
- A sophisticated utilitarian approach seems appropriate, but Daniels' account can be employed, too.
- Note the abstractions and idealizations upon which these conclusions rely!