Individual Human Rights within Public Health Approaches

WHO Guidelines Development Group on Infant and Young Child Feeding in the Context of HIV

Carl H. Coleman, J.D.
Professor of Law, Center for Health & Pharmaceutical Law & Policy
Seton Hall Law School, Newark, NJ, USA
Carl.Coleman@shu.edu
Public Health’s Population Focus

- The U.S. Institute of Medicine defines public health as “what we as a society do collectively to assure the conditions in which people can be healthy”
- A key characteristic of public health is a focus on population-level concerns
- In this sense, public health is different from clinical practice, which focuses on the interests of an individual patient
- Question: how can the concept of individual rights fit into public health’s population focus?
Why Is a Focus on Individual Rights Important for Public Health Activities?

- Focusing on individual rights enhances the efficacy of public health activities
  - Example: non-discrimination

- A focus on rights also reminds public health practitioners of their reciprocal obligations
  - Example: duties to health care workers

- Human rights principles are not barriers to essential public health activities, but they establish boundaries and parameters

Annex 9. Individual rights within public health approaches
The Siracusa Principles

Limitations on human rights must be
- in accordance with the law
- based on a legitimate objective
- strictly necessary in a democratic society
- the least restrictive and intrusive means available
- not arbitrary, unreasonable, or discriminatory
Individual and Community Interests in the Context of Counseling and Consent

- Informed consent is a basic principle of medical ethics.
- It is not itself a human right, but it is grounded in the human right to bodily integrity.
- Yet, the nature of the consent process can vary depending on the circumstances, and in some cases the requirement for consent can be waived entirely.
- Decisions about how the consent process should be structured reflect both individual and community-based concerns.
A continuum of options

Non-directive counseling (e.g., genetic testing; medical research)

Disclosure of all options combined with professional recommendation (e.g., most major medical treatment)

Disclosure of single option as standard, with notification of right to refuse (e.g., HIV testing)

Disclosure of single option as standard; right to refuse may be recognized, but patients are not notified of this right (e.g., TB treatment (?))

Nonconsensual interventions (e.g., taking blood samples during epidemic outbreak; TB treatment (?))
Considerations

- The first model—pure nondirective counseling—is used in situations where the risks and benefits are highly uncertain and idiosyncratic.

- The last model—nonconsensual interventions—is limited to situations where individual cases of noncompliance would seriously jeopardize important public health objectives.
  - Usually, burdens on the individual are minimal.
  - Significant burdens would have to satisfy the Siracusa principles.
  - This option is unrealistic when the patient’s cooperation in treatment is essential.
Considerations (cont.)

- Choices in the middle reflect a combination of individual rights and public health rationales
  - What would the “reasonable patient” want to hear? If there is a medical consensus in favor of a particular option, the reasonable patient would prefer a recommendation.
  - Are there externalities to the patient’s decision? If so, it may be appropriate to steer individuals towards particular decisions, without taking away their right to refuse.
Additional considerations related to parental rights and responsibilities

- Parental decisions for children are more constrained than decisions by competent adults.
- If a decision would be so harmful for the child that it rises to the level of “abuse or neglect,” the state may intervene to protect the child.
- This is true even if the state would not be justified in intervening in the case of a competent adult.
  - Example: refusal of blood transfusions.
Application to infant and young child feeding in the context of HIV

- Keep the non-directive approach if the risks and benefits are uncertain and idiosyncratic.
- Move to a single mandatory option if (1) public health goals require universal compliance; or (2) choosing a particular option would constitute “abuse or neglect”.
- Otherwise, rely on one of the approaches in the middle of the continuum.
Application to infant and young child feeding in the context of HIV

- Factors to consider:
  - Would the reasonable patient want a recommendation?
  - If patients are likely to ask for recommendations, should those recommendations be developed centrally, or by individual practitioners on a case-by-case basis?
  - Are there externalities to the decision (e.g., the impact of feeding policies on use of breastfeeding by non-HIV-infected mothers)?
    - Important to articulate the extent to which policies are motivated by these considerations and, if they are, whether they are in tension with the individual patient’s interests
  - How can policies be implemented in a manner that preserves a role for individual choice?