Ethical issues in the implementation of the WHO's End TB strategy

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Outline

- Why ethics?
- History, background, and methods
- Chapters
- In depth on individual chapters
- Next steps

Why ethics?

- Ethics is concerned with what should, or ought to, be done
  - Consideration of the way we ought to live our lives (including our actions, intentions, and habits)
- Cannot separate TB care and ethics
  - Addressing TB is fundamentally normative
- Not always clear what we ought to do

History and background

- 2010 WHO's *Guidance on Ethics of Tuberculosis Prevention, Care and Control*

- *End TB Strategy* – third principle
  - "Protection and promotion of human rights, ethics and equity"

- Goal: to help healthcare workers, policy makers, and the broader TB community
  - (a) understand the ethical values that underpin the End TB Strategy and
  - (b) help think through and address most pressing ethical challenges related to TB care

Methods

- Builds on 2010 ethics guidance document
- Three consensus building meetings with guidance development experts
  - June 2015, November 2015, June 2016
  - Healthcare workers, civil society, policy makers, human rights lawyers, and ethicists
  - Comprehensive global representation from all WHO regions
- Chapters written by content experts with guidance and edits from WHO core team
  - WHO TB program, WHO Ethics and Health program, external ethics support
- Document underwent internal (writers) and external expert review in late 2016

Chapters

Overarching Goals and Values

1. Ending TB as a Matter of Social Justice
2. Ethics: A Key Foundational Piece of the End TB strategy
3. Guiding Values and Principles to End TB
4. The obligation to provide access to TB services

Section One – Integrated, Patient-Centred Care and Prevention

5. Education, Counselling, and the Role of Consent
6. Diagnosis in the Absence of Treatment Services
7. Addressing Latent Tuberculosis Infection
8. Supporting Patients to adhere to Treatment and other health care recommendations
9. Patient treatment and care when recommended TB treatment regimens are not feasible
10. Palliative and End of life care
11. Children
12. Prisoners
13. Migrants

Section Two – Bold Policies and Supportive Systems

14. Infection Control
15. Isolation and Involuntary Isolation
16. Screening
17. Surveillance
18. Compassionate Use and Expanded Access to TB Drugs

19. Health-Care Workers' Rights and Responsibilities

Section Three – Research and Emerging Technologies

20. TB and Health Information Technology
21. New Frontiers in TB Care and Control
22. Rapid Sharing of Research Data

Chpt. 1: Ending TB as a Matter of Social Justice

- Social justice
  - rights and obligations of persons as members of societies and communities;
  - the fairness of social and political structures and processes;
  - the relationships between persons and between persons and the state;
  - how to fairly distribute advantages and burdens amongst members of a given society.

Social justice captures "…the twin moral impulses that animate public health: to advance human well-being by improving health and to do so by focusing on the needs of the most disadvantaged".

Lawrence O. Gostin and Madison Powers (2006), What Does Social Justice Require for the Public's Health? Public Health Ethics and Policy Imperatives, Health Affairs, 25(4), pp. 1053-1060.

Chpt 3: Guiding Values and Principles

- Equity
- Common Good
- Solidarity
- Reciprocity
- Harm Principle
- Trust and Transparency
- Duty to Care
- Effectiveness
- Proportionality
- Participation & Community Engagement
- Respect & Dignity
- Autonomy
- Privacy & Confidentiality

Chpt 7: Addressing Latent TB Infection

- Addressing LTBI critical for ending TB by 2035

- Key ethical challenge: balancing uncertainties & risk of harm
  - Future risk of harm to self and others from active diseases vs. potential adverse side effects of the drugs

- Proportionality key
  - Testing for concomitant diseases, e.g., HIV, that would increase risk of moving from LTBI to active TB
  - Conditions of a patient that would lead complications with treatment, e.g., evidence of liver disease

Chpt 11: Children

- Have often been neglected in TB care
  - E.g., non-child friendly diagnostics or drugs
  - Luckily changing for the better, e.g., TB Alliance work
- Careful attention to screening and reporting of child TB patients for sake of knowing prevalence of TB
  - Importance for planning and implementation at NTP level
- A matter of equity and fairness to continue to increase R&D targeted for children

Chpt 12: Prisoners

- In most countries, prisoners do not receive requisite levels of healthcare as in the general population
  - TB care beings from a position of disadvantage
- Same principles apply to treatment of prisoners as non-prisoners
  - E.g., dignity, autonomy, privacy and confidentiality, etc.
- Equity key
  - Must ensure that prisoners given proper care
  - Are not abandoned during TB treatment
- Isolation can never be used as form of punishment
  - Involuntary isolation as a last resort (see chpt 15)

Chpt 13: Migrants

- Often (politically) marginalized populations
  - Increased risk of having TB and being undiagnosed
- Guiding values in treating migrants for TB
  - Solidarity
  - Equity and Dignity
  - Autonomy
- Deportation or repatriation should only occur in instances where appropriate TB care is available in home country
- LTBI should not grounds for refusing entrance or removal from host country
  - A potential future risk
  - Risk of LTBI lower than active TB

Chpt 15: Isolation and Involuntary Isolation

- Harm principle justifies isolation used to reduce risk of transmission
- Overwhelmingly TB patients abide by treatment regimen
- In instances where a TB patient does not abide, involuntary isolation may be justified to protect others from harm of transmission
- Involuntary isolation cannot lead to abandonment
- Involuntary isolation is never to be used as punishment

Chpt 14: Isolation and Involuntary Isolation

Conditions necessary to justify involuntary isolation:
Isolation is necessary to prevent the spread of TB AND
Evidence that isolation is likely to be effective in this case AND
Patient refuses to remain in isolation though indicated AND
Patient's refusal puts others at risk AND
All less restrictive measures have been attempted prior to forcing isolation AND
Ensure all other rights and freedoms (e.g., basic civil liberties) besides that of movement are protected AND
Ensure due process and all relevant appeal mechanisms AND
Ensure that patient has, at least, basic needs met

Next Steps

- Will be published in the March 2017
- Assistance in dissemination
  - Spread the word!