Drug Resistant TB:

Human Rights and Ethical Challenges

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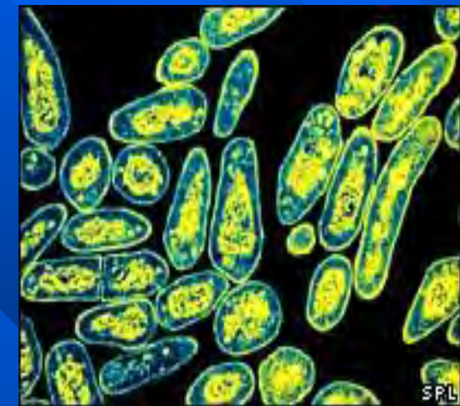
XDR TB – rights versus responsibilities?
- rights versus the public good?



- Ethical questions:
  - Beneficence, justice, autonomy
- Human Rights concerns:
  - Privacy, freedom of movement, right of access to care, right to refuse treatment, right to safe environment
  - State obligations
- Health workers often in the middle

What are Human Rights?

- Legitimate and valid demands or claims on society
- … for social and material resources, respect, tolerance
- Limit State power over individuals, groups
- Represent some fundamental need
- General or universal
  " … in some sense equally possessed by all human beings everywhere."
- Inherent - exist by virtue of being human
- Codified in national / international law
- Restricted only if interferes with others' rights

International Human Rights Law: When is it valid to restrict rights?

- to secure due recognition and respect for the rights and freedoms of others
- meet the just requirements of morality, public order and the general welfare
- in times of emergency, when there are threats to the vital interests of the nation (ICCPR, article 4)

Public Health = Common Good

Justification for Public Health Action

- Government should take steps necessary for prevention, treatment and control of epidemic, endemic, occupational and other diseases (ICESCR article 12)
- Examples:
  - Quarantine for SARS
  - Fluoridation drinking water
  - User fees
  - Etc…

Syracuse Principles (UNECOSOC 1985)

- Restriction is provided for and carried out in terms of law
- Legitimate objective
- Strictly necessary in a democratic society to achieve objective
- No less intrusive and restrictive means available to achieve same objective
- Not arbitrary, unreasonable, discriminatory

Typical Ethical and Human Rights dilemmas

(adapted from K Weyer, VanderWalt and Kantor, MRC, 2006)

1. Involuntary confinement vs. freedom of residence, profession, occupation , schooling

Typical Ethical and Human Rights dilemmas

(adapted from K Weyer, VanderWalt and Kantor, MRC, 2006)

2. Treatment interruption vs right to receive best available treatment
   a. Non efficacy of treatment
   b. Non adherence to treatment
3. Rights of others (family, neighbors, health staff, co-workers, other learners) to be protected from infections vs confidentiality
4. Right to refuse DST testing and/or subsequent treatment vs protection of others
5. Right to be heard before administrative decision made

Case 1

- 29 yr old female, HIV neg, with XDR TB
- No past history of TB; no contacts
- Adherent to treatment in hospital but still smear ++ on treatment at 9 months: Cm, Ofx, Eth, PAS, E, Z.
- Two young children at home cared for by sister.
- **Heading for treatment failure. Should a salvage regimen be tried? E.g. including linezolid, terizidone, clofazimine?**
- She is put on treatment but remains sputum +ve at 14 months.
- Decision is made to stop treatment but patient is adamant she wants to continue treatment.
- **Should she continue on treatment? If so, what treatment?**

Case 2

- 32 yr old female diagnosed with MDR in June 2009
- Started treatment (Mfx, Km, Eto, Trd, Z, E) at the clinic in July 2009
- Amikacin resistance result received after 8 weeks of treatment. Patient had improved clinically.
- 5 days later, first monthly culture reported negative
- Adjust treatment – Change Km to Cm
- Patient is adherent and lives alone in Khayelitsha
- **Should the patient be hospitalized for XDR treatment at this point?**

… and what if …

- There is a 2-year old child at home?

and …

- There are 5 adults and 6 children living in a 2 roomed shack?

- But the family are willing and are able to put up third room where she can sleep separately from the family? And home-based care / IC workers can support the family?

Case 3

- 40 yo male is a contact of known XDR
- Previously defaulted first line TB treatment twice and ART, now has CD4 of 35
- Started on DR-TB regimen July 2010, 2 weeks later result shows resistance to kanamycin and susceptible to ofloxacin
- Switch regimen to Cm, request bed at BCH – no beds available
- **Continue XDR treatment in the community?**

… and what if …

- The reasons for his defaulting were
  - First time, he had to go back to the Eastern Cape to look after his family when his mother died, and was unable to access care in the E Cape for 6 months;
  - He returned to the W Cape and restarted treatment but developed severe side effects, including physical and psychological consequences, so stopped treatment.
- Does it make a difference?

Case 4

- 28 yo male diagnosed MDR Aug 2007, susceptible to second line
- Started treatment in hospital, culture converted at 4 months, discharged at 6 months with injectable stopped – at that time, not available in community
- Patient is adherent on continuation phase at clinic
- Culture positive again 3 months later – DST taken later shows XDR-TB
- Possible re-infection with XDR in hospital
- **Should we re-admit for XDR treatment?**
- **How should the health system respond to this case?**

Case 5

- 25 yr old male diagnosed XDR Aug 2007; previous DS TB in 2003 - completed treatment.
- Started treatment in hospital, culture converted at 2 months, but erratic adherence, discharged himself at 4 months because he was feeling well and was unhappy in hospital. At time of leaving BCH, not known if he was sputum positive.
- Lives in a 2 bedroom shack with 3 other adults and 3 children under the age 16.
- He is reported to work at the taxi rank washing and cleaning the taxis and does not adhere to IC measures.
- **Should he be forcibly re-admitted for XDR treatment? (court order)**

Take home messages I

- Individual care versus Public Health imperatives:
  - both ethical and human rights dimensions
  - What appears obvious may not be efficacious from Public Health Control point of view (e.g. keeping non-adherent patient in hospital is bad for other's motivation)
- Need consistent policy across all ethical dilemmas: enforced hospitalisation (force in) vs. discharge for a bed (force out)
- Judgements about past and future adherence: What is the evidence? What values?

  → process that makes full psychosocial assessment before decision can be made

Take home messages II

- Enforced hospitalisation:
  - May be justified in selected cases; no blanket rule
  - All other options explored and exhausted
- Treatment withdrawal
  - No response to documented full course of treatment
  - Not candidate for surgery
  - No prospects of conversion

  → define threshold 18 months
- Procedural safeguards: Contracting patients (one more time if necessary), involving family, substance abuse assessment

Take home messages III

- Infection control critical to enabling wider range of measures that protect patient rights while achieving PH objectives: home assessments
- Base action, policy on evidence!
- Exhaust other measures!
- Health professional faced with unsavoury choices because of State policies – can the individual solve a systemic problem?

"It is unethical, illegal and bad public health policy to detain 'non-compliant' persons before making concerted efforts to address the numerous systemic deficiencies that make adherence to treatment virtually impossible …"

(NYC Working Group, cited in Lerner, 1999)