Ethics of Tuberculosis Prevention, Care and Control

MODULE 4: OBLIGATION TO PROVIDE ACCESS TO TB SERVICES

Objectives

Upon completion of this module, you will be able to:

• Describe a human-rights approach to TB prevention, care and control
• Discuss how the human-rights approach can be utilised for appropriate TB prevention, care and control that meets needs of patients

Human rights

• Grow out of the basic equality and human dignity shared by all human beings
• Found in international human rights treaties that set out the obligations that governments have to:
  • Citizens
  • International community
  • Individual citizens required to respect the rights of others
**Human rights - 2**

* Article 12: “Right of everyone to the enjoyment of the highest attainable standard of physical and mental health”
* Calls on governments to take steps necessary for "the prevention, treatment and control of epidemic, endemic, occupational and other diseases"

**Human rights - 3**

* General Comment 14 issued by the United Nations Committee on Economic, Social and Cultural Rights in 2000
  * Legally binding interpretation of the human right to health
  * Defines and describes the minimum core obligations of the human right to health
  * Components include availability, accessibility, acceptability and quality

**Human rights- General Comment 14 - 1**

* **Availability**: Functioning public health and health-care facilities, goods and services, as well as programmes, have to be available in sufficient quantity
* **Accessibility**: Health facilities, goods and services must be accessible to all
  * This includes non-discrimination, physical, economic, and information accessibility
Human rights- General Comment 14 - 2

- **Acceptability**: Health facilities, goods and services must be respectful of medical ethics & culturally appropriate; respectful of the culture of individuals, minorities, peoples and communities, sensitive to gender and life-cycle requirements, respect confidentiality and improve the health status of those concerned.

- **Quality**: Health facilities, goods and services must be scientifically and medically appropriate and of good quality. This requires skilled medical personnel, scientifically approved and unexpired drugs and hospital equipment, safe and potable water, and adequate sanitation.

Human rights approach to TB care - 1

- Addresses legal, structural and social barriers to quality TB prevention, diagnosis, treatment and care services.

- Emphasises:
  - **Appropriate treatments** that meet patients’ needs to prevent development of drug resistance.
  - Patients’ right to be **free from discrimination**.
  - Patients’ rights to be **free from forced or coerced treatment**.

Human rights approach to TB care - 2

- For drug-resistant TB, consider **community-based** treatment options.
  - Respect for patients’ rights.
  - Excellent treatment completion rates.
  - Protect public health.
Access to TB care

- Strong association exists between TB incidence and a country’s gross domestic product per capita
- Strong socio-economic gradient also found:
  - Within countries
  - Within cities
  - Across households
- Poorest individuals, families, communities, countries have highest risk of TB

Optimal conditions for uptake of TB services

- No discrimination
- No exposure to other risks
- Confidentiality maintained
- Access to information
- No coercion into accepting services without consent

Obligation of governments

- Provide universal access to TB care (Availability, Accessibility, Acceptability)
  - Grounded in governments’ duty to fulfil human right to life
  - Resource-limited countries which cannot fulfill these obligations completely should apply principle of progressive realisation
- Move as expeditiously and effectively as possible towards achieving these critical goals
- Regulate care in line with internationally accepted quality standards (Quality)
Premise for universal access

- As noted in human right frameworks, everyone has right to a minimum standard of health care
- Access to TB care should receive high priority:
  - Usually curative
  - Prevents spread of disease
  - Prevents development of drug-resistant strains

Benefits of universal access

- Prevents significant morbidity and mortality
- Slows the spread of infectious disease
- Reduces development of drug-resistant strains
- Inexpensive and highly cost-effective
- Decreases vulnerability to poverty
Universal access to MDR- and XDR-TB care

Achieve universal access to diagnosis and treatment of multidrug-resistant (MDR-) and extensively drug-resistant (XDR-) tuberculosis as part of the transition to universal health coverage, thereby saving lives and protecting communities.

International Standards for TB Care

“All providers who undertake evaluation and treatment of patients with tuberculosis must recognize that, not only are they delivering care to an individual, they are assuming an important public health function.”

- Basic principles of care for persons with, or suspected of having TB:
  - Prompt and accurate diagnosis
  - Standardized treatment regimens of proven efficacy
  - Appropriate treatment support and supervision
  - Monitoring of treatment response
  - Carrying out of essential public health responsibilities

Free TB care

- Meets government obligation to protect public’s health:
  - Ease burden of unaffordable costs
  - Treatment benefits extend to society as a whole
Costs of not providing free care

- Barrier to obtaining or completing a full course of TB treatment
- Individuals who are infectious are never cured
- Additional people exposed
- Development of dangerous drug-resistant strains

Free diagnosis and other services

- Free access to diagnostic measures for drug susceptible and drug resistant TB
- Prevents patients from receiving ineffective treatment to which they are resistant
- Ensures patients are cured
- Prevents additional spread of infection
- Prevents further development of drug-resistance
- Free access to preventive therapy
- Minimise the overall burden of disease
- Remove non-TB-specific financial barriers

Consider

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<thead>
<tr>
<th>Item</th>
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<tbody>
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<td>Sputum test</td>
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<td>Drug susceptibility test</td>
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<td>TB medicines</td>
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<td>Treatment for side effects</td>
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<td>Treatment for related conditions</td>
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<td>Transport costs</td>
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<td>Loss of wages</td>
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<td>Food costs (while queuing at facility)</td>
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<td>Other</td>
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Do patients carry costs related to the services and tests involved in TB prevention, diagnosis, treatment, care and support?
Root causes of MDR- and XDR-TB

- Improper treatment regimens
- Failure to ensure that patients complete the whole course of treatment

Free access to MDR- and XDR-TB treatment

- Even stronger case for ensuring free access to treatment of drug-resistant TB
- High costs underscores the importance of providing adequate resources to support basic TB care and control:
  - Infection control
  - DOTS
  - Community-based care programmes

International community obligations

- Provide financial and other assistance to countries that cannot offer universal access to care on their own
- Grounded in a number of different ethical principles:
  - Humanitarian
  - Redistribution of wealth
### Another compelling reason for universal access

- Growing drug resistance
- Only a matter of time before it impacts upon one’s own country

### Quality of TB drugs

- **Substandard drugs:**
  - Harm individual patients
  - Contribute to the development, spread, and amplification of drug-resistant strains
- **Governmental level obligation to:**
  - Assure quality of TB drugs
  - Ensure infrastructure for and sustainability of drug supply

### HIV Testing: Share your practice

- Are all patients with HIV being counselled and offered TB testing?
- What are the barriers to counselling and offering patients who are HIV-positive TB tests?
- What encourages you to counsel and offer TB tests to patients who are HIV-positive?

  HIV testing recommended in all patients with TB
Unfulfilled government obligations

- Healthcare providers actions:
  - Consider risks and benefits to both patient and public
  - Consult with patient and other health-care providers
  - Notify the national government
  - Advocate for urgent rectification

Ethical considerations for promotion of better access to TB care and treatment

- Patient-centred treatment approach
- Community-based care
- Patients as part of larger communities
- Social justice and equity

Ethical considerations: Patient-centred treatment approach

- Treatment should be accessible, acceptable, affordable, and appropriate
- Patients should have choices about location of treatment
- When directly observed therapy is used, patient should have choice about individuals who will be doing observing
### Ethical considerations: Promoting community-based care

- Achieves comparable results to hospitalisation and, in theory, may result in decreased nosocomial spread of the disease when provided by trained lay and community health workers
- Reduces burdens on health-care facilities
- More cost effective than facility-based treatment
- Enables governments with limited resources to serve greatest proportion of those in need

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### Ethical considerations: Focus on patients as part of larger communities

- Patients should be encouraged to form support groups
- Patients should be encouraged to work with their communities to address the social determinants of TB

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### Ethical considerations: Promoting social justice and equity

- TB programmes should take into account the needs of all patients
- Interventions should be gender sensitive
- Interventions should address different types of vulnerabilities:
  - Individuals who face increased risk of becoming infected and developing active disease
  - Individuals who face challenges of accessing and fully utilising services
Promoting social justice and equity: Special considerations for vulnerable groups

* Special consideration for needs of:
  * Women
  * Children
  * People co-infected with HIV

Promoting social justice and equity: Special considerations for vulnerable groups - 2

* Specific tailored interventions for vulnerable groups including:
  * People living in extreme poverty
  * Indigenous populations
  * Refugees
  * Asylum seekers
  * Migrants
  * Mine workers
  * Prisoners
  * Substance users, including those who use alcohol
  * Homeless people

Let's discuss...

* Divide into groups, based on the facilitator's instructions
* Move to the place designated for your group
* Spend 20 minutes discussion time in the following way:
  * 5 minutes reading through the question and information provided in "Obligation to Provide Access to TB Services: Activity 3 Delegate Hand-out" and noting:
    - Most critical barrier that limits access to TB services in the community you serve, with specific regard to vulnerable groups,
    - What you currently do or what you can do in your role to address this barrier
  * 5 minutes each:
    - Discussing the barrier, as well as the solutions (current or proposed)
    - Soliciting feedback from group members regarding the solutions
    - Asking group members, who may have similar experience to share their solutions
Activity: Group Discussion

- For the community you serve, what is the most critical barrier that limits access to TB services, particularly for vulnerable groups?
- What actions would you propose to remove these barriers in order to ensure the ethical obligation to provide access to TB services is upheld?