

Quality of Care for People Living with Drug-Resistant Tuberculosis: Gaps and Solutions

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Objectives

- To review the current global situation of DR-TB
- To discuss the historical approach to the disease
- To present barriers to quality care for persons living with DR-TB
- To propose possible solutions to overcome these barriers



DR-TB: Global Overview

- More than half a million persons newly diagnosed each year and fewer than 20% of them diagnosed and started on treatment.
- Success rate of 65% among those who are treatment.
- Regimens are long, difficult and lead to permanent disability.
- DR-TB contributes to 1/3rd of deaths due to antimicrobial resistance globally.
- More than 1 million people exposed to and infected with DR-TB each year.

DR-TB: Historical Approach

- Ignore it: not as virulent, not as transmissible, will “take away” resources from DS-TB.
- Public health approach which is program-centered and blames people for developing drug resistant TB.
- Attitude that people are “lucky” to be receiving DR-TB therapy and should be “grateful” for whatever they get.
- **QUALITY OF CARE NOT CONSIDERED A PRIORITY**



Courtesy
of Tara
Lloyd

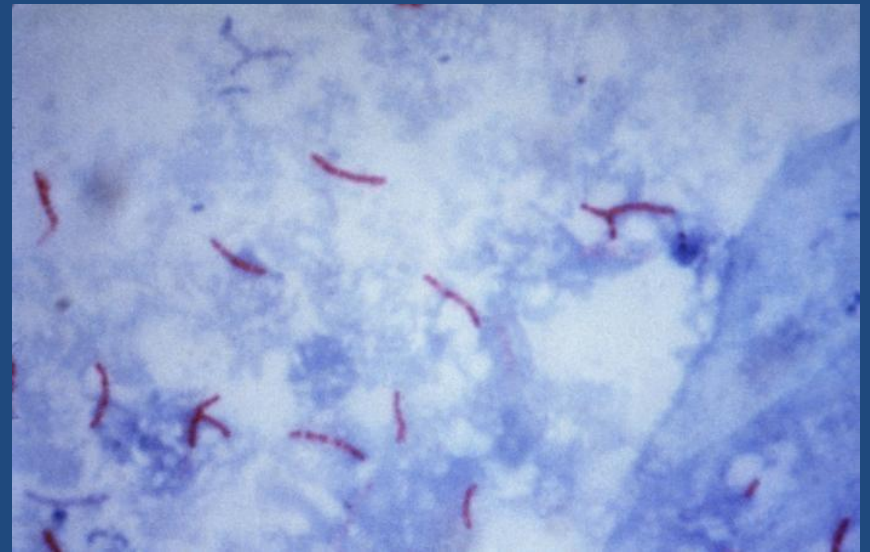
Quality issue 1: the use of regimens with limited efficacy, significant toxicity, and high pill burden

- Global treatment success rate 65%;
- 18-33 pills daily along with daily injection for 9-24 months;
- Side effects occur in almost all patients, with 25% suffering permanent disabling consequences of treatment.



Quality issue 2: standardized treatment without drug susceptibility testing

- People are given medications to which their *M. tuberculosis* strains have resistance;
- People are denied access to medications to which their *M. tuberculosis* strains have susceptibility;
- Lack of investment in building capacity for DST;
- Lack of funds and innovation for novel diagnostics.



Quality issue 3: non-quality assured medications and drug stock outs

- Few people are treated (less than 20%) so small market;
- Ordering cycle occurs every 2 years—innovation cannot be accommodated;
- Domestic procurement as part of Global Fund transitions.



Quality issue 4: lack of access to newer and repurposed drugs

- Few than 15% of people in need of new drugs have received them.
- TB community prefers to “protect drugs” instead of people.
- High prices, lack of registration, rationing of medicines.



Quality issue 5: high rates of adverse events coupled with minimal monitoring and management

- Adverse events include nausea, vomiting, skin color changes, hearing loss, vision loss, peripheral neuropathy, psychosis;
- Studies show patients feel “treatment is worse than the disease;”
- Patients not counseled about side effects out of fear they will refuse treatment;
- Lab tests not routinely done, out of pocket expenses incurred;
- Limited access to medications to alleviate or treat side effects.



Quality issue 6: care provided by multiple providers in the private sector

- “Private sector” encompasses a wide range of providers;
- People do not want to go to the public sector because of “poor quality care”;
- Complicated treatment journey navigating the health system.



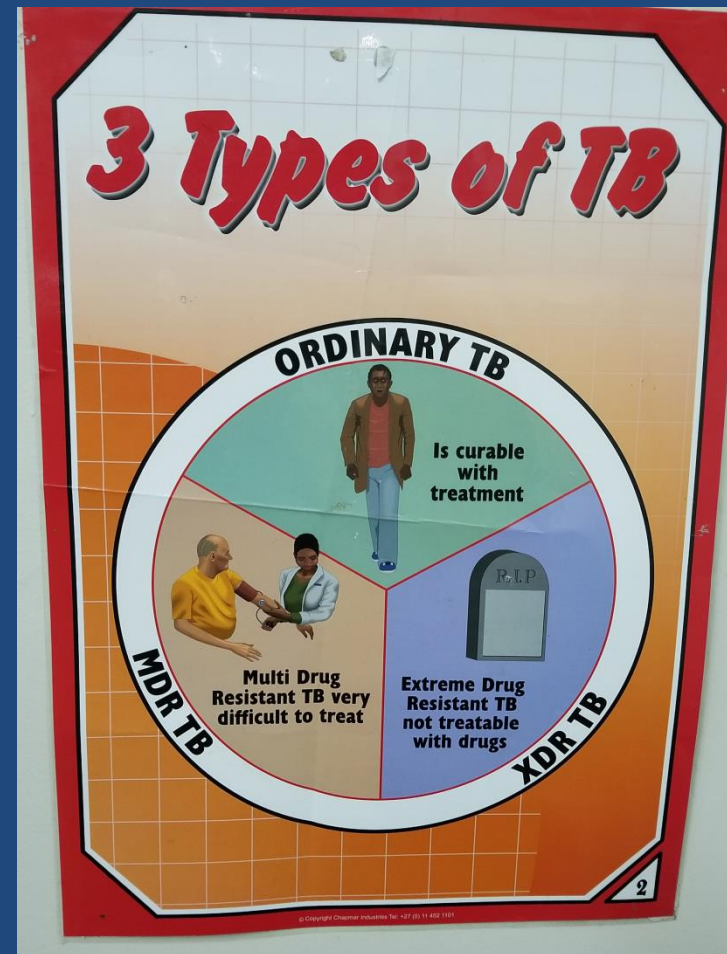
Quality issue 7: high rates of depression, anxiety, and stress

- People with DR-TB often have multiple other health and social problems;
- Life-threatening illness associated with loss of work, normal social roles;
- Individual and family existence threatened;
- Medications can contribute to decline in mental health.



Quality issue 8: stigma and discrimination

- TB associated with significant amount of blame and shame;
- Frank discrimination towards people with DR-TB by health care providers, family members, general community;
- People lose jobs, housing, marriages;
- Fear-based infection control practices exacerbate these.



Possible Solutions

- Improved regimens and treatment approaches linked to access to these clinical advances;
- Targeted therapy based on drug susceptibility testing to allow for the use of effective drugs and avoidance of ineffective drugs which only cause toxicity



Possible Solutions

- Procurement of medications for a quality-assured supplier of via the Stop TB Partnership's Global Drug Facility.
- Ensure adequate supplies of new medications are procured and evaluate access to them (i.e. percentage of people needing them who receive them) as part of program monitoring and evaluation



Possible Solutions

- Basic packages of services offered as an essential part DR-TB care, with reporting on access to these types of support in addition to routine TB program outcomes ;
- Improve treatment literacy for people living with DR-TB and their support networks and utilize counselors, social workers, and peers to provide and ongoing counseling and support throughout care.



Possible Solutions

- Provide supportive counseling and services as routine DR-TB care.
- Enlist the services of multi-disciplinary teams made up of counselors, social workers, and persons with expertise in psychiatry/psychology.



Possible Solutions

- Use existing laws and court systems to uphold the rights of people living with DR-TB;
- Implement programs to immediately address the socioeconomic needs of people living with DR-TB, including conditional cash transfers, nutritional support, disability grants, etc.
- Implement a human-rights based approach to TB with accountability mechanisms at all levels.



Overall

- Limited measures of studies on quality of care in DR-TB;
- Undertake formal studies in key settings and adopt formal quality measures as part of routine monitoring and evaluation activities undertaken by TB programs. This would include from the time of symptom development through post-treatment follow-up;
- Need to measure against targets;
- Unlikely that current systems will allow for this: need for novel methods and funding streams.



Thank you
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