Social and economic support for MDR-TB patients: a special imperative

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Health and Quality of Life Outcomes

Measuring health-related quality of life in tuberculosis: a systematic review
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Abstract

Introduction: Tuberculosis remains a major public health problem worldwide. In recent years, increasing efforts have been dedicated to assessing the health-related quality of life experienced by people infected with tuberculosis. The objectives of this study were to better understand the impact of tuberculosis and its treatment on people’s quality of life, and to review quality of life instruments used in current tuberculosis research.

Methods: A systematic literature search from 1981 to 2008 was performed through a number of electronic databases as well as a manual search. Eligible studies assessed multi-dimensional quality of life in people with tuberculosis disease or infection using standardized instruments. Results of the included studies were summarized qualitatively.

Results: Twelve original studies met our criteria for inclusion. A wide range of quality of life instruments were involved, and the Short-Form 36 was most commonly used. A validated tuberculosis-specific quality of life instrument was not located. The findings showed that tuberculosis had a substantial and encompassing impact on patients’ quality of life. Overall, the anti-tuberculosis treatment had a positive effect of improving patients’ quality of life; their physical health tended to recover more quickly than the mental well-being. However, after the patients successfully completed treatment and were microbiologically ‘cured’, their quality of life remained significantly worse than the general population.

Conclusion: Tuberculosis has substantially adverse impacts on patients’ quality of life, which persist after microbiological ‘cure’. A variety of instruments were used to assess quality of life in tuberculosis and there has been no well-established tuberculosis-specific instrument, making it difficult to fully understand the impact of the illness.
Is it enough with efforts to heal the sick body to improve the quality of life of patients?

What else apart of new diagnostics and new drugs do the M/XDR-TB patients need?
What are the “quality of life” domains affected in people with MDR-TB?

- Physical
- Emotional
- Social
- Spiritual
- Economic
When is the quality of life of MDR-TB patients affected?

a) when there is no access to treatment

b) while receiving treatment

c) after being declared cured

b) once treatment failure is declared
Why it is right to foster improvement in the quality of life of those affected with MDR-TB?

• **Public health reasons**
  – While the patient is on treatment
    • Neglect of suffering is obstacle for treatment adherence
  – Once treatment failure is declared
    • patients will remain a source of transmission; high risk of further amplification of resistance
  – When the patient is cured but left with sequelae
    • high risk of amplification of resistance if receiving inappropriate treatment for sequelae or relapse (higher risk of relapse but low quality of evidence)
Why it is right to foster improvement in the quality of life of those affected with MDR-TB?

“While people with TB have an ethical duty to complete therapy, providers’ obligations to the patient and the public create a duty to support patients’ ability to adhere to treatment”. 
Why it is right to foster improvement in the quality of life of those affected with MDR-TB?

“The process of [TB] treatment involves significant burdens that patients undergo not only for their own benefit but also for the benefit of the community. According to the ethical principle of reciprocity, when individuals accept burdens for the benefit of the community it is appropriate for society to provide something in return”.
How to improve quality of life in people with MDR-TB? Is social support the answer?

- Social support is the perception and factual condition that a person is cared for, or receives assistance from others, and that the person is part of a supportive social network
  - emotional (e.g., nurturance),
  - tangible (e.g., financial assistance),
  - informational (e.g., advice), or
  - companionship (e.g., sense of belonging).
## How to promote quality of life in MDR-TB?

<table>
<thead>
<tr>
<th>“When”</th>
<th>Currently</th>
<th>Gap to fill</th>
</tr>
</thead>
<tbody>
<tr>
<td>without treatment</td>
<td>slow progress in universal access to PMDT</td>
<td>universal access to health care</td>
</tr>
<tr>
<td>while on treatment</td>
<td>focus is on delivery of SLDs / management of adverse drug reactions</td>
<td>holistic care, including social support, and not only medical treatment</td>
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<tr>
<td>after being cured</td>
<td>barely any follow up after discharge from PMDT</td>
<td>linking other health services if there is sequelae</td>
</tr>
<tr>
<td>once treatment failure is declared</td>
<td>almost non-existent</td>
<td>universal access to end-of-life care services, including social support</td>
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Analysis of economic support to TB patients in Global Fund round 7 and 10 TB grants

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Questions, methods, and approach

• Collaboration between Stop TB Department and GF secretariat

• Review of approved round 10 TB and HIV grants (only TB grants analysis included here)

• Review of round 7 approved grants with phase 1 (two years) follow up data to assess if expenditure correspond to budget.

• Variables:
  - Proportion of TB grants with any type of economic support included
  - Type of economic support
  - Rationale for economic support
  - MDR only vs. all TB forms of TB
  - Total amount budgeted
  - Amount per beneficiary
  - Budget for economic support as part of total TB grant budget
Results

• Of 26 approved TB proposals, 21 (81%) included some economic support activities (food, cash, transport support, income generating activities)
• On average 18 US $ budgeted per beneficiary
• 40% of economic support activities targeted only MDR-TB patients
• The economic support budget represented on average 3.5% of total TB grant budget
• No initiative with clear assessment of effectiveness of the interventions
Economic support, TB components of Global Fund round 10, 19 countries

Type of support:
- Food and transport
- Food only
- Food and enterprise
- Food and cash
- Other

Rationale for support:
- Improve adherence
- Poverty alleviation
- Not clear
Conclusions

• Most TB grants from Global Fund has economic support activities, but representing a very small part of the total budget

• Food support is the main activity, followed by transport support

• The rationale focuses mainly on improved adherence

• MDR-TB patients often targeted

• No impact evaluation data available
THE TB ELIMINATION STRATEGY
“Zero TB deaths, Zero TB disease, Zero TB suffering”

VISION: A world free of TB

TARGETS FOR 2025
1. 75% reduction in deaths due to TB (compared with 2015)
2. 40% reduction in TB incidence rate (compared with 2015)
3. No catastrophic expenditures for families affected by TB

PRINCIPLES:
- Government stewardship and accountability with monitoring and evaluation
- Protection and promotion of human rights, ethics and equity
- Adaptation of the strategy and targets at country level
- Inter-country collaboration and global support

COMPONENTS

1. UNIVERSAL HIGH-QUALITY TB CARE AND PREVENTION
   a. Rapid diagnosis of TB including universal drug susceptibility testing; systematic screening of contacts and high-risk groups
   b. Treatment of all people with any form of TB including drug-resistant TB, with patient support
   c. Collaborative TB/HIV activities and management of TB co-morbidities
   d. Preventive treatment for high-risk groups and vaccination of children

2. BOLD POLICIES AND SUPPORTIVE SYSTEMS
   a. Political commitment with adequate resources for coordinated TB care and prevention
   b. Engagement of communities, civil society organizations, and public and private care providers
   c. Universal Health Coverage and regulatory framework for vital registration, case notification, drug quality and rational use, and infection control
   d. Social protection, poverty alleviation and actions on other determinants of TB

3. INTENSIFIED RESEARCH AND INNOVATION
   a. Discovery, development and rapid uptake of new diagnostics, drugs and vaccines
   b. Operational research to optimize implementation and adopt innovations
Summary

• MDR-TB affects the quality of life of individuals and families
• There are ethical and public health reasons to foster improvements in quality of life in MDR-TB
• Current efforts in social support in MDR-TB tend to be restricted to patients on treatment
• Benefits of social support in MDR-TB may not be limited to increased adherence to treatment
• Gaps in social science research in TB prevent a better understanding of the role of social support in TB care and control
What does a patient-centred approach in Programmatic management of MDR-TB (PMDT) mean without social support?

Shouldn’t universal access to Programmatic management of MDR-TB also include universal access to social support?