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**Extrapulmonary Tuberculosis treatment
literacy and health system readiness: A
survivor-led assessment of primary
health care gaps and community
misconceptions in South Africa**

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Why Focus on Extrapulmonary Tuberculosis (EPTB)?



- ❑ Extrapulmonary Tuberculosis (EPTB) remains one of the most under-recognised forms of TB despite contributing significantly to illness, disability, and reduced quality of life.
- ❑ Patients with EPTB often face delayed diagnosis, treatment confusion, inconsistent management, and stigma.

Problem Statement

- ❑ My treatment journey exposed critical gaps in EPTB clinical knowledge, communication, continuity of care, medicine supply management, and community understanding of TB

Objectives



- ☐ Reflect on a 12-month EPTB treatment journey
- ☐ Document community TB misconceptions and stigma
- ☐ Highlight the role of Community-Led Monitoring
- ☐ Demonstrate the value of survivor-led advocacy
- ☐ Provide recommendations

Methodology

Component 1: Survivor Journey

- ☐ Clinical encounters
- ☐ TB treatment pathway review
- ☐ communication assessment

Component 2: Community-Led Monitoring

- ☐ Vryheid (145)
- ☐ Gamalakhe (126)
- ☐ Glebelands Hostel (80 men, including PWDs)

From Patient



Results



Health System Challenges

- Repeated requests for sputum samples
- Limited EPTB clinical knowledge
- Delayed treatment transitions
- Limited clinical monitoring
- Poor communication regarding treatment duration

Medicine Supply Challenges

- Drug shortages resulted in four months of double-tablet dosing.

Patient Impact

- Confusion regarding treatment progression
- Emotional distress and frustration
- Reduced trust in the health system
- Treatment fatigue
- Increased adherence risks

Community-Led Monitoring Findings



These findings were identified across all 3 communities, reaching n=351 participants

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1. Treatment literacy gaps

2. Poor communication

3. Community misconceptions

4. Stigma

5. Medicine supply concerns

CLM helps ensure patient experiences inform programme improvements.

Results: Community Misconceptions



- ☐ TB treatment can stop after the intensive phase.
- ☐ **Extrapulmonary Tuberculosis (EPTB)** is not "real TB."
- ☐ Stop treatment when symptoms improve
- ☐ Confusion around TB-related deaths
- ☐ Limited understanding of treatment completion

Why These Findings Matter

These misconceptions contribute to delayed health-seeking behaviour, poor adherence, treatment interruption, stigma, and reduced retention in care.

TB Care Cascade, Gaps and Impact



Stage	Gap	Impact
Diagnosis	Limited EPTB literacy	Delayed diagnosis
Treatment	Poor Communication	Confusion
Monitoring	Limited Monitoring	Reduced trust
Adherence Support	Drug shortages	Adherence risk
Completion	Community misconceptions	Treatment interruptions

These barriers contribute to poor adherence, stigma, reduced retention in care, and reduced trust in health services.

Programmatic & Policy Implications

Improve EPTB management at the PHC level

Strengthen provider competency

Invest in survivor-led interventions

Institutionalise CLM

Strengthen medicine availability systems

Recommendations



1. Institutionalise EPTB training
2. Strengthen counselling
3. Improve communication
4. Ensure uninterrupted drug supply
5. Integrate survivor-led literacy initiatives

Final Reflection:

- ✓ Successful TB treatment requires accurate information, effective communication, uninterrupted treatment, and a health system that listens to patients.
- ✓ **Patients experience the health system differently from how programmes measure it. Survivor voices help reveal the gaps hidden in plain sight.**

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Thank You!

Ngiyabonga!