Linking Social Support with Pillar 2/
Universal Health Coverage component of the
End TB strategy

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Samson Haumba

Improving systems. Empowering communities.

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Presentation outline

- Goal of TB care and Control
- Introduction to ETS and Pillar 2
- Why is this important to the country context: Swaziland context
- How it fits into the conceptual framework and proposed packages for social support
- Key lessons
Goal of TB care and control programmes

• Achieve universal access to high-quality diagnosis and patient-centred treatment

• Reduce the human suffering and socioeconomic burden associated with TB

• Protect public health, including protecting poor and vulnerable populations from TB, TB/HIV, and MDR-TB

• Support development of new tools and enable their timely and effective use

• Protect and promote human rights in TB prevention, care and control
Tuberculosis and vulnerability

- Tuberculosis (TB) disease occurs most often within the context of economic and social vulnerabilities, and often experience
  - psychological,
  - social and
  - economic problems
- These may impact ability to complete treatment.
- Can be exacerbate preexisting vulnerabilities such as
  - migrants,
  - the homeless,
  - prisoners,
  - people living with HIV infection,
  - patients with substance abuse problems,
  - social/cultural minorities,
  - other marginalized groups.
Economic burden of TB

- 58% of household cost affected by TB are indirect costs\(^1\) (patients lost income)
- 20% are non-medical costs (travel, food, accommodation etc.)
- And only 22% are medical costs
- These figures indicate that health systems through universal health coverage program can address only a small portion of the total economic burden related to TB
- Social protection systems should be responsible for alleviating burden caused by non-medical and indirect costs

1. Knut Lönnroth, Tadayuki Tanimura, Ernesto Jaramillo, Diana Weil, WHO 2013
The End TB Strategy: Vision, goal, targets

**Vision:** A world free of TB
*Zero TB deaths, Zero TB disease, and Zero TB suffering*

**Goal:** End the Global TB epidemic (<10 cases per 100,000)

**Target 1**
95% reduction in deaths due to TB (compared with 2015)

**Target 2**
90% reduction in TB incidence rate (compared with 2015)

**Target 3**
No affected families face catastrophic costs due to TB
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3 pillars

- Integrated, patient-centered TB care and prevention
- Bold policies and supportive systems
- Intensified research and innovation
Pillar 2—Bold Policies and Supportive Systems. How it works?

A. Political commitment with adequate resources for TB care and prevention

B. Engagement of communities, civil society organizations, and all public and private care providers

C. Universal health coverage policy, and regulatory frameworks for case notification, vital registration, quality and rational use of medicines, and infection control

D. Social protection, poverty alleviation and actions on other determinants of TB
Pillar 2 - Bold Policies and Supportive Systems
What we want to achieve?

TB affected households facing catastrophic costs 0%

- UNIVERSAL ACCESS to health services including TB prevention, diagnosis, treatment and palliative care
- SOCIAL PROTECTION to prevent and eliminate poverty due to ill health
- SOCIAL ASSISTANCE to contribute towards TB control goals
The Problem statement

• Universal health care coverage, even universal, can address only a small portion of TB economic burden
• Pillar 2 targets cannot be achieved without having well functional social protection systems in place because for the very poor, catastrophic costs in seeking TB care
  – Lead to further impoverishment
  – Irreversible options such as bad loans and selling of property
  – Treatment interruptions and poor outcomes
  – Delay in seeking care and ongoing transmission of tuberculosis
... and beyond costs, social impacts

- Psychological and social effects of tuberculosis impact the patient causing
  - Patient and their family may experience stigma, isolation, feelings of helplessness, familial emotional trauma,
  - Medication side effects, and

- Stigma in the context of TB illness unfortunately may leads to:
  - lack an access to health care services,
  - Social isolation and rejection from families,
  - harassment as a result of TB.
Swaziland as a country context

✓ Covers an area of 17,364 km2 and is situated between South Africa and Mozambique;
✓ Has four administrative regions Hhohho, Manzini, Lubombo and Shiselweni.
✓ US$ 3,475 (2014 estimate)
✓ GDP - composition by sector: agriculture: 7.6%; industry: 47.8%; services: 44.6% (2013 estimate)
✓ The population estimates show 1,106,000; 75% lives in rural areas and 68% lives are live poverty line
✓ TB prevalence is estimated at 605 per 100,000
✓ TB incidence rate is estimated at 733 per 100,000.
✓ 75% of TB-infected patients are also living with HIV.
✓ DRS of 2009 showed that 7.7% of new cases and 33.9% of retreatment cases are MDR-TB
• Do you have any data on coverage of population with health services in Swaziland, where does the country stand in terms of universal coverage of health services? Where do TB social support interventions fit into the broad social protection system—is this largely donor driven? Any plans for sustainability?
NTCP Social support interventions

• The NTCP with support from the Global Fund is offers a minimum package which includes community treatment supporters only

• A new package is being negotiated to include nutritional support and transport allowance for the patients.

• NTCP in collaboration with implementing partners has successfully piloted a comprehensive patient support: Nutritional, Psychosocial, transport allowance, stipends e.t.c. in two regions which has proved to yield good results particularly on adherence and treatment success.
Results of pilots

• The treatment success rate for DR TB patients from the piloted sites in 2015 was 79% compared to 62% for the non-piloted sites.
• The death rate was 18% for piloted sites and 26% for non-piloted sites.
• Lost to follow up rate average of 5% in piloted sites and 10% in non-piloted sites.
• Therefore, Swaziland would like to adopt and scale up this comprehensive strategy to improve favorable patient outcomes for DR TB patients.
• NTCP will also be conducting a study of non-medical costs of TB care in the country.
Best Practices of UHC & Patient Centered care

• URC provided support the community MDR-TB team at the National TB hospital to conduct outreach services

• The support included:
  – providing transportation,
  – Provision of personnel,
  – Provision of mobile phone and airtime for patients follow up
  – GIS mapping of the patients whose homes have been visited.
Objectives of the community MDR-TB outreach

- Conduct home assessments to determine suitability for ambulatory care
- Provide health education to patient and family on adherence, infection control, symptoms and signs of TB, recognition and management of drug side effects.
- Contact tracing in the community
- Defaulter tracking for patients missing appointments
- Link the patients to the rural health motivators in the community
Community MDR-TB outreach activities

Home assessments

Health Education
Community MDR-TB outreach activities (2)

Contact tracing

Linking patients to care
GIS Mapping of MDR-TB patients

- Use GIS mapping to
  - define distribution of patients against available health services
  - Locate patients who have missed appointments
  - Detect and investigate hotspots or outbreaks
  - Inform planning for additional health services (DR-TB initiation sites)

- GIS mapping and Patient mapping tools are useful tools for delivering patient centric care.

- It also improves:
  - Communication
  - Record keeping and analysis
  - Decision making

- Use of GIS mapping is a cost efficient and feasible intervention for improving MDR-TB patient care
Achievements in MDR-TB patient outcomes.

- Patients Mapped: 1,036
- Home assessments: 973
- Contact tracing: 2,345
- Defaulters tracking: 250
- Linkages to HIV care and treatment: 195
- Linked to HIV testing: 85
- Health Education (family and neighbours): 4,653
- Health education (Community DOTS supporters and RHM): 185
- Treatment success as of March 2015: 66%
Culture Conversion rates for cohorts of MDR-TB patients initiated on treatment 6 months prior.
## MDR-TB treatment success for patients enrolled from Jan 2010 - Mar 2012 at the National DR-TB hospital

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**# of MDR-TB patients initiated on treatment**

**# of MDR-TB patients with outcome of cure**

**# of MDR-TB with outcome of treatment complete**

**# of MDR-TB patients with outcome of cure and treatment complete**

**Treatment success rate**

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**Treatment success rate**: 66%
Challenges

- **Accessibility**: Some places are not reachable with a car thus require the team to walk in order to reach that homestead.
- **Mobile patients**: Patients providing wrong addresses or are staying in rented homes and may leave at any time and not have treatment supporters.

- **Absence of the patient at home**: The patient may not be home during the home visit and we find a child or an old granny requiring us to re-visit that homestead for home assessment and health education.
To enable UHC, Social protection aims to provide

– social assistance to extremely poor individuals and households;
– social services to special groups who need special care and access to basic services that would be otherwise denied;
– social insurance to protect people against the risk and consequences of livelihood shocks; and
– social equity to protect people against social risks such as discrimination or abuse’
Social support packages

- Social can be organized into 5 basic categories:
  1. Services to mitigate the financial impact of TB treatment;
  2. Direct provision of key treatment support services (i.e. transport, nutrition and housing);
  3. Psychosocial, counselling and mental health services;
  4. Linkages and networks with other community social and development services (i.e., micro-finance and livelihood development services); and
  5. Providing support for caregivers of TB patients.
Designing a system linking Social protection and UHC

• Currently, package has not been defined. We propose a model based on the understanding of the
  – Social determinants of health
  – Factors that influence health seeking behavior
  – Best practices that have tested and identified packages that work
  – Describing a framework
How social protection initiatives may be best integrated with current TB control activities

- Access to Health Services
- Barriers
  - Transportation costs
  - Fear of Financial instability
  - Fear of stigma, social norms
  - Fear of loss of employment

Free diagnostics
Free treatment and care
Financial Impact mitigation

- Financial support may be provided through routine payments to a patient or their caregiver, in cash or through cash transfer systems as:

  - Direct economic assistance program & incentives to patients;
  - Transport reimbursements, and treatment allowances;
  - Cash transfers
    - Unconditional – without any type of obligation to be met,
    - Conditional – with some behavioral requirements like treatment adherence.
Treatment support enablers or motivational packages

 ✓ Transportation:
   • Bus tokens, passes, taxi vouchers, (may be offered in addition to transportation reimbursement with cash transfers described above).

 ✓ Stable housing:
   • Shelters, rent assistance, other housing programs (homeless, difficult family situations, too ill to go home, but too well to be in the hospital, from very remote areas).

 ✓ Material needs:
   • Hygiene kits, clothing and/or footwear, newspapers, board games, or other household goods.

 ✓ Nutritional needs:
   • Under-nutrition is itself a risk factor for TB, and can also be as a consequence of TB. Low body mass index as well as lack of adequate weight gain during TB treatment are associated
Nutritional Packages as an enabler

✓ The WHO Nutrition Advisory Group, 2013 recommends Key Principles of Nutritional Care and these should be provided to TB patients

✓ Basic measures to address nutritional needs of TB patients
  1) Conducting an initial nutrition assessment of TB patients with further monitoring;
  2) Providing ongoing counseling for patients on their nutritional status;
  3) Management of severe acute malnutrition
  4) Evaluation for a proper treatment adherence and comorbidities low BMI after two months of TB treatment or lose weight during TB treatment
  5) Micronutrient supplementation for all pregnant women as well as lactating women with active TB.
Nutritional Packages as an enabler

• TB is often associated with substantial upheaval in a patient’s life, and can have profound psychological and social effects.
  ✓ Individual counseling or case work;
  ✓ Support groups or self-help groups;
  ✓ Community engagement to support TB patients; and
  ✓ Provider training around interpersonal counselling and
  ✓ Identification of mental health needs and referrals
    • introducing a simple mental health screening questionnaires
    • Referrals for counselling or other mental health services
Linkages with other treatment, social support and development services

• Unfortunately, a patient often experiences TB disease in connection with or along with other health and social issues.

• Engaging CBOs and Networking care and support for TB patients at the community level

• Coordination of referrals for social services to be delivered at single venue

• Income generation: 60% of the total TB economic burden can be attributed to income loss due to:
  ➢ of loss of employment due to illness or
  ➢ time away from work to attend the clinic
  ➢ Away from work to attend to family member
Quick wins or innovation? : Using DOTS supporters on social support

While TB programs and TB providers may not be in a position to directly support income generation for TB patients, some steps that may be considered include:

- Coordinating treatment and monitoring appointments around a patient’s work schedule;
- DOTS provider may assist the patient to discuss their treatment with their employer and may provide counselling to dispel myths or stereotypes;
- Coordination or referrals for TB patients to other income generation programs such as microcredit loans, vocational training/training programs, or microenterprise activities;
- Conducting outreach with civil society to identify community services which might benefit TB patients;
- Creation of home banks as an income generating activity (IGA) for affected families.
Key Lessons

**Figure 4.** Partnership for Social Support

- Governmental Organization
- NGOs
- International Organizations
- CBOs
- Private Organizations

Partnership
Thanks!