Integrating palliative care and end of life care into TB/MDR-TB programmes

Robert Makombe
26th October 2916
47th Global Annual Lung Health Conference
Liverpool
Definition of Palliative Care

An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

WHO, 2015
Background

- Palliative care traditionally defined by hospice (a place of rest for travelers and pilgrims)
- Traditional hospices
  - Managed by religious orders
  - Cared for the terminally ill
  - Accommodated the incurable and destitute
- Palliative care traditionally catered for patients with terminal non-communicable disease
- In the pre-ART era, palliative care and hospices were the main responses to HIV
Background

- There are linkages between palliative care and end-of-life care
- But they are not the same thing
- Both are a compassionate response to patient needs using a patient-centred approach.
- Public health approach and principles (prevent and cure) developed before palliative care became established as a discipline
Domains of Palliative Care

- **Structure and process of care**: comprehensive interdisciplinary assessment of patient and family
- **Physical Aspects of care**: Pain, other symptoms, and treatment side effects are managed using best practices
- **Cultural aspects of care**: Assesses and aims to meet the culture-specific needs of patients and families
- **Psychological and social aspects of care**: Psychological and psychiatric issues are assessed and managed
- **Spiritual and religious aspects of care**: Assesses and addresses spiritual concerns
- **Care at end of life**: Signs and symptoms of impending death are recognized and communicated
- **Ethical and legal aspects of care**: Patient’s goals, preferences, and choices are respected and form basis for plan of care
Growing Priority of Palliative Care

• World Health Assembly Resolution 58.22 (2005): “Improved palliative care as a core component of health systems in every country.”
• African Consensus Statement (2013): Ministers unanimously adopted a consensus statement for palliative care integration into health systems in Africa, with 6 objectives:
  1. Development of policy frameworks to integrate palliative care into hospital and community home-based care health services (HIV, cancer, CDs and NCDs)
  2. Integration of PC services into national health budgets
  3. Ensure availability of, and access to, essential medicines and technologies
  4. Integration of palliative care into the nursing, medical school and other relevant training programmes and capacity building
  5. Sharing palliative care best practices, using multidisciplinary teams focused on physical, psychosocial and spiritual aspects
  6. Development of partnerships between governments and other players in health for sustainability of palliative care responses, using quality improvement approaches at all levels
Palliative Care and Tuberculosis

Geneva 2010: Declaration and call for action by TB experts to reinforce and incorporate palliative care into global M/XDR TB

“Access to palliative care for adults and children with M/XDR–TB is a human right and promotes dignity”

“Palliative care is an essential component for the provision of care for adults and children with M/XDR-TB wherever in the world their receiving care”
SIXTY-SEVENTH WORLD HEALTH ASSEMBLY

WHA67.19

Agenda item 15.5

24 May 2014

Strengthening of palliative care as a component of comprehensive care throughout the life course

1. URGES Member States:¹

(1) to develop, strengthen and implement, where appropriate, palliative care policies to support the comprehensive strengthening of health systems to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels, with emphasis on primary care, community and home-based care, and universal coverage schemes;

(2) to ensure adequate domestic funding and allocation of human resources, as appropriate, for palliative care initiatives, including development and implementation of palliative care policies, education and training, and quality improvement initiatives, and supporting the availability and appropriate use of essential medicines, including controlled medicines for symptom management;

(3) to provide basic support, including through multisectoral partnerships, to families, community volunteers and other individuals acting as caregivers, under the supervision of trained professionals, as appropriate;

(4) to aim to include palliative care as an integral component of the ongoing education and training offered to care providers, in accordance with their roles and responsibilities, according to the following principles:
Key Concepts of WHA Resolution 67.19

Globally

• To recognise access to palliation as a fundamental human right
• To provide safe medication and good quality palliative care to millions of patients around the world
• To work on social, cultural and legal barriers and strengthen capacity at country level

Country level

• National policies to support health systems in providing equitable access to integrated, efficient palliative care, across all levels of care (Universal Health Coverage)
• Allocation of human and financial resources
• Appropriate use of controlled medicines (review of regulations)
• Development of educational programs
• Support to home care givers
• Innovative partnerships (NGOs, PPP, etc.)
Key Concepts of WHA Resolution 67.19

• Palliative care understood as
  – Long term care
  – Related to NCDs as well as infectious diseases
  – For children, adults and older people
  – In addition to, and not necessarily instead of treatment

• Based on sound ethics framework
  – **Human dignity**: free informed decisions; privacy; special attention to vulnerable people, prevention of discrimination
  – **Justice**: equitable access to good quality health care and optimization of risk / benefit ratio for all patients
  – **Person-centred care**
End TB Strategy

Pillars, principles and components equally applicable for palliative care for TB
Rationale for Palliative Care for TB and M/XDR TB

• Palliative care helps to control symptoms associated with TB, and underlying comorbidities (HIV, diabetes) or TB medications

• Palliative care can improve patient wellbeing, adherence to TB medicines, and retention in care

• Palliative care approach is particularly important for MDR TB patients, for relieving physical and psychosocial suffering due to disease and its treatment

• Rising number of patients in whom treatment fails (transition to end-of-life care)
Promise of Palliative Care for Tuberculosis

Palliative Care for Tuberculosis begins at diagnosis, improving the quality of life for people with tuberculosis

- Early identification and treatment to ease pain, physical, spiritual and psychosocial suffering
- Help patients for more effective treatment adherence for better outcomes
- Help patients to whom treatment has failed
- Improvement of quality of life of patients and families
Logical Framework for Integrating Palliative Care into X/MDR TB Care

End-of-life Supportive Measures

Draws on the work of the Canadian Palliative Care Association and Frank Ferris, MD.
Example from South Africa

South Africa is one of six countries that contribute 60% of global TB burden

- TB notifications, 2015: 294,603 (318,193 in 2014)
- Estimated TB incidence, 2015: 834 cases/100,000 pop.
- MDR-TB started on SLD, 2014: 18,734

WHO Global TB Report, 2016
Raising Priority of Palliative Care for TB in South Africa

- Guidelines made reference to the need for palliative care to be integrated into the National TB program
- Palliative care to be provided to TB patients according to the recommendations of overall national protocols and guidelines
Preparatory Consultancy

June 2014: Consultative mission

• Meetings with key stakeholders:
  – WHO, NDOH, Hospice Palliative Care Association (HPCA), others
  – To review palliative care needs for patients with complicated and severe forms of TB and to determine available services and infrastructure for PC in different provinces

• Visits conducted to Western Cape and Free State Provinces
  – To discuss provision of TB and other palliative care support with provincial and district health teams and NGOs
  – To develop consensus and awareness on key palliative care opportunities and needs

• Outcomes
  – Draft framework and action plan for palliative care services for TB patients aligned to WHO and other international palliative care guidelines
  – Sensitisation seminar on palliative care for MDR/XDR-TB patients
  – Draft palliative care guidelines developed
Development of Draft Guidelines

• May 2015: 3-day symposium
  – Definition of the nature and extent of palliative care in South Africa
  – Consensus on strategies to include in the care being provided
  – Review and revision of draft palliative guidelines (contents, acceptability, 8 domains of PC)

• >150 participants (WHO, palliative care experts and stakeholders from NDOH, PDOH, academic and research institutions, palliative care practitioners and CBOs, patients, national and international technical and funding partners)

• Input from symposium incorporated into draft palliative care guidelines

• Guidelines referred to National Department of Health for review by relevant Directorates and through different levels of health systems

• Draft guidelines to be used to develop and conduct training curriculum and to inform other related trainings
Lessons Learnt

- Palliative care and social support are bidirectional
- Adoption of TB palliative care guidelines requires consideration and integration with other national frameworks for palliative care for all conditions, including NCDs
- National ownership and leadership is essential for adoption of TB palliative care guidelines
- Partnerships are essential
Acknowledgements

- National Department of Health, South Africa
- USAID Washington
- USAID South Africa
- Stephen Connor
- Ernesto Jaramillo