

Palliative Care for Patients with Drug Resistant Tuberculosis

The missing piece of the puzzle!

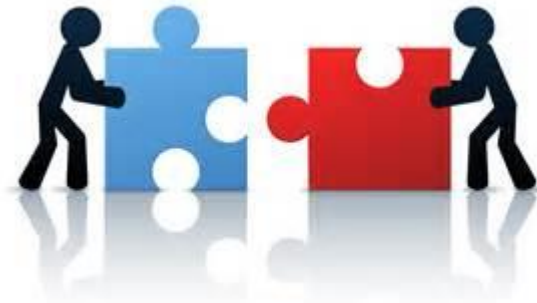
What can TB learn from HIV?



TB

AWA CC

^



Dr. Thilo Govender

Public Health Medicine Specialist



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7 October 2016

Acknowledgements

- “If I have seen a little further it is by standing on the shoulders of Giants”

Sir Isaac Newton 1676

- The dedicated community of health care workers at all levels in our health system
- Our Partners
- The Patients and their Families



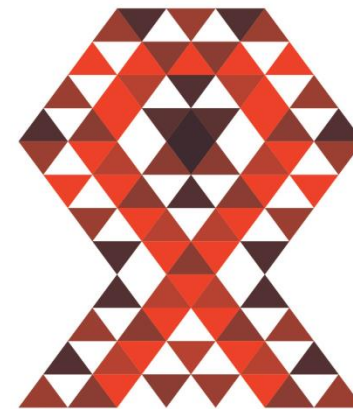
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Moving from Advocacy to Treatment ...and Retention in Care



AIDS 2016
21ST INTERNATIONAL
AIDS CONFERENCE
DURBAN, SOUTH AFRICA JULY 18-22, 2016
WWW.AIDS2016.ORG



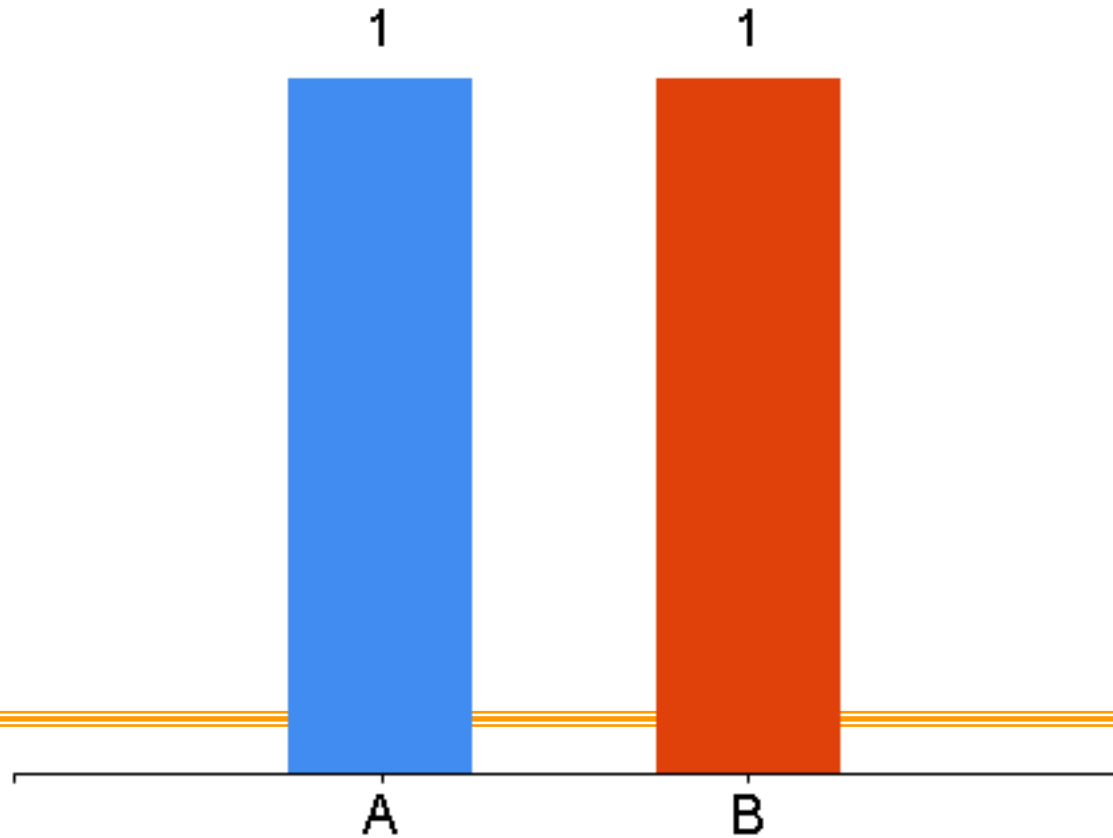
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Question 1

Palliative Care is the same as end-of-life care

- A. True
- B. False



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FALSE!



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Palliative Care



- Palliative care is 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



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Components of Palliative Care

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;



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- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

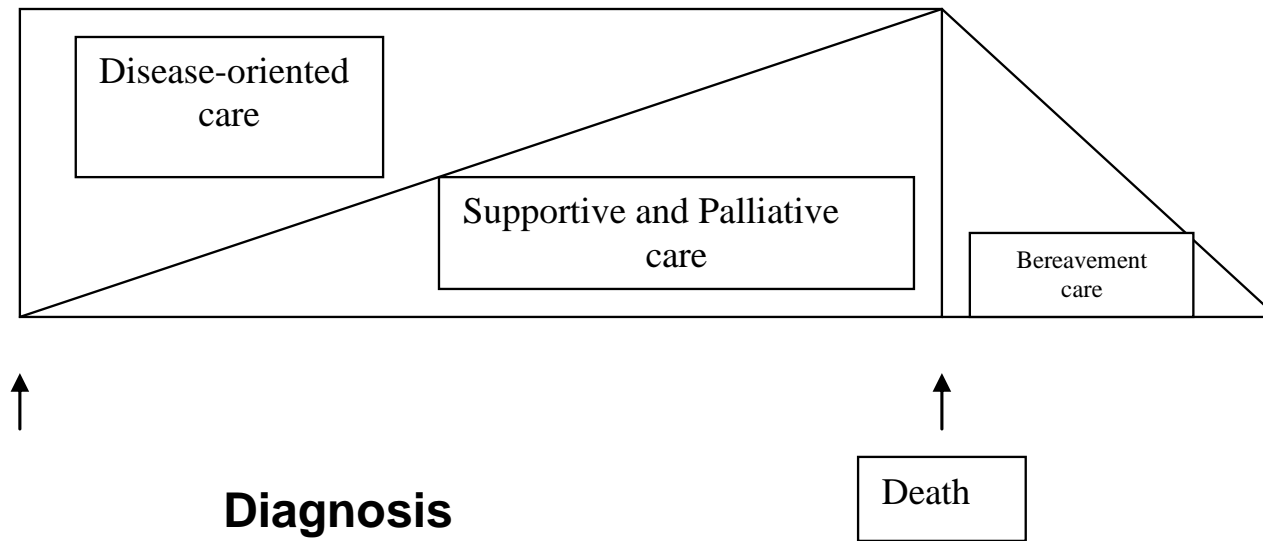


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Role of Palliative Care in the Continuum of Care



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- **What does end of life care involve...**
- End of life care is support for people who are approaching death. It helps them to live as well as possible until they die, and to die with dignity. It also includes support for their family or carers.
- **When does end of life care begin?**
- When end of life care begins depends on your needs.
- The General Medical Council considers patients to be approaching the end of life when they are likely to die within the next 12 months.
- This includes patients who are expected to die within the next few hours or days, and those with advanced incurable conditions.



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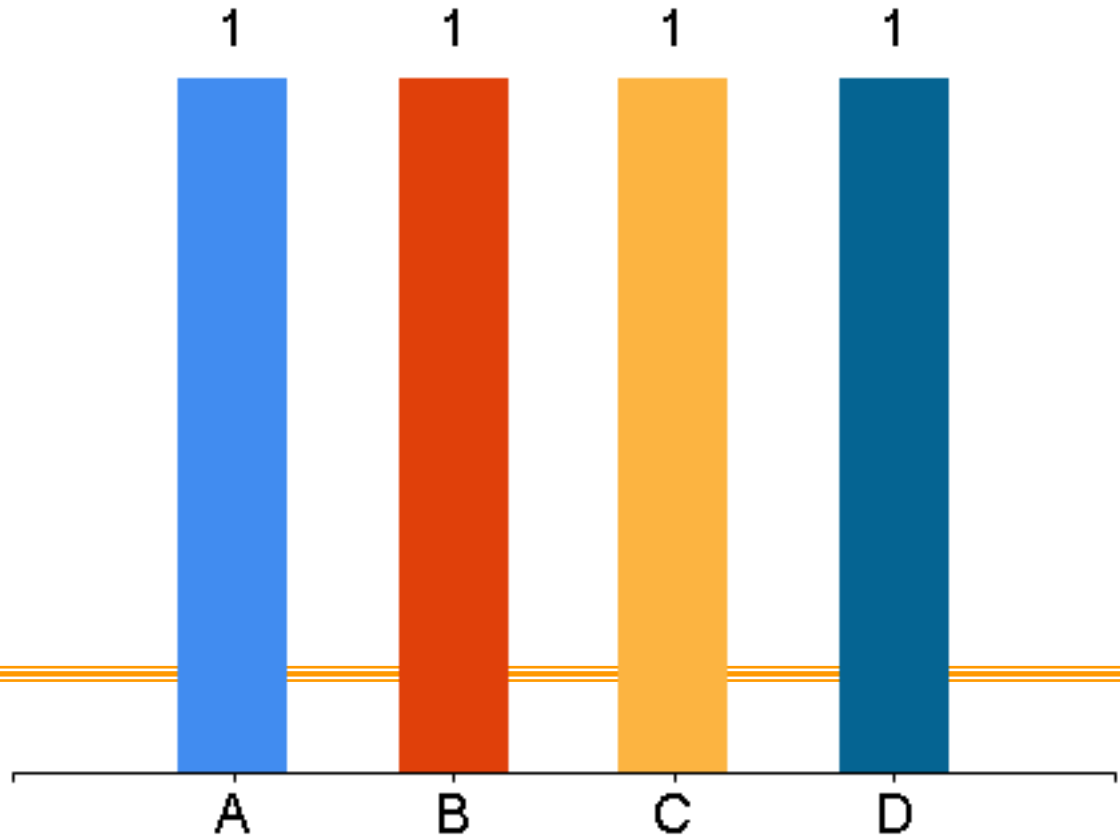
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Question 2

What is the treatment success rate for XDR-TB in South Africa?

- A. 75%
- B. 30%
- C. 45%
- D. 20%



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Treatment Success Rates: 2012 Cohort

- MDR-TB treatment success rate was 50%
- **XDR-TB- 20%**
- **D**



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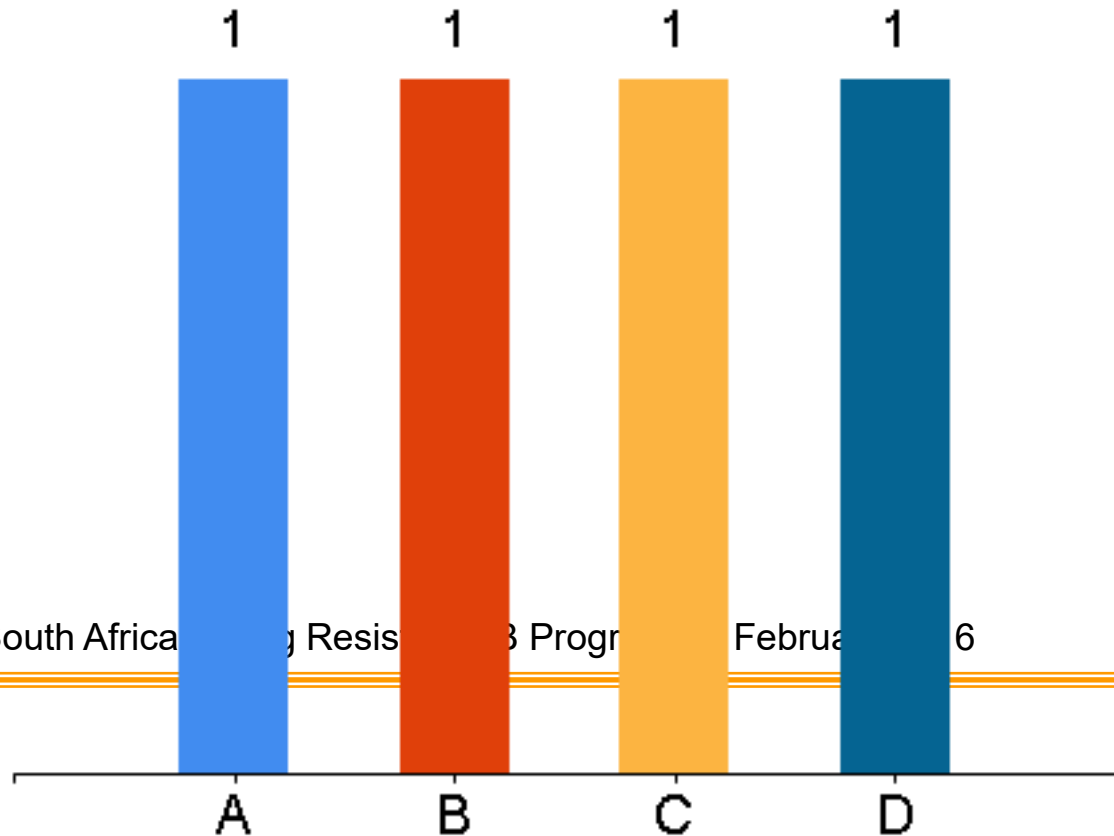
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Question 3

What is the mortality rate for XDR-TB?

- A. 20%
- B. 35%
- C. 47%
- D. 50%



WHO Report of the Evaluation of South Africa's Tuberculosis Resistant TB Program February 2016



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Answer

C: 47% Mortality

Take home message

Lets cure
drug-sensitive TB!

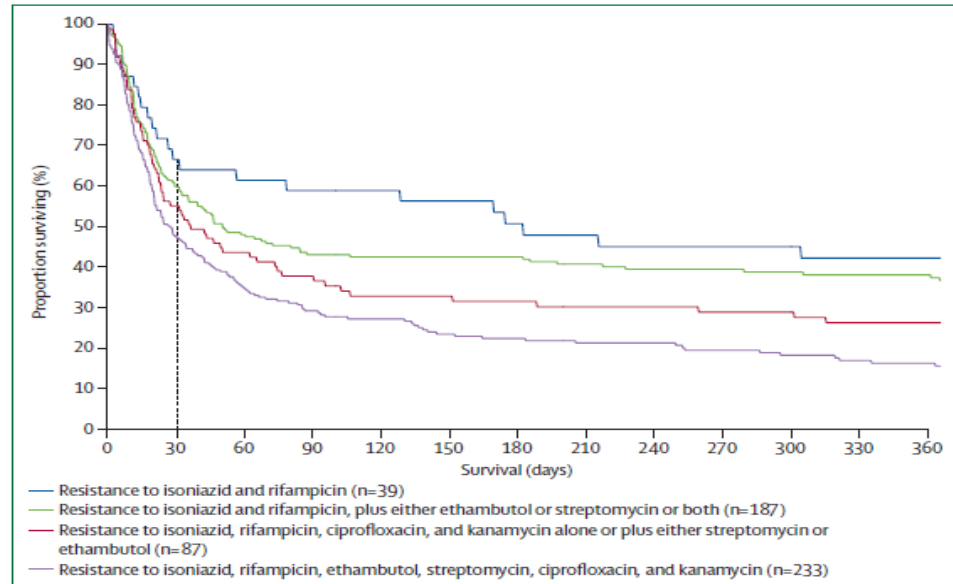


Figure 5: Kaplan-Meier survival plot by drug-resistance pattern for patients with multidrug-resistant and extensively drug-resistant tuberculosis, 2005-07 (log-rank $p < 0.0001$)
Median survival was 182 days (95% CI 31-395) for patients with tuberculosis resistant to isoniazid and rifampicin; 50 days (95% CI 35-106) for patients with tuberculosis resistant to isoniazid and rifampicin, plus either ethambutol or streptomycin or both; 36 days (95% CI 23-74) for patients with tuberculosis resistant to isoniazid, rifampicin, ciprofloxacin, and kanamycin, alone or plus either streptomycin or ethambutol; and 27 days (95% CI 20-38) for patients with tuberculosis resistant to isoniazid, rifampicin, ethambutol, streptomycin, ciprofloxacin, and kanamycin. Figure reproduced from Gandhi and colleagues³⁴ by permission of the American Thoracic Society.



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A Case for Palliative Care DR-TB

Palliative and end-of-life care in the global response to multidrug-resistant tuberculosis

Richard Harding, Kathleen M Foley, Stephen R Connor, Ernesto Jaramillo

June
2012

- The evidence for Palliative Care for Drug Resistant Tuberculosis
- Long Treatment Journey
- Poor patient outcomes
- HIV Co-infection
- Persistent risk of transmission of DR-TB

Global control of tuberculosis: from extensively drug-resistant to untreatable tuberculosis

March 2014

Keertan Dheda, Tawanda Gumbo, Neel R Gandhi, Megan Murray, Grant Theron, Zarir Udawadia, G B Migliori, Robin Warren



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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:



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World Health Assembly Resolution 67.19

23 January 2014

From Strategic Policy....Local Action

- Policies
- Resources:
 - Human resources
 - Essential Medicines
 - Quality Improvement Programs
 - Funding
- Partnerships
- Education and Training



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NATIONAL STRATEGIC PLAN

on HIV, STIs AND TB

2017 - 2022



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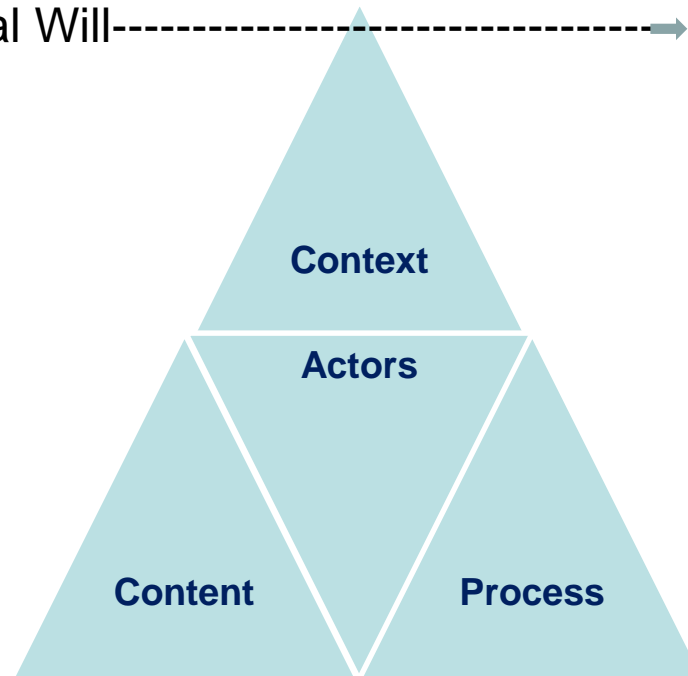
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Health Policy

What governments choose to do!

Political Will-----> Outcomes



'Doing' health policy analysis: methodological and conceptual reflections and challenges

Gill Walt, Jeremy Shiffman,² Helen Schneider, Susan F Murray, Ruairi Brugha and Lucy Gilson

Health Policy and Planning 2008;23:308–317

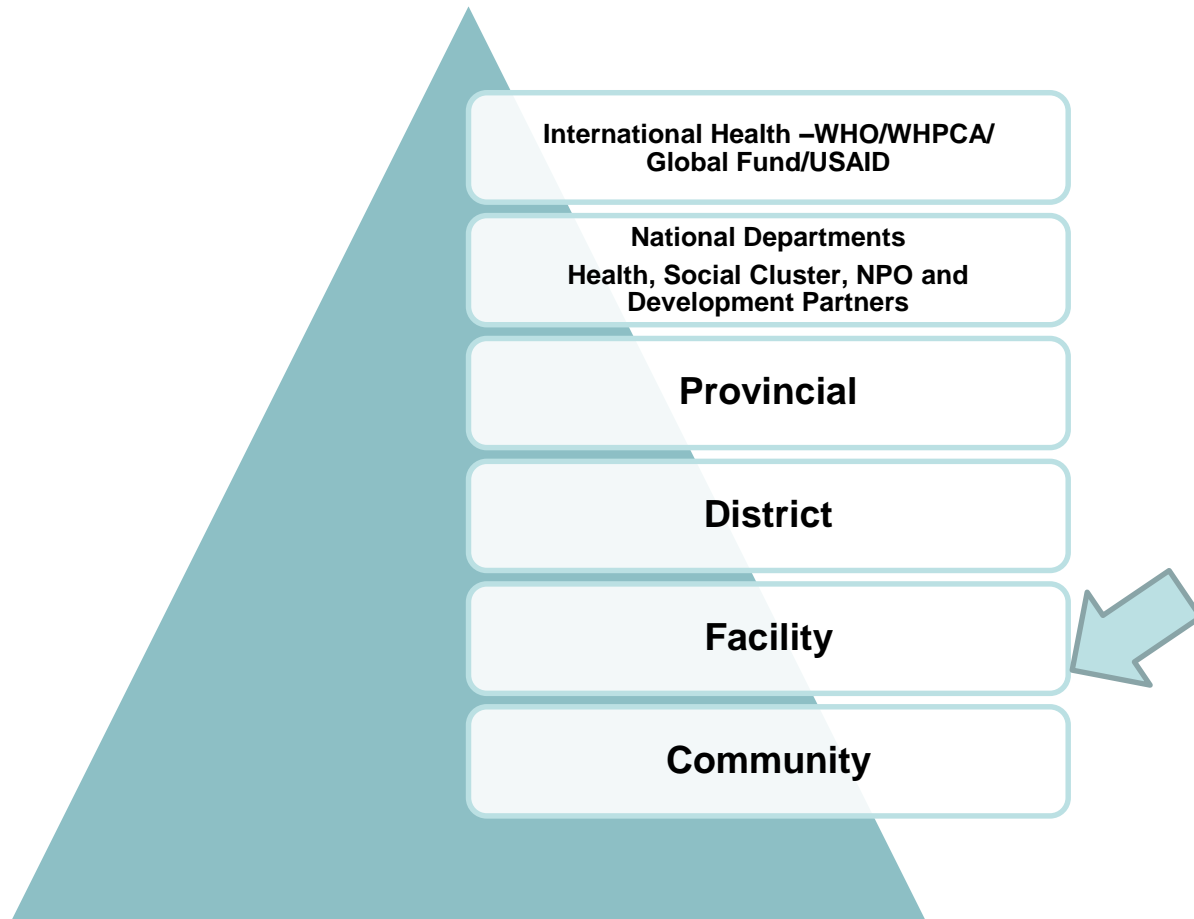


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ACTORS



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Why should we listen to patients?



SIDE EFFECTS OF DRUG-RESISTANT TB DRUGS



Process

- Palliative Care Forum
- Stakeholder Analysis
 - Management
 - Nurses
 - Pharmacists
 - Social Workers
 - Clinicians
- Education and Training
 - Short Course, In-service, Formal
- Referral Pathways



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Context

- The history of King Dinuzulu Hospital Complex...
- 1939: King George V Jubilee Hospital 139 beds for the treatment of Tuberculosis
- 1946: Springfield Military Hospital incorporated
- 1956: King George V Hospital 1291 beds TB, Psychiatric Services, Surgical Services Orthopaedic Spinal and Cardiothoracic services
- 2016: King Dinuzulu Hospital Complex 662 beds-224 beds for DR-TB



Renovated multi-story building



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Background

- DR-TB Workshop
- IDT
- Self-administered questionnaire
- 10 Variables
- 9 Tick box
- 10 Free text



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Results

- Sample size N= 32
- Professional Groups
 - Nurses
 - Doctors
 - Pharmacists
 - Other
- Experience



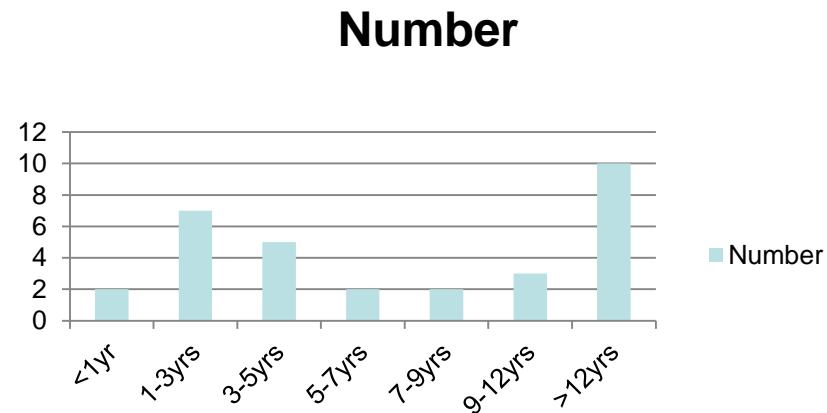
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Years of Experience in DR-TB

- Important finding: Bi-modal distribution
- Institutional Memory
- Clinical Experience
- The changing patient journey



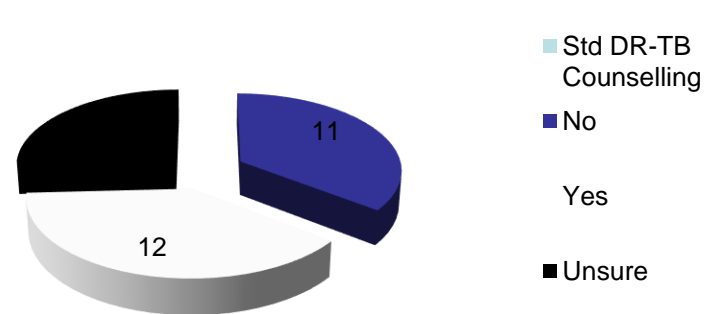
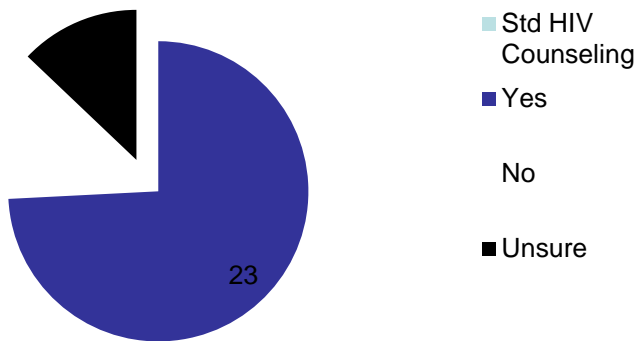
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HIV vs DR-TB Counselling

- Good knowledge of standardisation of HIV Counselling
- Lack of Clarity on DR-TB counselling



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DR-TB Counselling

- Lack of Standardisation
- Adherence and Appointments \rightarrow 100%
- Emerging Themes
 - Diagnosis
 - Treatment
 - Sputum
 - HIV Co-infection
 - Infection Control



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DR-TB Counselling

- Emerging Themes
 - HIV Co-infection
 - Cure with DR-TB
 - Continue ARVs
 - Cost of DR-TB
 - Spiritual Support: Faith in God
 - Acknowledge milestones in the treatment journey
 - Consequences of defaulting
 - Social support and disclosure

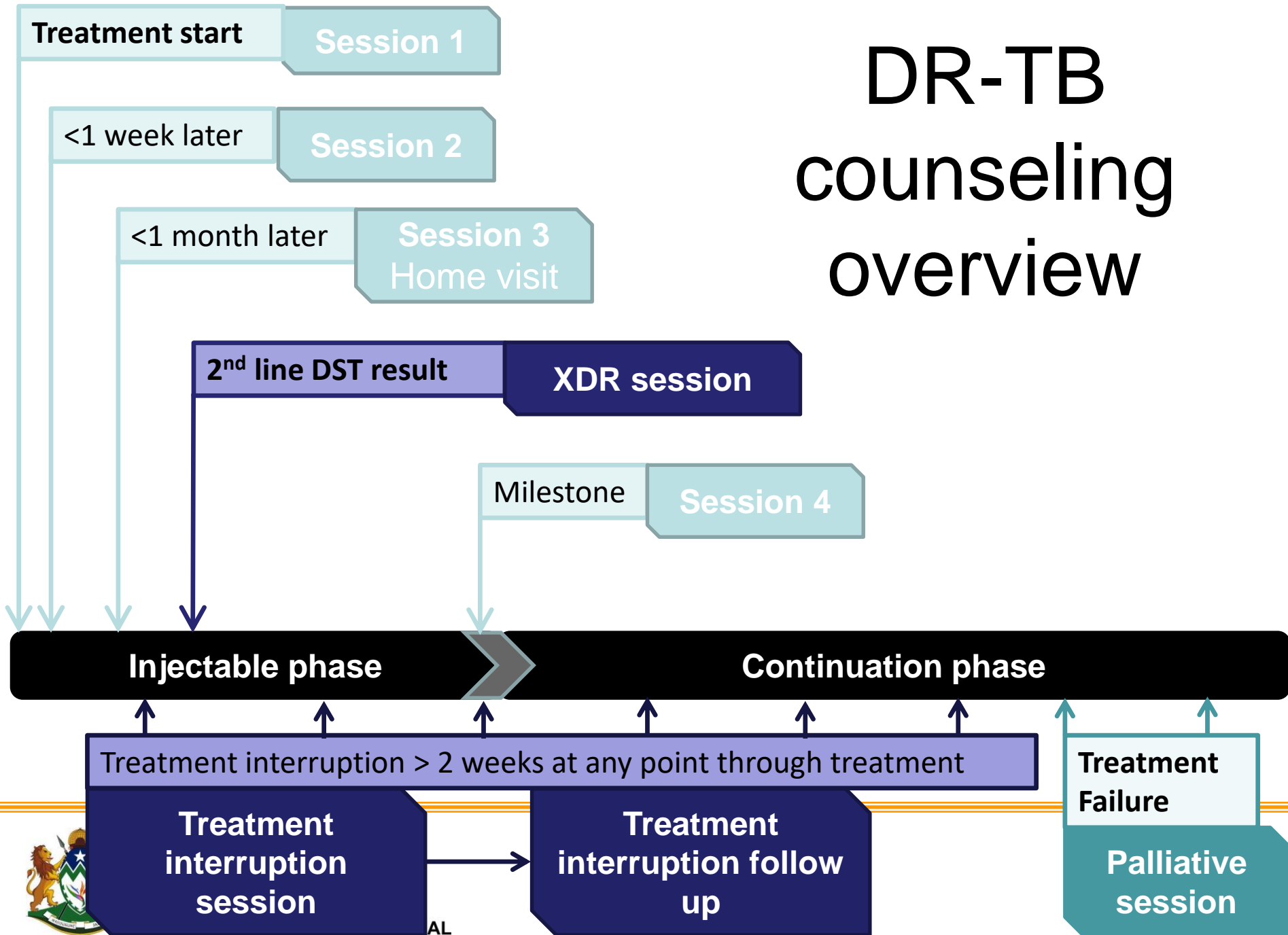


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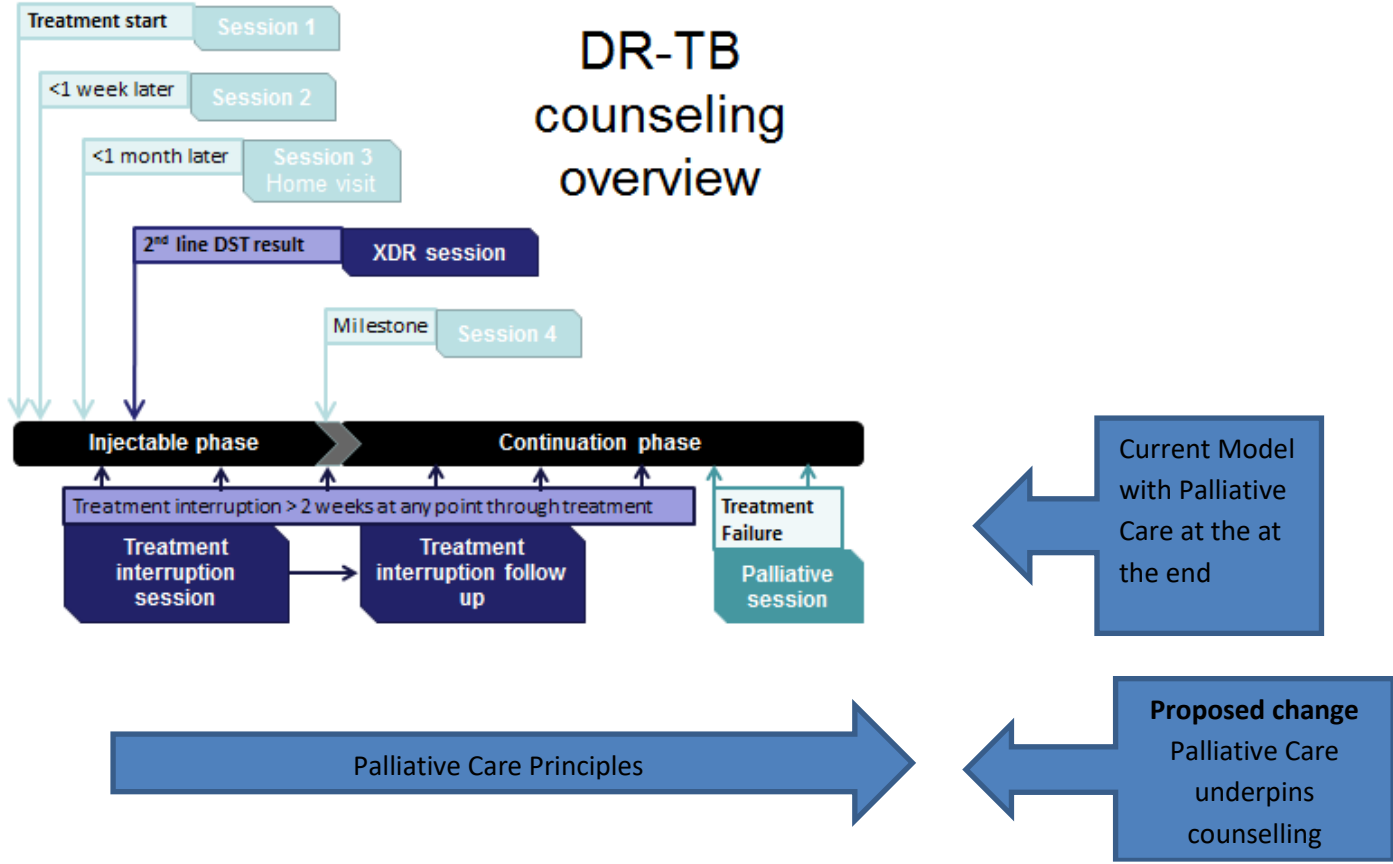
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DR-TB counseling overview



DR-TB counseling overview



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Guidelines for Providing Palliative Care to Patients with Tuberculosis



<http://hpca.co.za/item/tb-guidelines-english-version.html>



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Concluding Thoughts

- Structured Adherence Support for TB is an entry point for Palliative Care
- Start the Palliative Care conversation with...
 - Yourself
 - Your family
 - Your patient: Nothing about me without me!



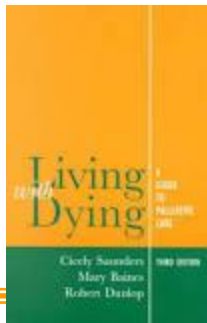
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You matter because you are you.
You matter to the last moment of
your life, and we will do all we can
not only to help you die peacefully,
but to live until you die.

Dame Cecily Saunders



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I have walked that long road to freedom. I have tried not to falter; I have made missteps along the way. But I have discovered the secret that after climbing a great hill, one only finds that there are many more hills to climb. I have taken a moment here to rest, to steal a view of the glorious vista that surrounds me, to look back on the distance I have come. But I can only rest for a moment, for with freedom come responsibilities, and I dare not linger, for my long walk is not ended.”



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