



“THE BIG TB, IT IS TB, BUT IT’S MORE THAN TB:”

**EXPLORING DR-TB PATIENTS CHARACTERISTICS AND
TREATMENT EXPERIENCES**

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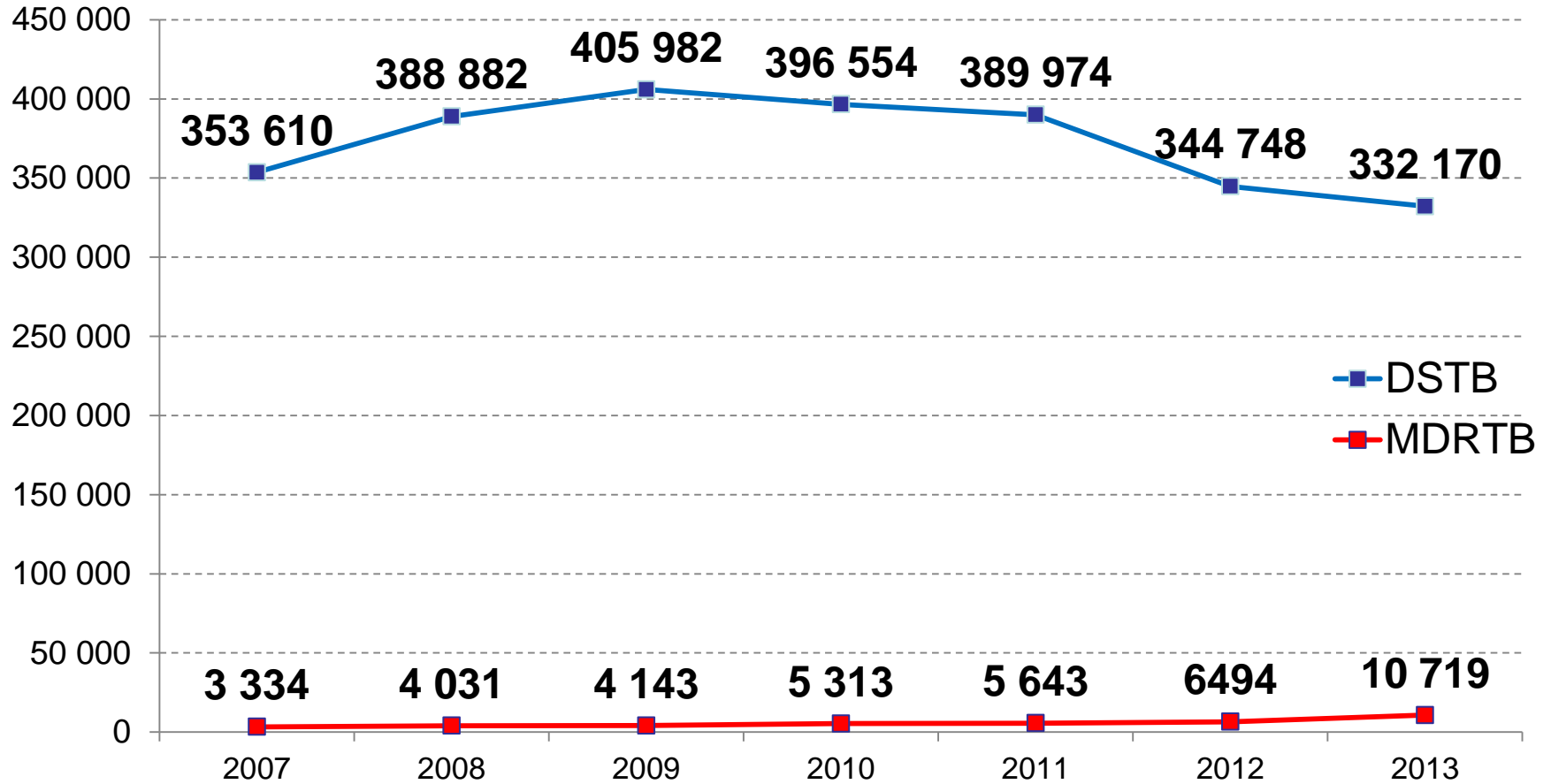
OUTLINE

- Background
- Aims and methodology
- Results
- Conclusion (summary)

BACKGROUND

- South Africa: A high burden of DR-TB
- Limitations of the treatment
- Poor treatment outcomes

TB situation in South Africa

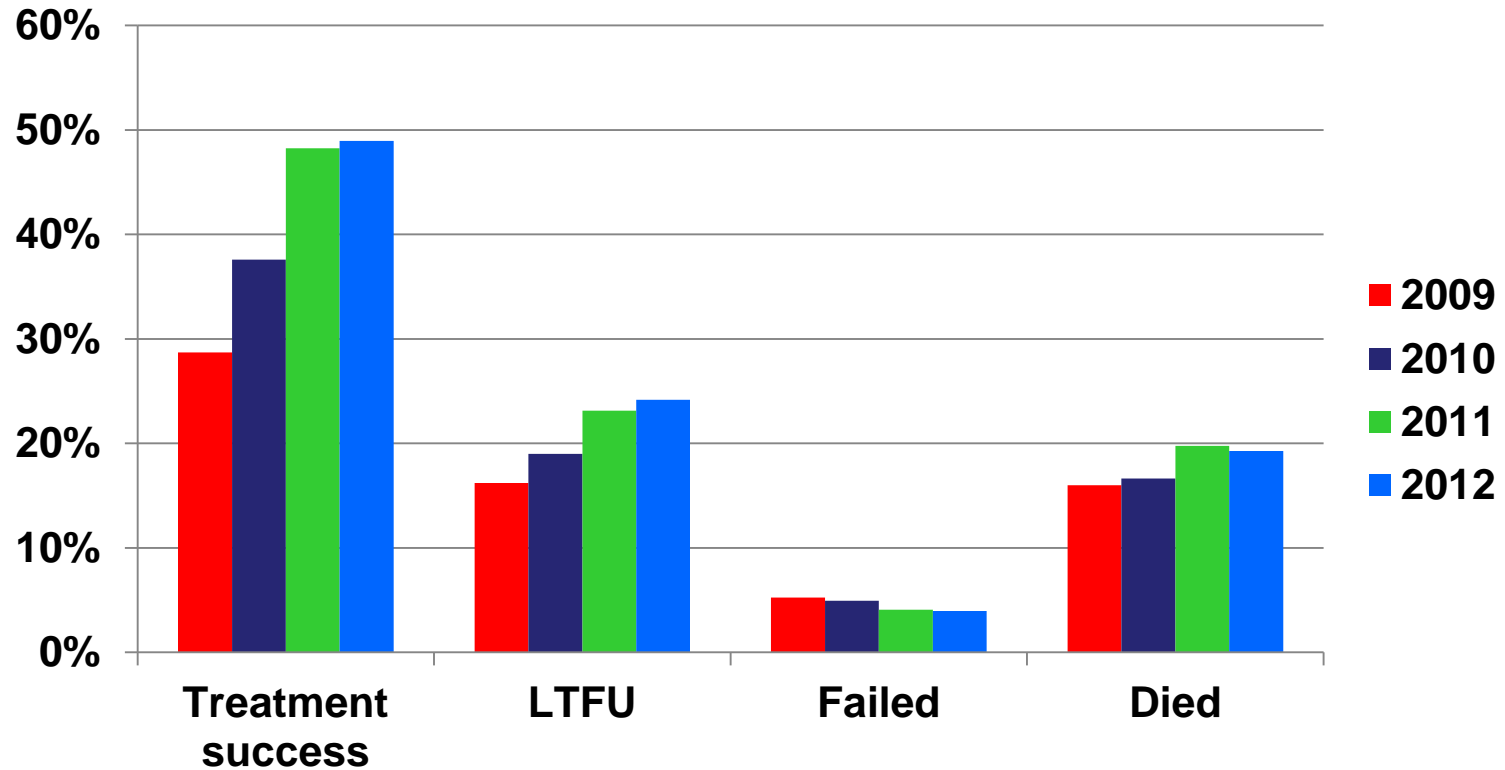


Limitations of treatment

- Poor drugs
- Huge pill burden (especially if HIV-positive)
- Daily injectable for 6 months
- Long treatment (24 months)
- Severe adverse events:
 - Irreversible hearing loss



DR-TB treatment outcomes 2009-2012



AIM AND METHODOLOGY

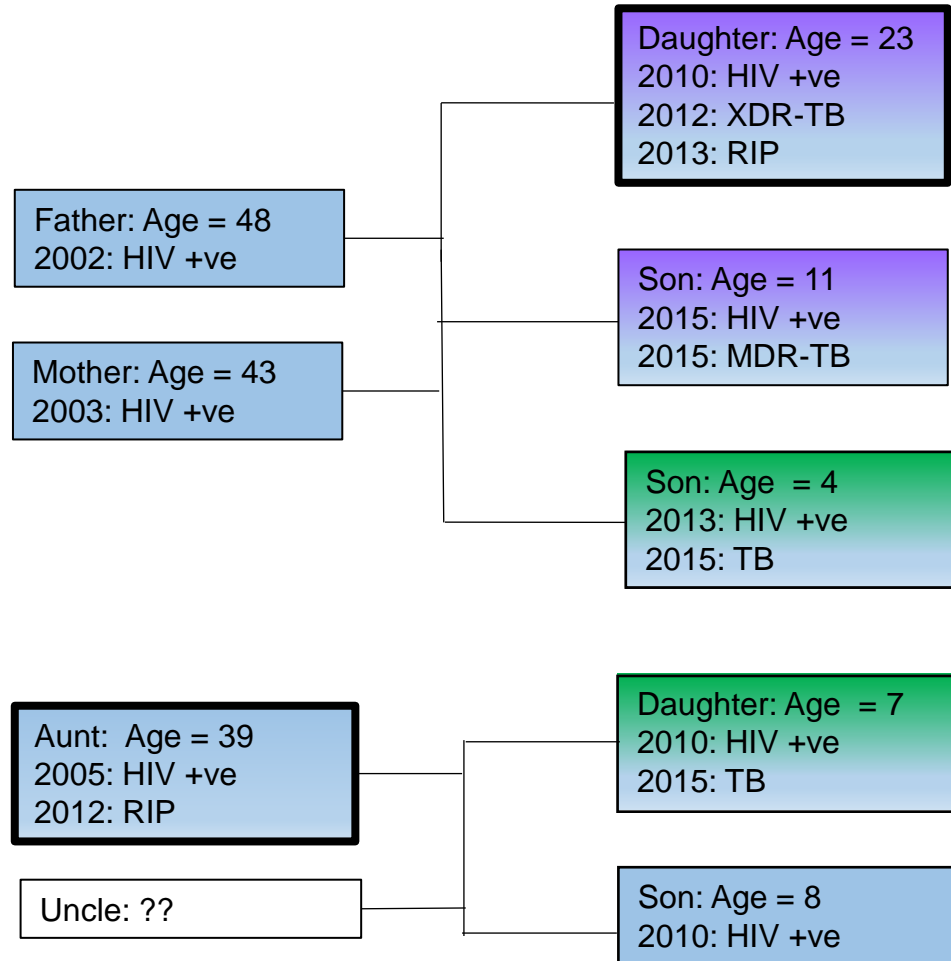
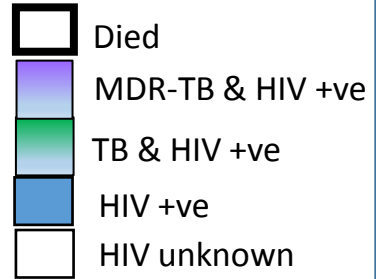
Aim:

To explore the characteristics and treatment experiences of patient's with DR-TB.

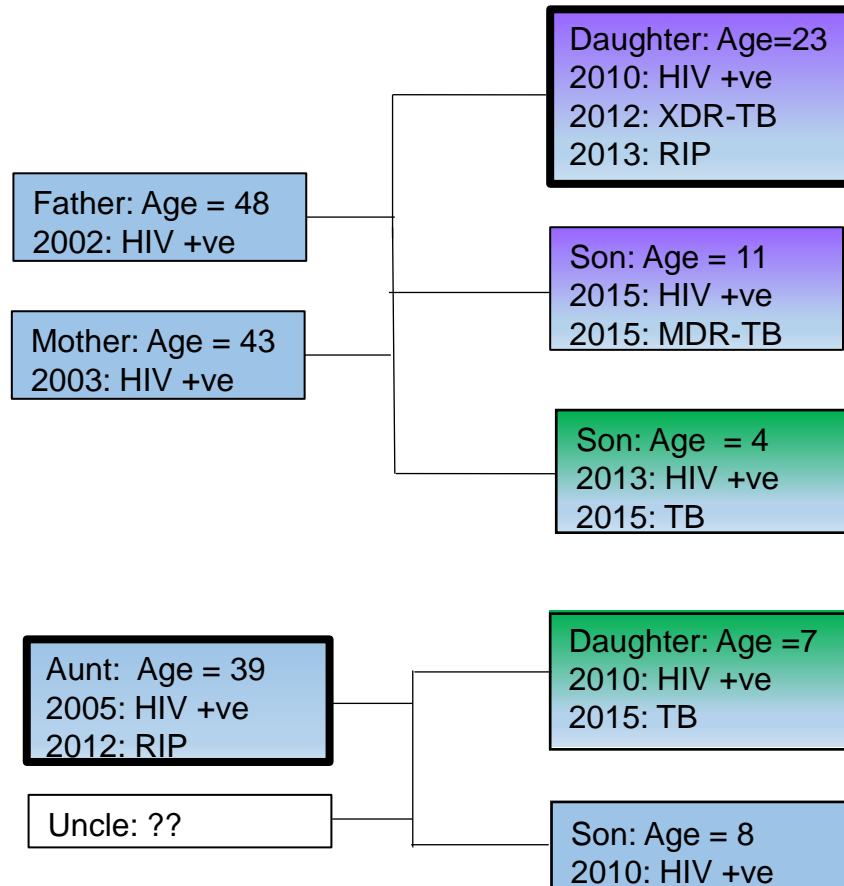
Methodology:

- Interviews were open-ended and conversational;
- 16 interviews with adults and 27 caregivers of children with DR-TB;
- Interviews subject to thematic analysis to identify themes (open and axial coding used)

Burden of disease - Xaba household



Catastrophic expenditure on health



Household income vs expenses

Monthly income:

Regular: 4 child care grants: R1320

Irregular: Father day jobs if he can find them.

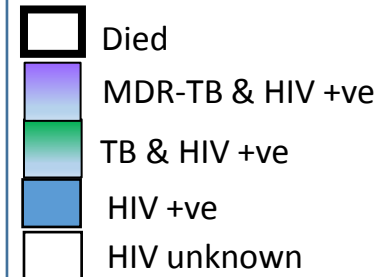
Monthly expenses:

- Travel to hospital: R50/trip (R200/month)
- 2 loaves bread & 1 litres milk: R40/day (R900/month)
- Chicken a week: R30 (R120/month)

Total food = R1020

Borrows:

± R150 a month for transport



Cost of monthly trip to KDH for monitoring and repeat medications



Day 1:
Leave home at 10am
Child misses school

R200 for taxi
@ R100 each

Night 1:
District hospital
bench

Day 2:
Travel to TB
specialist
hospital

Cost of food
for trip: R75



| Costs of monthly treatment | |
|----------------------------|--|
| Taxi | R200 + R200 |
| Food | R75 + R75 |
| Total financial costs | R550 |
| Other costs | Mother: 3 days away from home and her financial responsibilities Child: 3 days away from school |

INTERVIEWS (Patient centered care)

Mrs. Xaba:

“If I had been able to talk to someone like this when my daughter was sick, she would never have died.”

Mrs. Cebekhulu:

“I went to tell the teacher my son had DR-TB and would only return to school in 6 months time. A week later the school principal phoned to tell me my son could not go back to that school as I hadn't told her.”

INTERVIEWS (Health system failures)

Mrs. Buthelezi:

“I spent R500 getting here. The hospital transport broke down, so we got to KDH late at 3pm. We were told it was too late for us to see the doctors.”

Sister (19 years) of Sandile (7 years):

Sister in tears so we sat and chatted to her to find out the problem. “My cousin had to bring Sandile last time. I was too sick. The nurse is cross with me as when Sandile and my cousin came last time, they forgot to get ART in the other building.”

PATIENT CENTERED CARE

‘Patient-centeredness means putting the person of the patient at the centre of the consultation and attempting to understand the patient’s thoughts, feelings and expectations, as well as his or her symptoms.

A patient-centered approach demands a shift from thinking and responding in terms of disease and pathology, towards understanding and caring for people and their problems.’

Henbest R & Fehrsen G. *Patient-centredness: Is it applicable outside the West? Its Measurement and Effect on Outcomes*, **Family Practice**, OUP, 9:3,1992 p311

SUMMARY

- DR-TB is a complex disease requiring a complicated health system response:
 - Health systems failures compromise adherence.
- Adherence difficult when:
 - Households ravaged by a high burden of TB and HIV;
 - No financial resources;
 - Stigma/dual stigma.
- Patient-centered care
- Adherence support

‘Effective caregiving requires more than intent or sentiment...
it requires... being in relation with others’

Benner, P.; *Caring as a Way of Knowing and Not Knowing*, in **The Crisis of Care: Affirming and Restoring Caring Practices in the Helping Professions**, S. Phillips & P. Benner (Eds.), Georgetown University Press, Washington D.C., 1994, p45

‘Caring is a relationship between the one-caring and the cared-for. It is a relationship of concern in which the other’s existence matters to you as the one-caring.’

Noddings Nel, **Caring a feminine Approach to Ethics and Moral Education**, University of California Press: Berkeley, Los Angeles, London, 1984, p 33.

Acknowledgements

All MDR-TB patients

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Thank you

