



# **Barriers and Outcomes: TB patients co-infected with HIV accessing Antiretroviral Therapy in Rural Zambia**

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**Zambart Project**



## **Renewal Study, 2006-7**

- Explores how poor households in rural Zambia and peri-urban South Africa experience & respond to TB – alongside high HIV prevalence and food insecurity
- Anthropological study conducted in:
  - Pemba/Batoka, Choma District, Southern Province
  - Mbekweni, Paarl District, Western Cape



## ART in Zambia

- Late 2002, ART piloted (2 teaching hospitals, PMTC, military, police)
- Early 2004, ART extended (provincial hospitals, selected PHC), US\$10 @ month
- June 13<sup>th</sup> 2005, ART free & rolled out
- 2007: ART available in all 72 districts, in 107 public health facilities
  - 149,199 People living with HIV on ART

## Method

- 8 TB patient households (9 TB patients) & 7 comparative households
- Visited from diagnosis to end of TB treatment (8 months) at least four times, 2006-7
- Informants: TB patient, primary caregiver, key woman, head of household
- Themes: livelihood activities; food security; direct & indirect costs of TB; food requirements; support networks; access to TB medication; access to ART; mobility; patient recovery; future plans; death

“The microbe is nothing; the terrain is everything” (Pasteur)

- Chronic & seasonal poverty
- Limited livelihood options
- Fragile local economy
- 2/8 affected households very poor
- 6/8 affected households poor
- 8/8 food insecure

## Profile of 9 TB Patients

Sex and age of TB patient	Length of time to diagnose TB	TB outcome	Primary Caregiver	HIV Status
30-year-old man	4 months	Cured	Mother	LWH
54-year-old man	9 months	Died, October 2007	Mother	LWH
25-year-old woman AND 38-year-old man	10 months (woman) 2 months (man)	Cured	Mother	LWH
25-year-old man	20 months	Cured	Mother	LWH
30-year-old woman	4 months	Died, April 2007	Co-wife	LWH
21-year-old woman	10 months	Cured	Grandmother	LWH
41-year-old man	3 months	Cured	Wife	HIV-
55-year-old woman	9 months	Cured	Daughter	HIV-

## HURDLES IN ACCESSING ART

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## **ECONOMIC BARRIERS**

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## **Impoverished by TB**

- Prolonged diagnostic period – 2-20 months
- TB patients not able to contribute to household living until 4 months into treatment; primary caregivers' livelihoods also affected
- 6/7 co-infected TB patients relocated when sick, leaving livelihoods behind
- Farming activities in 7/8 households disrupted by TB; food production impacted by TB e.g. 7/8 drop in harvest 2006/7 and two had no harvest
- Nutritional status of households worse at end of TB treatment (anthropometric measurements in children >5)

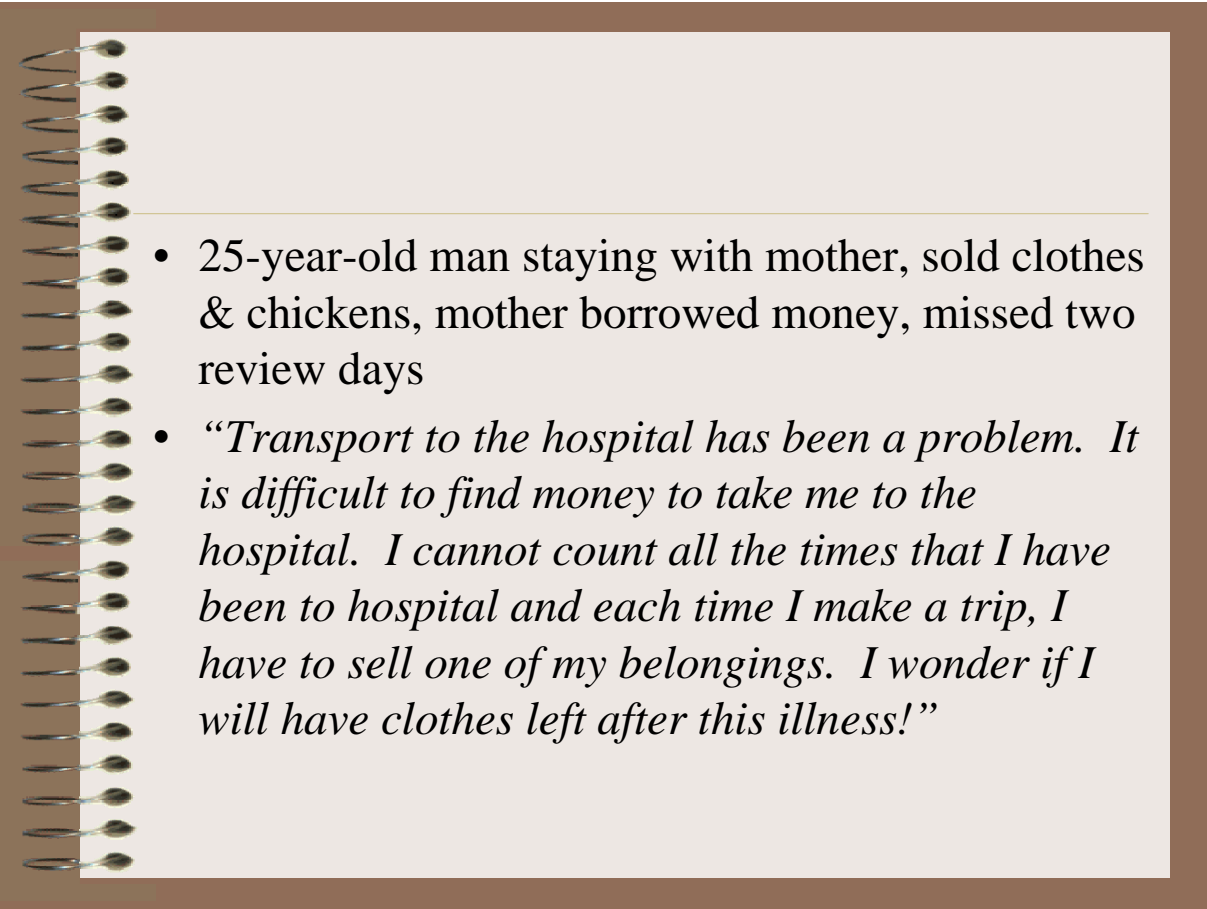
**TB patient household field  
2006-7**

**Comparative household field  
2006-7**



## **Distance & High Transport Costs**

- ART clinics 40 & 60 kms away; each trip cost US\$3-7.50, if accompanied double
- Snap-survey at ART clinic (Feb 2007):
  - 32/49 stayed outside town
  - 29/32 paid to reach clinic
- Household with 2 TB patients spent US\$50 by time started ART – borrowed money, sold a cow, *“money was not easy to come by, people die because they have no money to go to the hospital”* [mother]

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- A graphic of a spiral-bound notebook with a brown cover and a light beige page. The spiral binding is on the left side. The page contains two bullet points.
- 25-year-old man staying with mother, sold clothes & chickens, mother borrowed money, missed two review days
  - *“Transport to the hospital has been a problem. It is difficult to find money to take me to the hospital. I cannot count all the times that I have been to hospital and each time I make a trip, I have to sell one of my belongings. I wonder if I will have clothes left after this illness!”*

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## **Hunger & Medication**

- Need to take medication with food
- Change in household diet because of TB – more fish, eggs, meat, soft drinks, fruit purchased
- No household in receipt of food aid

## Lack of food & ART

- ART Clinic February: Most clients had not eaten before leaving home and by mid-afternoon were tired and hungry - *“A hungry man is an angry man! I am so hungry and you are taking so long to attend to me – do you want me to get angry?”* [man at ART clinic]
- Needing to eat and take ART a long-term problem:
  - *“I tell you suffering from TB and taking ART but no food is torture”* 25-year-old co-infected man
  - Cannot afford the *“balanced diet”* of fruit, groundnuts, *“relish”* recommended by ART clinic, *“We can only afford vegetables so I will never gain weight”*, 25-year-old co-infected woman

## Funeral costs

- 2 deaths during fieldwork
- Costs astronomical – US\$210 and US\$184
- Both households ended up in heavy debt

A graphic of a spiral-bound notebook with a brown cover and a light beige page. The spiral binding is on the left side. The page is mostly blank, with the title 'SOCIAL BARRIERS' centered in the lower half.

## **SOCIAL BARRIERS**

A graphic of a spiral-bound notebook with a brown cover and a light beige page. The spiral binding is on the left side. The page contains the title 'Loss of Social Status' and a bulleted list of two items.

## **Loss of Social Status**

- 6/7 relocated, moving to a more subordinate household position
- 5/7 marriages broke down when sick with TB

## Marginal Social Status

- Co-wife's husband told her not to start taking ARVs and *"to not drink them anywhere near his house"*
- 21-year-old co-infected woman divorced, lost her only child (a baby), staying with mother's mother, refused to discuss HIV and access ART

## Denial

- 3/7 in denial about HIV status:
  - 21-year-old woman shifted to town at end of TB treatment
  - 38-year-old man bullied by mother into accessing ART but when shifted to father's house, stopped accessing ART
  - 30-year-old man confused by wife's discordant status and preference for traditional medicine

## Enacted Stigma

- All experienced some form of rejection, isolation, gossip and name-calling
- All isolated in household when had TB (made to eat and sleep separately)
- Visited less by friends and relatives
- Disclosure difficult
- Trips to clinic visible and monitored by others

## Anticipated Stigma

- *“I feel it is the right time to tell my relatives about my HIV status. I think that when I do, they will fear and shun me. Already they are not free with the knowledge that I am a TB patient; HIV will only make it worse”* [54-year-old co-infected man]
- Undermined his ability to attend ART clinic

# Gender Relations

- Men lost self-esteem & found it hard to make demands on households, including using scarce resources to access ART
- More difficult for men to relocate to other households in search of food and care
- Once better, men expected to provide & hard to allocate money to accessing ART
- Women's access to ART undermined by having less authority, less cash, having mobility socially sanctioned

# HEALTH FACILITY BARRIERS

## Steps to Starting ART

1. HIV test
2. Patient history, physical examination, liver function, CD4 test. Co-trimoxazole and multi-vitamins dispensed.
3. CD4 results reviewed, adherence counselling, accompanied by a buddy. ART started.
4. Side-effects and adherence assessed

## Congestion, Administration

### - 25 year-old co-infected woman -

- *“The ART clinic is a long process. You go early in the morning and get back late at night”*
- *“Hey! It’s not easy at all. It is not even easy to open a file. First, there are many papers to fill in and many questions to answer”*

## **Losing blood, electricity cuts**

### **- 38 year-old co-infected man -**

- *“There were many problems. When I first went to the ART clinic, I was told to give blood so that tests would be done. When I went back for my results, I was told the results were lost. Before I left I gave them more blood. When I went back the second time I was told that my bloods was destroyed because there was a power failure so my results were not ready. I gave blood the third time and it finally went well. I was not given the medicine the same day – I had to go back. On my fourth trip, I was given aspirins for two weeks and an appointment was made for me to visit the clinic after two weeks. I went and then some tests were done. I made about five trips to the clinic before I finally started my ART drugs”.*

## **Faulty equipment**

### **- 54 year-old co-infected man -**

- Reached clinic to find CD4 machine was not working; his health deteriorated rapidly, he missed his next two week appointment and died two weeks later.

# Long waiting times

## - snap survey -

- 33/49 visited clinic before. On last visit:
  - no-one had spent less than one hour
  - 2/33 spent 1-2 hours
  - 2/33 spent 2-3 hours
  - 27/33 spent more than 3 hours

**OUTCOMES**

## **Outcomes of 7 co-infected - death, denial & transformation -**

- Death: 4/7 died;
  - 2007: 30 year-old woman after a month on ART; 54 year-old man before starting;
  - 2009: 30 year-old man in a discordant relationship (never started ART); 38 year old man (started & then stopped ART)
- Denial: 1/7 did not start ART; 21 year-old woman in a marginal position
- Transformation: 2/7 started & remained on ART; 25 year-old man, 25 year old woman

## **Transformation two-fold - regained health & appearance -**

- *“I was in a very bad state when I got here. My relatives thought I was dead. I think even the taxi-driver who brought me here will have a shock of his life when he sees me. He will think he has seen a ghost. I remember how terrible I looked when you first saw me. But here I am very fit! I never thought I would get well and look the way I am looking today. It is a miracle! The medicine has done wonders” [38 year-old co-infected man]*

## And..social transformation

- Networks contracted when had TB
- Networks expanded when started to recover e.g. 25 year-old man returned to wife and children, 38 year-old man returned to work in town, 25 year-old woman moved to stay with sister in town

## Pemba ART Delivery Centre

- July 2007
- *“That is a wonderful thing! I think I will change to be seen there. It is nearer to home”* [25 year old woman]
- July 2008, 268 PLWH on ART but approx 50% not returning for routine appointments, staff short, delays in CD4 results

## Conclusions

- Advantages of integrated TB & HIV services
- Stagger into ART programme, depleted by managing TB
- ART a free service BUT other costs; many steps, high transport costs, congestion, lengthy administrative procedures, shortage of staff, health system inefficient
- Long-term struggle to access special foods
- Startling transformation in short-term
- Vulnerability of rural location

## Recommendations

- Social Protection for TB patients in Zambia – food aid & grants
- Introduction of a more comprehensive nutritional programme into TB and HIV programmes
- Using TB programme as an entry point for HIV services
- More prompt diagnosis of TB
- Reducing steps in process of ART enrolment
- Extending ART delivery to peripheral centres
- At ART clinics, address congestion, reduce administrative procedures, improve management of samples & availability of equipment, increase staff

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