



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 13th 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

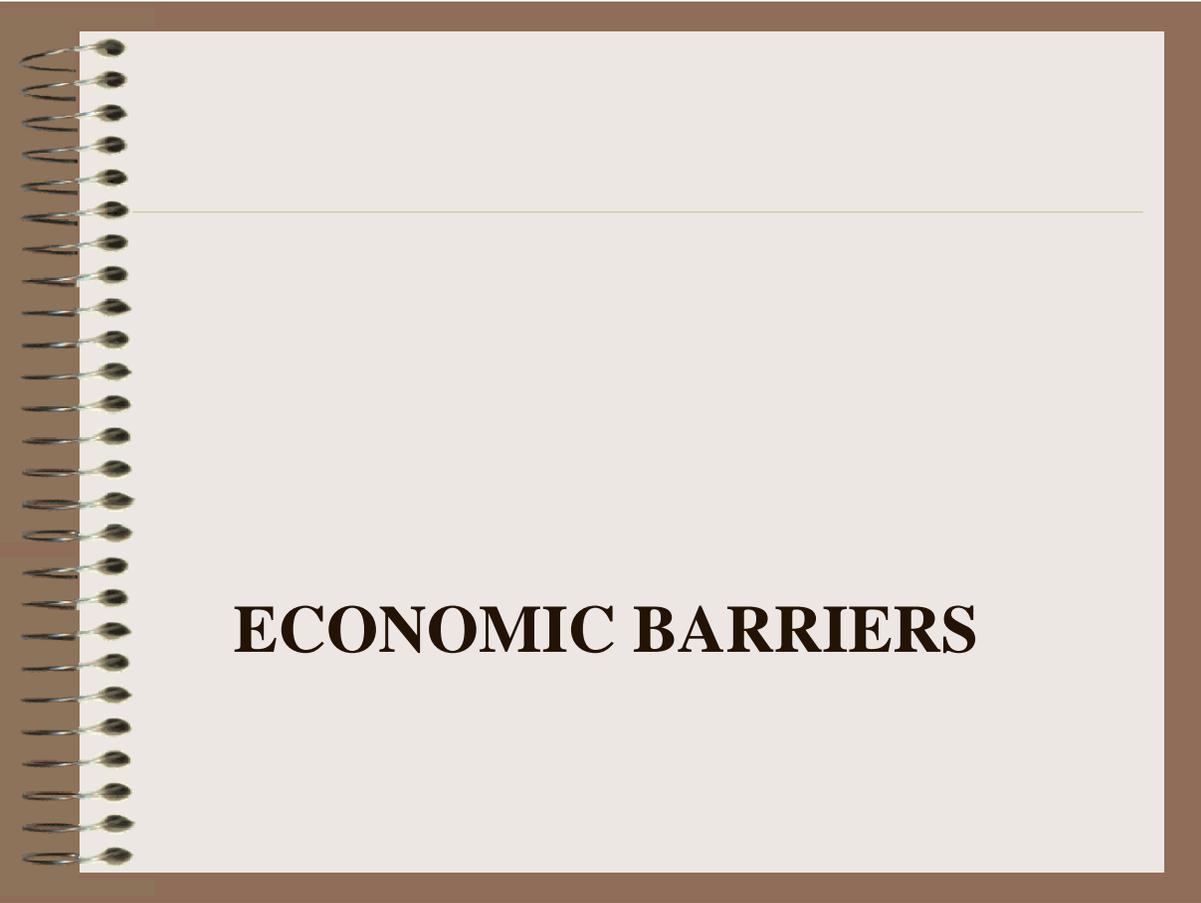
“The microbe is nothing; the terrain is everything” (Pasteur)

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

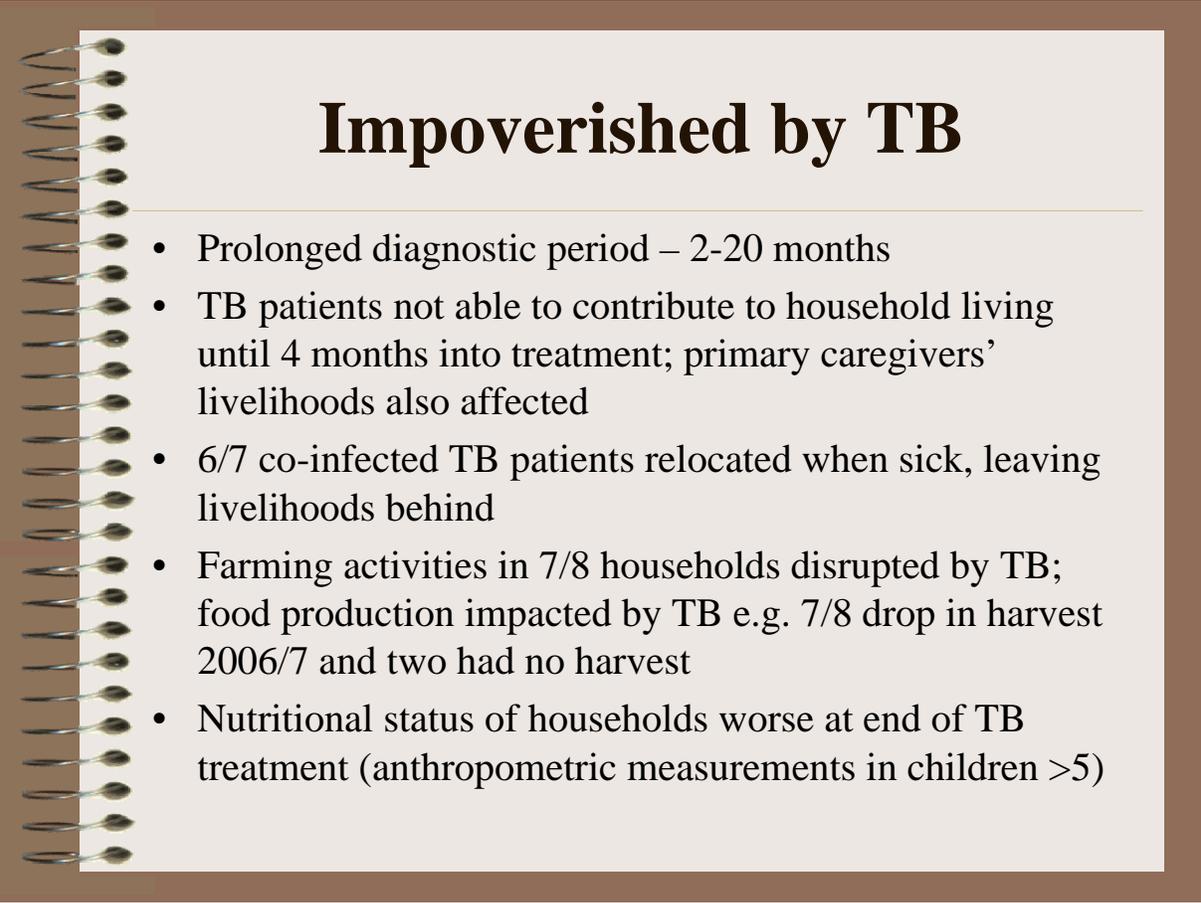
Profile of 9 TB Patients

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



ECONOMIC BARRIERS



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)

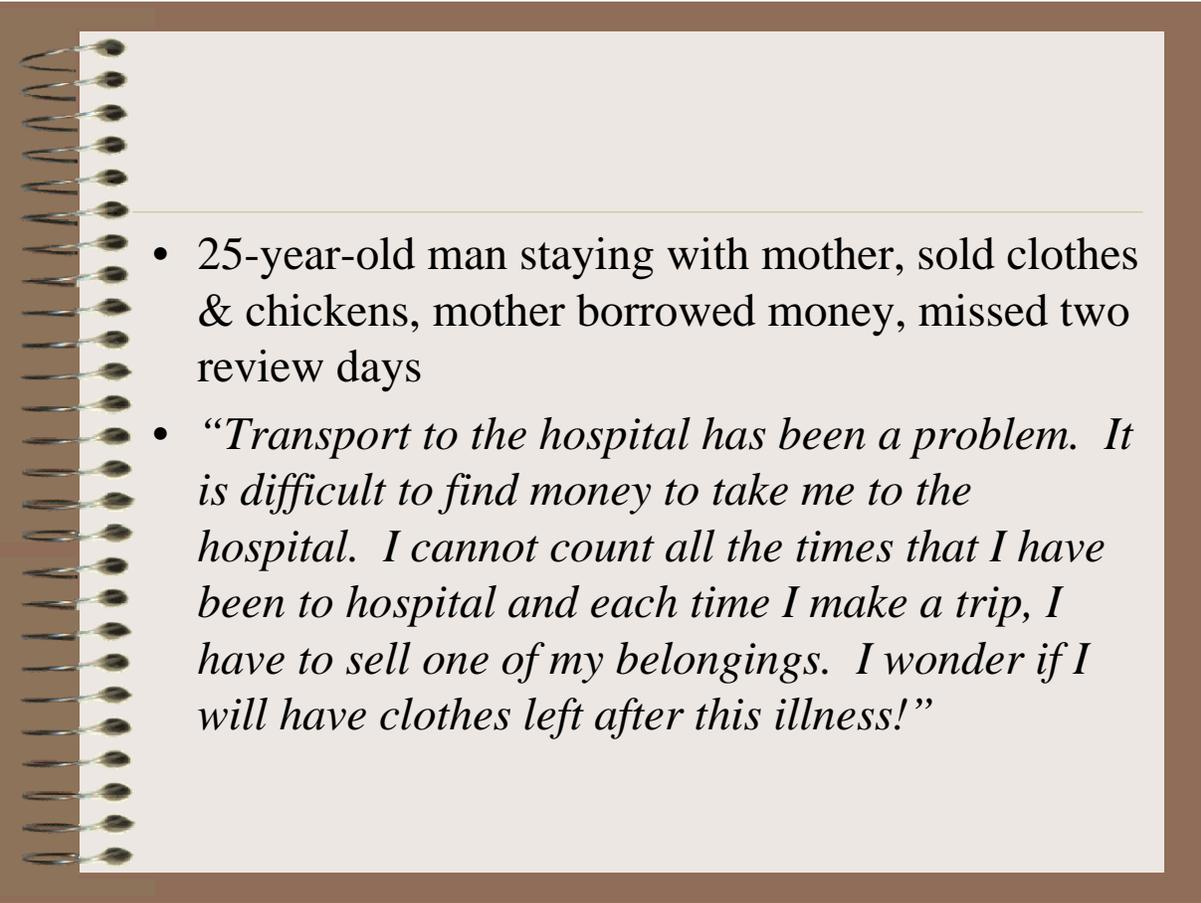
TB patient household field
2006-7

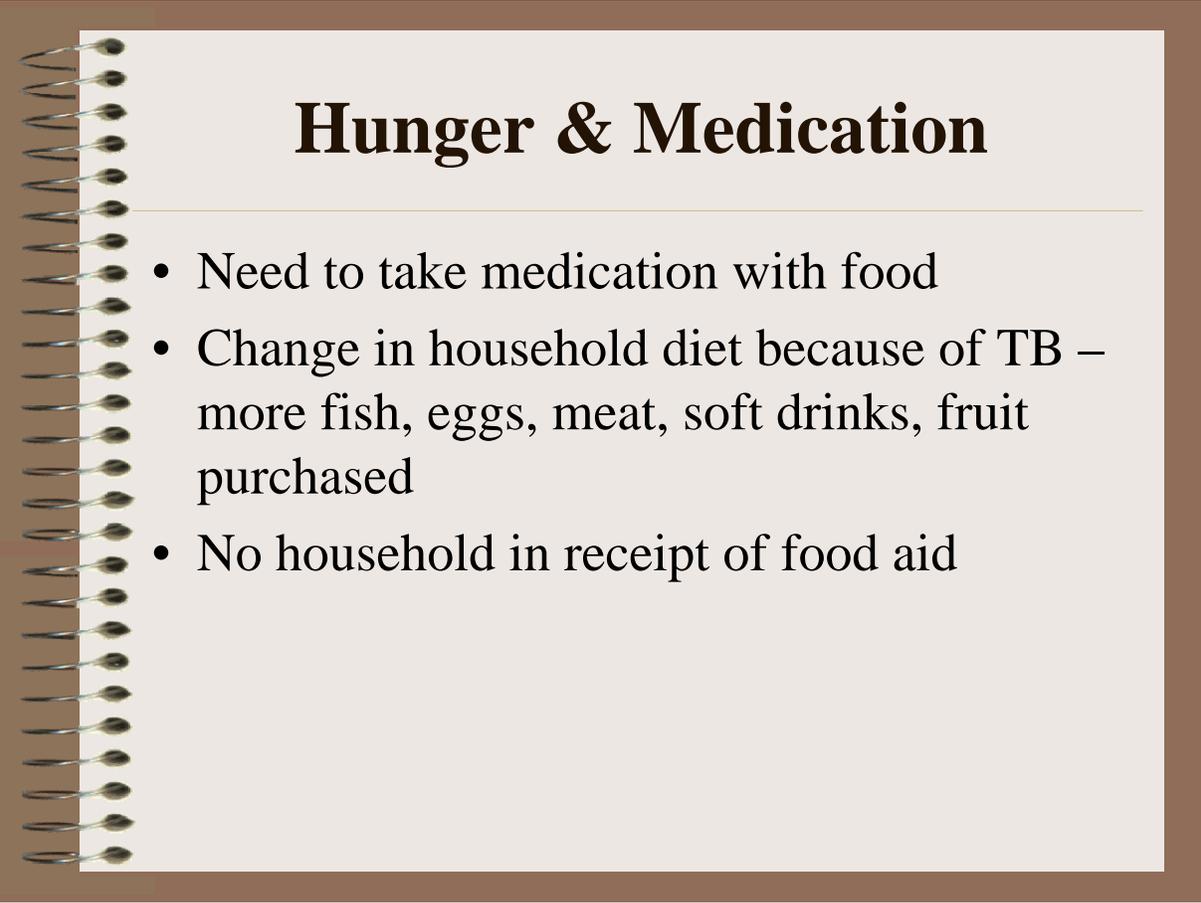
Comparative household field
2006-7



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!”*

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 a section header and three bullet points.

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

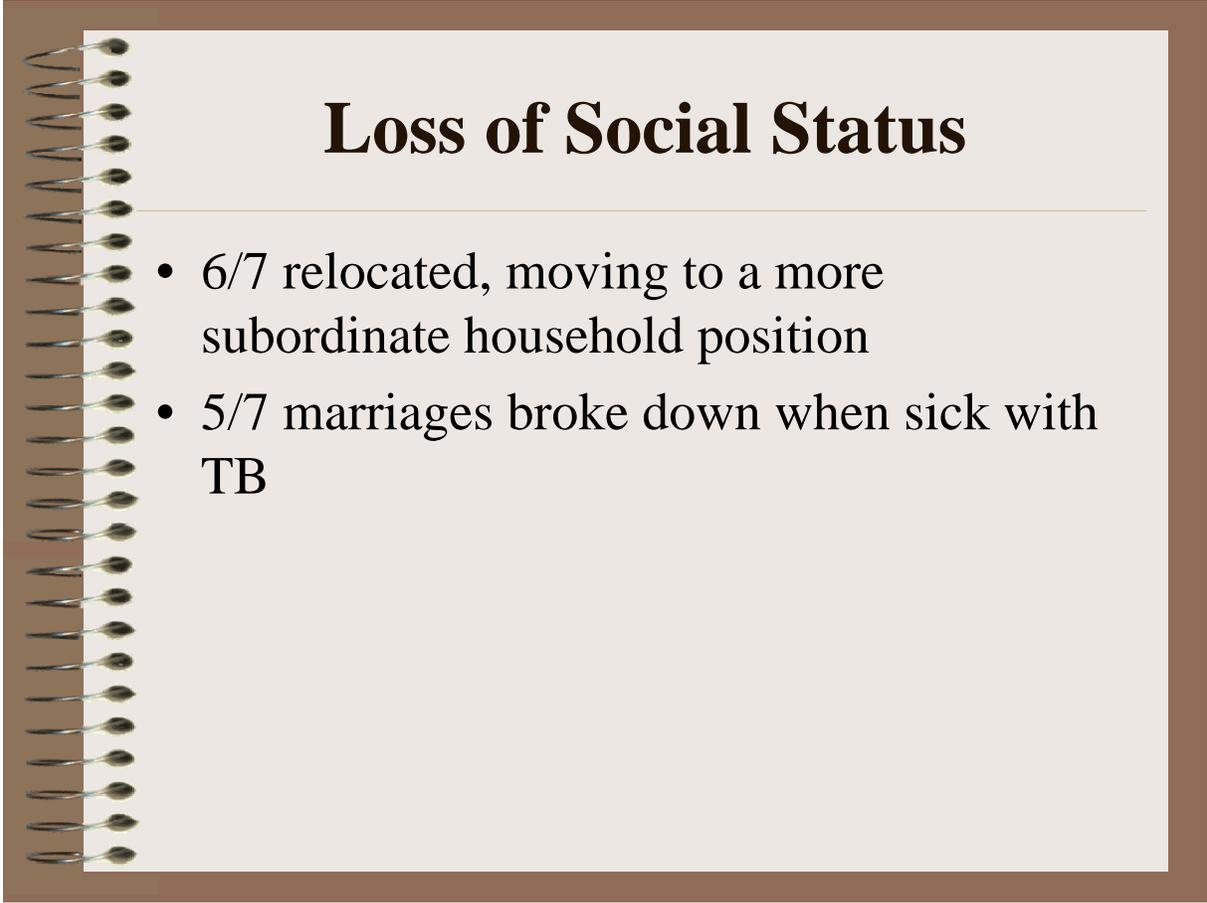
- ART Clinic February: Most clients had not eaten before leaving home and by mid-afternoon were tired and hungry - *“A hungry man is an angry man! I am so hungry and you are taking so long to attend to me – do you want me to get angry?”* [man at ART clinic]
- Needing to eat and take ART a long-term problem:
 - *“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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