



Zambart Project



The Converging Impact of Tuberculosis, HIV/AIDS, and Food Insecurity in Zambia and South Africa

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ACRONYMS

ANC	African National Congress
ART	Antiretroviral Therapy
CAB	Community Advisory Board ¹
CBD	Central Business District
CREATE	Consortium to Respond Effectively to the AIDS TB Epidemic
CWD	Catholic Welfare Development
DCT	Diagnostic Testing and Counselling
DOT	Directly Observed Therapy
DTTC	Besmond Tutu TB Centre
FAO	Food and Agriculture Organization of the United Nations
IFPRI	International Food Policy Research Institute
HBC	Home-Based Care
LWH	Living with HIV
MDR	Multi-drug-resistant
NGO	Nongovernmental organization
NHC	Neighbourhood Health Committee
LSHTM	London School of Hygiene and Tropical Medicine
PLWH	People living with HIV
RDP	Residential Development Plan
SA	South Africa
TB	Tuberculosis
TST	Tuberculin Skin Test
USAID	U.S. Agency for International Development
VCT	Voluntary Testing and Counselling
XDR	Extra-drug-resistant
ZAMBART	Zambia AIDS-Related Tuberculosis Research Project
ZAMSTAR	Zambia and South Africa TB and AIDS Reduction Study
ZAR	South African Rand (currency)

Exchange Rate:

The exchange rate was variable in both Zambia and South Africa during 2006-7, so in this report, an average rate is used:

- US\$1 = 6 South African Rand (ZAR)
- US\$1 = Kwacha 5000

¹ Community Advisory Boards are community groups commonly set up by clinical trials to represent the community participating in the research. Sometimes existing community groups are used, and sometimes new groups created.

ABSTRACT

An anthropological study carried out in 2006/7 in rural Zambia and peri-urban South Africa documented the impact of co-infection with TB and HIV on poor households in the context of poverty and overstretched public health services. The anthropological research was conducted in 18 households affected by TB throughout the period of TB treatment and in 17 comparative non-affected households. Findings reveal that families experience disease alongside desperate social and economic inequities, with more absolute poverty and a deeper degree and prevalence of food insecurity in rural Zambia. Charting patient's journeys from falling sick with TB to completing treatment revealed that most faced a protracted diagnostic period, ping-ponging between treatment options with trips to the government health services the most frequent. Most were extremely sick and emotionally fragile once diagnosed, many had relocated back to their parents' home, and, all were no longer able to contribute to household livelihood. During the first months of TB treatment, patients and caregivers experienced contracted mobility and networks, reduced income and increased expenditure on 'special foods'. Foods prescribed for TB patients were beyond the normal diet of households, especially in rural Zambia. As caregivers did their utmost to provide these foods (soft drinks, meat, eggs, fish, porridge), tensions and food insecurity in the households escalated, often resulting in family quarrels and caregivers themselves falling sick. In peri-urban South Africa, disability grants, food aid from the government health services and chequered food aid and material support from NGOs helped households through this period. But in Zambia, although emotional and technical support reached the households through government health services, a household counselling intervention and visits of church members, no affected household received any food aid or material support from state or NGOs and support from extended kin was very limited. More extreme coping strategies were subsequently adopted—for example selling clothes, begging, relocating—and affected households spun into deeper poverty and by the end of treatment were mostly severely short of food and in nutritional jeopardy. Across both countries, most TB patients were unable to resume previous livelihoods and most (n=13) were co-infected with HIV, throwing them onto another more long term disease trajectory. Accessing antiretroviral therapy (ART) was much more feasible in peri-urban South Africa and much harder in rural Zambia. Stigma related to TB and to HIV was more pronounced in rural Zambia but still persisted in both countries. Outcomes of TB treatment were mixed in both countries. Better outcomes included co-infected patients who started ART and experienced physical and social transformations and HIV-negative TB patients who successfully completed treatment. However, five TB patients died, one fell sick with relapse TB, two co-infected patients never started ART and one patient was not aware of his HIV status and was unwell. In the short term, only one Zambian household and five South African households recovered from the event of TB. Recommendations oscillate around reducing diagnostic delay in government health services and the provision of a comprehensive nutritional programme and social protection for TB patients and people living with HIV (PLWH).

EXECUTIVE SUMMARY

Zambia and South Africa (SA) are two countries that are seriously affected by the dual epidemics of tuberculosis (TB) and HIV. Both are attempting to integrate public TB and HIV services to reach co-infected people. But there is little evidence on how the synergy of co-infection with TB and HIV plays out for affected families in the context of poverty and overstretched public services. An anthropological study carried out in 2006/7 documented the social and economic impact of TB, HIV and food insecurity on poor households in rural Zambia and peri-urban SA. Anthropological research was conducted in 18 households affected by TB throughout the period of TB treatment and in 17 comparative non-affected households.

Wider Context of Vulnerability

Conversations about illness were chequered with exclamations of '*it is hard,*' '*I am suffering,*' '*I have fallen.*' Despite the provision of free treatment for both TB and HIV and increasing access to antiretroviral therapy (ART), findings from both Zambia and South Africa demonstrate that families experience disease alongside desperate social and economic inequities. In SA, inequities are rooted in the legacy of apartheid and in stark urban poverty—characterised by unemployment, disillusionment of youth, pronounced alcohol and drug abuse, violence, crime, xenophobic trends, overcrowding, poor housing, and 'shack' fires. In Zambia, these inequities reflect the growing chasm between rich and poor as well as rural poverty—manifested in poor infrastructure, narrow livelihood opportunities, food insecurity, limited access to health services, and the absence of government welfare support.

The TB Trajectory

Usually accompanied by a family member, it took individuals with TB symptoms between 2 weeks and 10 months to get diagnosed and put on treatment; two women took 18 and 20 months to get diagnosed. By this time, many of them were extremely frail, ill and frightened and emotionally fragile and often eventually admitted into hospital. Relocation back to parents was a feature of the therapeutic search especially in Zambia. In their quest to get well, patients moved between self-treatment, private clinics, government health centres and hospitals, traditional healers and spiritual healers, with visits back and forth to government health centres the most frequent. Inadequate consultations and misdiagnoses of other illnesses by government health services were particularly evident in Zambia. Patient agency was more evident in South African TB patients who were proactive about getting government health services to investigate TB.

This protracted diagnostic search was a catastrophe for both patient health and the household economy. Seeking alternative treatment in both countries and the distances to health services in rural Zambia involved considerable financial outlay; most Zambian households had spent not less than four times their monthly income by the time patients were diagnosed.

Once diagnosed, patient and caregiver mobility was restricted and they were mainly confined to their household often for months. Networks dependent on mobility and health fell away, as did their ability to reciprocate in relationships. The entire

household, especially the caregivers, found their mobility and networks contracted too, and as a consequence, there were fewer people for the household to turn to for financial support.

Affected families both lost the productivity of an adult family member and at the same time needed to muster resources to seek treatment and adequately care for the patient. All TB patients were unable to earn a living for some months; men found this particularly hard. Only seven out of the 19 TB patients were to try to resume their previous livelihoods by the end of TB treatment; most lacked the physical strength or the capital and either remained unemployed or did less taxing work. Caregiver livelihoods were also disrupted further depleting household income.

The farming economy in rural Zambia proved to be especially vulnerable if TB patients were critically sick during the farming season. Half of the affected Zambian households were left severely short of food in the 2006/7 season and household nutritional jeopardy was evident from anthropometric measurements of children under five. Nine of the 10 TB patients in peri-urban South Africa managed to access a disability grant of R870/US\$137 a month which, combined with other welfare grants and other sources of income, was a boost to individual and household income. Often received two to four months into TB treatment, expenditure of the grant was wide ranging.

A culture of TB medication being accompanied by food—TB drugs are perceived as both causing hunger and demanding food intake—threw many affected households into further jeopardy and sharpened desires, food insecurity and tensions. Prescribed by government health staff, and embedded in the need for nourishment during illness, special foods required by TB patients included eggs, fruit, instant porridge, soft drinks, meat, fish and chicken. Such foods were beyond the normal diet of households and although caregivers tried their utmost to provide them, often at the cost of other members and other household needs, patients could not frequently access the food they desired especially in rural Zambia. A change in household diet and increased expenditure on food were more notable in Zambia. And for those patients co-infected with HIV, juggling special nutritional needs over other household requirements stretches indefinitely.

Common strategies to meet additional costs in both countries were asset stripping (in Zambia, livestock and clothes; in South Africa, household goods and cars) and borrowing money and food (from neighbours, relatives, and friends). Additional strategies in rural Zambia were ‘piecemeal’ (casual daily labour), trading, relocating (the patient or children), and begging; and in South Africa, applications to secure a disability grant.

Co-infection with HIV and Access to ART

Out of 19 TB patients, 18 had tested for HIV. Although this would appear to imply that health services in both countries are successfully integrating TB and HIV services, the presence of an intervention to enhance integration in both settings should be noted. Thirteen of 19 TB patients were co-infected with HIV; most (n=8) tested for HIV after being diagnosed with TB, reflecting a trend in both countries that people mostly test only once they are sick. Eleven of the thirteen were on ART by the end of

the study, but four of the co-infected patients died after starting ART. These deaths imply that although TB services are a good entry point for HIV testing, testing at this stage of HIV infection is also too late for too many.

A thread that runs through the journeys of all the TB patients in this study is stigma related to ‘TB/HIV’. Central to the experience of TB, for both patients and their households, is both anticipated and enacted stigma. TB patients all experienced verbal stigma (gossip, name-calling, insults) and social exclusion, particularly when they were physically frail and once they were diagnosed and labelled as TB patients. Rejection was another common form of stigma; five relationships with spouses or partners broke up during TB illness. Overall, stigma related to both TB and HIV was more pronounced in rural Zambia. There were more fears around TB transmission and social and physical exclusion of TB patients was much more evident. Public health messages about isolating TB patients and giving them separate utensils promoted this type of stigma in rural Zambia. The public health approach in peri-urban South Africa did not appear to advocate separation within the household; indeed, caregivers rather brought TB patients into communal space and eating in order to keep a closer eye on them. Disclosure of both TB and HIV was also more limited in rural Zambia compared to peri-urban South Africa where it was wider and apparently safer. Lower levels of TB and HIV stigma in peri-urban South Africa is partly explained by the longer history of TB in Western Cape, more accessible services, HIV advocacy and less absolute poverty. However, it was evident that stigma still persists in both settings.

Accessing ART was much more feasible in peri-urban South Africa due to shorter distances, the disability grant and less absolute poverty, but trips to Eastern Cape and transport costs to ART clinics outside Mbekweni did and could cause interruptions to treatment. Many more hurdles to starting and staying on ART were documented in rural Zambia. These included: denial of HIV infection, lack of support from close kin, distance, transport costs, the minimum of four visits required to start ART, congestion at the clinic, lengthy administrative procedures, shortage of staff and inefficiencies in the health services (losing blood samples, having no power, the CD4 machine² breaking down). In Zambia, it took TB patients in this study on average five visits to start ART; regular reviews were then required.

Presence and Absence of Support

Close matrilineal kin and, once diagnosed, government health services emerged as the most consistent source of support to affected households. Caregiving fell mostly to women—mainly mothers. Indeed, eight TB patients (six in Zambia) migrated back to their mothers when they fell ill. Only one primary caregiver (in SA) was a father, and fathers or brothers were often instrumental in sourcing money and came to the forefront at funerals. Caregivers in both countries were often dealing with TB in the wake of other recent family deaths. By four months of treatment, caregivers were

² CD4 machines are tests that are used to assess the immune system of PLWH. PLWH often start ART when the CD4 count reaches a low point, around 350-200 cells per microliter. Medical professionals also refer to CD4 tests to determine the efficacy of ART.

increasingly strained and tensions mounted between the patient and the caregivers, often resulting in quarrels, verbal insults and/or denial of care. Many caregivers fell sick themselves at this stage. In South Africa, tensions, especially between siblings, would escalate when disability grants were awarded to the TB patient and then ebb once the TB patient had recovered and resumed work or expenditure of the disability grant had been spread across the household.

Once diagnosed, the government health services in both countries provided consistent and compassionate TB services. External support that reached the households during TB illness was confined in rural Zambia to visits by household counsellors (part of a trial intervention) and by church members, whereas in peri-urban South Africa, three households were in receipt of sporadic food parcels and visits from NGOs and all households received welfare support of some kind. It was a travesty that in rural Zambia despite the presence of 14 NGOs working with TB and HIV in the area, none of the affected households were in receipt of food aid or any other form of material support. This absence of support partly reflects a shift in HIV policy from ‘handouts’ to income generation and also indicates the limited reach of volunteers, such as home-based care (HBC) caregivers, in the context of poverty. Kin outside the household in rural Zambia were fragmented and did not extend much material support to the affected households, whereas in peri-urban South Africa extended kin was more consolidated and more supportive. In both countries, people living with HIV (PLWH) support groups were effective in boosting the self-esteem, networks and income generating opportunities of four co-infected patients.

Outcome

Across the two settings and countries there are mixed outcomes. Some outcomes are distressing. Five TB patients died—four of whom were co-infected with HIV. Two died during TB treatment and three after completing TB treatment and whilst on ART. In the three cases of death during fieldwork, the death and funeral of the TB patient incurred astronomical costs; in Zambia, the funeral costs were 16 times higher than the monthly income; in SA, the costs were equivalent to a month’s income but offset by inherited assets and a funeral grant. Two co-infected patients never accessed ART in rural Zambia due to a combination of denial and poverty. And four South African patients were not well by the end of TB treatment—subsequently two were to die and one was to be treated for relapse TB.

Better outcomes were documented for six TB patients co-infected with HIV who started ART and experienced a transformation back to good health which spilled out to new opportunities (resolutions to stop smoking and drinking, PLWH support networks and citizenship) and to rekindle relationships and livelihood opportunities fractured by illness and poverty. This transformation is particularly startling in rural Zambia, but this study was not in a position to determine how sustainable this transformation might be.

Five TB patients who were HIV negative and survived TB treatment resumed livelihoods and slotted back into their established networks with more ease. However, three of the five resumed heavy drinking and smoking, one continued to be unwell and fell sick with relapse TB. The one TB patient whose HIV status was unknown in the study was also not well by the end of TB treatment.

In the short-term, only one household in Zambia and half (n=5) the households in South Africa recover from the event of TB. In the long-term, loss of livelihood, and the wider context of rural and peri-urban poverty and, in South Africa, the disillusionment of youth cast shadows over the future of these households too.

Conclusion and Recommendations

The study demonstrates that all affected households are adversely impacted by the event of TB in an adult member in short term, especially if the TB patient has a pivotal role in the household and if the household is anyway poor or very poor. In Zambia, with very few buffers, the effects were more long term and the majority of households had fallen deeper into poverty and were in debt and short on food by the end of TB treatment. For co-infected TB patients and their families, the issues of livelihood and food requirements stretch indefinitely. In South Africa, affected households were kept buoyant by the disability grant and other welfare initiatives, but in the long term most were unable to resume their previous livelihoods.

This research recommends that, in the context of poverty, food aid and transport costs or disability grants are made available to TB patients and PLWH on ART by the state and that NGOs are better co-ordinated through government health services. The effectiveness of the disability grant in SA in buffering absolute poverty speaks to the need for similar social protection during TB treatment in Zambia and other countries. In addition, more prompt diagnosis of TB by government health services; a more substantial nutritional programme for TB patients; more effective integration and co-ordination of voluntary testing and counselling (VCT), TB and HIV services at community level; more access to counselling at a household level; and more targeted anti-stigma education for TB are recommended for both countries. Further recommendations specific to Zambia are that ART services in rural areas are rolled out to more peripheral centres and are made more efficient. And specific to South Africa, we recommend that disability grants are paid more promptly.

INTRODUCTION

Zambia and South Africa are two countries that are seriously affected by the dual epidemics of tuberculosis (TB) and HIV. In 2005, the WHO Regional Committee for Africa declared TB as an emergency in Africa, explicitly linking the rise in TB cases and mortality in Africa to HIV/AIDS, poverty, and weak health systems (WHO 2005). An anthropological study carried out in 2006/7 documented the converging impact of TB, HIV, and food insecurity on poor households in rural Zambia (Southern Province) and peri-urban South Africa (Paarl District).³ This study was one of a group of studies funded by the Regional Network on HIV/AIDS, Rural Livelihoods, and Food Security (RENEWAL, International Food Policy Research Institute). Combined, the studies aim to generate priorities for research and action on HIV/AIDS and food security, and strengthen in-country capacity to respond to the epidemic. The grant for this study was awarded to the Zambia AIDS-Related Tuberculosis Research (ZAMBART) Project,⁴ who subcontracted the Desmond Tutu TB Centre (DTTC), University of Stellenbosch, to carry out the research in Western Cape.

The aim of this comparative study was to explore, for a small number of poor households, how individuals and their households experience and respond to TB alongside high HIV prevalence and food insecurity, and in the context of the re-emerging phenomena of TB and widening access to antiretroviral treatment (ART). Focusing on how the event of TB unfolds within a household—and within two very different socioeconomic contexts—this report charts the journeys of 19 TB patients and their households from the onset of symptoms to the end of the period of TB treatment. The significance of the study is to provide evidence on how co-infection with TB and HIV affects households in the context of poverty and overstretched public health services. Given the current trend of rising food prices, early evidence that food insecurity threatens ART programmes (*PlusNews* 19 August 2008) and the scale of the dual TB and HIV epidemics in Sub-Saharan Africa, this evidence is critical.

BACKGROUND

‘The microbe is nothing; the terrain is everything’

(Pasteur, quoted in Farmer 2001, p. 37)

As pinpointed by Louis Pasteur, any advances made in understanding the mycobacterium tuberculosis are limited unless more is also understood about the “terrain” or wider context of TB. As early as the 1960s, Dubois argued that the

³ Virginia Bond, a social anthropologist, is the principal investigator for the study and wrote the grant proposal, with support from Wendy Fisher (ZAMBART) and Emma Murray (DTTC). Two women social science graduates - Mutale Chileshe and Busisiwe Magazi – from Zambia and South Africa, carried out the fieldwork and used the research data to successfully do M.Phils (by research) in Social Anthropology at the University of Cape Town. Bond supervised their work throughout, assisted by colleagues at the Social Anthropology Department, University of Cape Town. Their UCT supervisor, Susan Levine, in particular, gave considerable support to the direction of their M.Phil dissertations, as well as guiding Magazi in her methodological approach. Chileshe and Magazi have independently analysed and written up their research; Bond, with support from Clare Sullivan (Communications Officer, TARGETS Consortium, with a masters degree in Anthropology and Development from the University of London), took a lead in the comparative analysis and writing this report.

⁴ Project No. 2006X031.UTH.

existence of TB in industrialised nations was a reflection of social disadvantage, proposing that TB was also a “social disease” and to understand it “demands that the impact of social and economic factors on the individual be considered as much as the mechanism by which tubercle bacilli cause damage to the human body” (Dubois, quoted in Farmer 1997, p. 348). Thomas McKeon’s historical analysis demonstrated that the decline of TB and other infectious diseases in urban cities in Britain between 1840 and 1960 was mainly due to improvements in living conditions (better housing, sanitation, nutrition, and safe water), rather than advancements in treatment or the isolation of infected people in sanatoria (Mosley 2004). In the early 21st century, Farmer wryly commented, “In this century, at least, tuberculosis has not really emerged so much as re-emerged from the ranks of the poor. One place for disease like tuberculosis to ‘hide’ is among poor people, especially when the poor are socially and medically segregated from those whose deaths might be considered more significant. Who are these throwaway people?” (Farmer 1997, 2001:187). The association between TB and poverty globally is well established; 17 of the 22 countries accounting for 80% of the world’s TB burden are classified as low income, and 98% of the 2 million annual deaths from TB and 95% of the new cases occur in developing countries (WHO 2005). With the high levels of poverty in Zambia and the epidemiological evidence in South Africa that the burden of disease falls heavily on the black population (Myer, Ehrlich, and Susser 2004), both countries demand more understanding of the social impact of TB.

The Dual Epidemics—TB and HIV

In countries with high HIV prevalence, TB has re-emerged as an epidemic. In Zambia and South Africa, between 55% and 70% of TB patients are living with HIV (see Table 1). TB is harder to diagnose in people living with HIV (PLWH). TB is more likely to be disseminated in the body of someone living with HIV and most PLWH have sputum negative TB. PLWH are also more likely to have other chest problems that show up in an X-ray, which further complicates diagnosis (Godfrey-Faussett and Ayles 2003).

Both countries are attempting to integrate public TB and HIV services to reach co-infected people, particularly given the increasing availability of Antiretroviral Treatment (ART) and the opportunity to use TB diagnosis as an entry point for HIV services. A commitment to roll out ART and provide this treatment free in the public sector had been made in 2003 by the South African government and in 2005 by the Zambian government.

Government TB and HIV Services in Mbekweni and Pemba/Batoka

In both Zambia and South Africa, government-run TB services are free of charge and include the outpatient department (where suspect TB patients are initially seen by a clinician or nurse) and a designated space for diagnosed TB patients. In Zambia, this is referred to as a “TB corner” and is usually outside in a converted garage or in a separate room. In South Africa, the “TB clinic” is in a designated room. In both countries, suspect TB patients are asked to submit sputum (two samples in South Africa, three in Zambia). TB treatment regimens differ in both countries: in Zambia, an eight-month regimen is followed and in South Africa, a six-month regimen is

followed. In both countries, this designated TB space (overseen by a nurse) is where the TB register is kept, TB notifications are made, and where TB patients go to be

Table 1: Comparison of the settings—Mbekweni and Pemba/Batoka

Site	Location and housing	Population	Poverty indices	Government TB services	TB and HIV statistics
Mbekweni , Paarl Health District, Western Cape, SA	Peri-urban, satellite to Paarl (a peri-urban town), 60 km east of Cape Town CBD.	32,000 - predominantly Black African isiXhosa-speaking community; average age 26 to 28 years, active and strong ties to rural Eastern Cape	Low average income per household per year – ZAR 5,505 – ZAR16, 158 compared to provincial average of ZAR 76,000. 48.5% of SA population below national poverty line. Malnutrition trends in children under five and poverty gap ratio increasing. Income poverty increasing (Ohiorhenuan 2003).	Two primary health centres: Mbekweni and Phola Park. Mbekweni larger and older. Both have TB clinics, VCT centres, ART clinics. Refer patients to Paarl East Hospital, 10 km away. Mbekweni patient load: 300 @ day. Phola Park patient load: 100 @ day. Mbekweni staff = 17 (1 doctor, 7 nurses, 3 medical assistants, 1 pharmacist, 1 counsellor, 2 administrative clerks, 2 cleaners). Additional ZAMSTAR staff 2006-2009 = 1. Treatment supporters. Phola Park staff = 8 (1 doctor, 4 nurses, 1 counsellor, 1 administrative clerk, 1 cleaner). Additional ZAMSTAR staff 2006-2009 = 1. Treatment supporters.	TB case-notification: 1,359/100,000 (Paarl District Department of Health 2006) HIV Prevalence: 15% (Western Cape Department of Health 2006) 61% of TB patients co-infected with HIV (WHO 2005) August-December 2006: 281 TB notifications in Mbekweni
Pemba/Batoka , Choma District, Southern Province, Zambia	Predominantly a rural area with villages (mud brick and thatched houses) with two small townships (Pemba and Batoka), 20 km apart, on line of rail and main road	65,000 - mainly Tonga, scattered population with traditional leadership (headmen, chief); ties to Gwembe Valley and plateau; migration pattern to plateau.	40% of population extremely poor, 23% moderately poor, and 37% non poor (CSO 2004). Meals often reduced and quality poor – 8% of households have 1 meal a day, 37% have 2 meals (LCMS 2003). Nutritional status of children under five: 49% stunting (height-for-age), 4% wasting (weight-for-height), and 24% underweight (weight-for-age) (ZDHS 2001/2)	Four primary health centres – Pemba, Batoka, Kasiya, and Muzoka. Pemba is a TB diagnostic and VCT centre and the biggest health centre. Refers patients to hospitals 40 or 60 km away. Patient Load: 100 patients @ day. Staff = 11 (1 clinical officer, 8 nurses, 1 laboratory technician, 1 environmental officer). 2 additional nurses and 2 lay counsellors based there 2006-2009 for ZAMSTAR. 20 TB treatment supporters and Neighbourhood Health Committee. Pemba became ART delivery centre in July 2007.	TB case-notification: 550/100,000 (MoH 2006) HIV prevalence: 18% (NAC 2004) 56% of TB patients co-infected with HIV (WHO 2005) August-December 2006: 21 TB notifications in Pemba/Batoka

weighed, reviewed, and receive treatment. Directly Observed Therapy (DOT) is carried out in the first two months of treatment for those patients who live close by; volunteers (treatment supporters) and home-based care (HBC) caregivers in many communities are relied on to give some treatment support to TB patients who live too far from the clinic or are too sick to reach the clinic, but in reality, this support is often inconsistent and varies. In both countries, TB patients should be referred for voluntary counselling and testing (VCT) or undergo VCT within the TB clinic or corner. They should then be referred to the ART clinic. In Zambia, changes were made to the TB register in 2006, adding two columns to reflect if the TB patients have been referred for VCT and whether the patients are started on ART. Some nurses at Pemba/Batoka said they would hold off discussing HIV with a TB patient if they were too sick or depressed. Since mid-2007, Zambia has adopted a diagnostic testing and counselling (DCT) policy with TB patients; this means that TB patients are told they will be tested for HIV unless they wish to “opt out.” Some nurse-counsellors in Pemba/Batoka appeared uncomfortable with this DCT policy.

In South Africa, part of the TB services is the process of applying for a disability grant. Any TB patient who has started TB treatment may apply for a state disability grant. The award of the grant is made subject to individual review of the application. The doctor from the local clinic needs to supply relevant information about the patient and a state doctor from the provincial administration reviews the application. A final decision is made by social services. The grant is only awarded for the length of time a patient is on treatment. Other chronic health problems can also qualify people for disability grants, including HIV, arthritis, and high blood pressure. An individual would not receive two disability grants. In Mbekweni clinics, on Tuesdays, people get a chance to apply for disability grants, after the doctor’s recommendation. People collect application forms from the local community hall where the Department of Social Welfare satellite office is housed and a representative from the department helps assist people to fill in forms in the clinics.

METHODOLOGY

Intervention

This study was carried out within the framework of a community-randomised trial. The Zambia and South Africa Tuberculosis and AIDS Reduction Study (ZAMSTAR) is a seven-year trial (2004 to 2011) that aims to measure the effectiveness of three different approaches to reduce TB in poor communities with high HIV prevalence, working within government health systems.⁵

Two sites were selected from 16 ZAMSTAR sites in Zambia and 8 ZAMSTAR sites in Western Cape, South Africa. One rural site in Zambia was selected—namely Pemba-Batoka in Choma District, Southern Province—and one peri-urban site in Western Cape with strong ties to Eastern Cape—namely Mbekweni in Paarl District, Western Cape.

⁵ The study is being carried out by the ZAMBART Project, the London School of Hygiene and Tropical Medicine, and the Desmond Tutu TB Centre, University of Stellenbosch, with support from John Hopkins, under the Consortium to Respond Effectively to the AIDS TB Epidemic (CREATE).

Different interventions had been randomly allocated to each site by ZAMSTAR in 2006. Pemba/Batoka had been allocated two interventions—namely optimising the integration of TB and HIV services at the clinic level and household counselling (see Sismanidis et al. 2008). Mbekweni had been allocated one intervention—optimising the integration of TB and HIV services at clinic level. A team based within the government health district offices carries out these interventions and associated research activities. The local ZAMSTAR teams housed both women researchers in this study.

Study Design

Conducting this study within a number of trial sites was a co-funding arrangement that provided an opportunity to both build research capacity of host countries and conduct more in-depth social science research. Previous social science research in the trial had consisted of rapid, broad-brush-surveys of all 24 sites (16 in Zambia and 8 in Western Cape) and, in six sites, focus group discussions (with HBC caregivers, traditional healers, school children, formal health providers) and individual interviews with TB patients. RENEWAL was an opportunity to both conduct ethnography in two sites and to build the capacity of African social scientists. The study adopted an anthropological approach, with a focus on case studies of households affected by TB throughout the period of TB treatment as well as case studies of comparative non-affected households. In anthropology, the validity of the case-study approach lies not in representation but with an in-depth analysis of events coupled with a rigorous enquiry in a small number of carefully selected cases that exposes features of the system as a whole (Mitchell 1983).

This study focuses on households as opposed to families. Although all households in the study were made up of close kin, the study did not set out to capture in any detail linkages with the wider kin—a “cluster” approach would have captured more about the family as a whole and would be an interesting approach for future research of this type (see Peters, Kambewa, and Walker 2007; Samuels, Drinkwater, and McEwan 2006). The methods used are presented in Table 2, which shows the methods in the sequence that they were carried out.

Ethical Clearance

Ethical clearance was obtained for the study from the University of Zambia’s Ethics Committee and from the University of Stellenbosch’s Ethics Committee. Written informed consent was obtained from all study participants. All names in any charts or figures are pseudonyms.

Recruitment

The households affected by TB were identified through government clinics; newly diagnosed TB patients and their households were approached by researchers and asked if they would participate in the study. Newly diagnosed TB patients are defined as TB patients diagnosed and on treatment for between two weeks and one month. Comparative households were selected on the basis of close proximity, wealth group (equivalent to the affected households), and agreement to participate. In rural Zambia, affected households helped identify comparative households, since they were

Table 2: Sequence of methods

Methods	Research Questions	Participants	Time Frame
Discussion with CAB	Community Entry – introducing study	CAB members	August/September 2006
Focus Group Discussions	Current Food Economy (availability, affordability, accessibility); changes in food economy over time; food particular for people with TB; seasonal variations in income sources, expenditure, employment opportunities, cash activities, morbidity and mortality; wealth ranking of community	Zambia: Elderly women and men; 3 NHC groups; HBC SA: 3 women’s sewing groups ; Peace Committee; Garden Project	September – November 2006
Market Observations	Food availability, pricing, quantity, purchase	Zambia: 2 markets (Pemba and Batoka) SA: Local supermarkets and fruit & vegetables stalls	Zambia: Nov 2006 - April 2007 SA: Nov- December 2006
Semi-structured Household Questionnaire	Kinship composition, mobility and migration links with urban and rural places, sources of income, external assistance, assets, expenditure, deployment of resources in response to food insecurity in households affected by HIV and TB. Over 6-8 months, changes in income and expenditure, livelihood activities & mobility patterns, any events of significance	Head of Household & Key Woman Zambia: 8 TB patient households and 7 comparative households. SA: 10 TB patient households and 10 comparative households	At least four interviews over 6-8 months; first interview most intensive, subsequent interviews shorter
Anthropometric Measurements	Height, weight and mid upper arm circumference of children aged 12 to 59 months	All 35 households (Zambia x 15, South Africa x 20)	Zambia: Twice, 8 months apart SA: Once, at first contact
Semi-structured Individual Interviews	Direct and indirect costs of caring for TB patient; food desires, requirements & prohibitions; other needs during illness; forms of external support; access to and experiences with TB and HIV medication; social networks that provided support during TB; mobility; patient recovery; plans for the future; death and funeral.	TB patient Households x18: Key woman, Primary Caregiver, TB patient, Head of Household Comparative Households x 17: Key woman, Head of Household	At least four interviews – close to diagnosis, at 2 months, at 4/6 months and at 6/8 months. Usually many more visits made.
Field Diary & Participant Observation	Observations and conversations outside interviews or instead of interviews	The Community	Throughout 10 months of fieldwork

anxious for researchers to select households whom they were on good terms with. In urban South Africa, this strategy did not work since households were often not familiar with one another, so the local research assistant used her knowledge of the area to approach nearby households in the same section and/or street. In both countries, it was harder to recruit comparative households who could not always understand the point of their involvement or were reluctant to be associated with a study of TB and HIV.

Although the response rate among affected households was good (only two households in South Africa and one household in Zambia of those approached did not wish to take part in the study), recruitment was held back by the ZAMSTAR interventions and research activities in both sites, but in particular in Pemba. If the TB patient died, visits were made to the bereaved households at least twice after the death in order to establish events leading up to the death, details of the funeral, and adjustments—emotional, practical and financial—in the households after the death. Chileshe and her research assistant attended one funeral; it was not possible to attend the others due to them both being held some distance from the field site.

Study Participants

Nineteen TB patients were recruited from 18 households (10 in South Africa and 8 in Zambia—one household in Zambia had two TB patients; see Tables 3 and 4 for the affected households in South Africa and Zambia). Seventeen comparative households were recruited: 7 in Zambia and 10 in South Africa.

Table 3: Profile of affected households in Zambia

	TB Patient Profile	HH members	HH Composition	SES	Wealth Ranking, Area & Food Security
HH 1A	30-year-old man	8	Hoh Widow 53 yrs (LWH not on ART) Son 30 yrs (TB patient) Wife 22 yrs (HIV-negative) Daughter of patient 3 yrs Daughter of patient 6 months Daughter of hoh 14 yrs Granddaughter of hoh 7 yrs Grandson of hoh 4 yrs	Owens two burnt brick & thatched houses & outside kitchen in family compound Patient used to work on ranch & help M with goat business but broke arm & lost job Hoh trades in wild foods, second-hand-clothes, goats, but businesses curbed by own illness & care of patient Small farming on dry fields & in garden Wife to patient sells vegetables by roadside	Poor Village – 6 km from Township; 1 km from main road Food insecure
HH 2A	54-year-old man	18	Hoh 72 yrs (woman) Son 54 yrs (TB patient) 8 Grandsons (28, 26, 21, 13, 10, 5, 2, 1 yrs) Son 38 yrs Daughter-in-law 31 yrs 6 Granddaughters (33, 15, 15, 13, 13, 3 months)	Owens large family compound – one big and five tiny burnt brick & thatched houses. Two outside kitchens in family compound. Patient owns burnt brick & thatched house in township Patient mechanic at local garage but stopped working when sick Small farming on dry fields Other adult children & grandchildren involved in: bicycle repairing, photography, trading in vegetables	Poor Village – 11 km from main road, but small clinic 5 km away Food insecure TB patient relocated
HH 3A	25-year-old woman AND 38-year-old man	14	Hoh male 70 yrs Wife 57 yrs Daughter 11 yrs Daughter 11 yrs Daughter 25 yrs (TB patient) Stepson 38 yrs (TB patient) Daughter 30 yrs Daughter 27 yrs 3 Grandsons (10 yrs, 9 yrs, 8 yrs) 3 Granddaughters (8 yrs, 6 yrs, 3 yrs)	Owens 5 burnt brick & thatched houses & outside kitchen in family compound Hoh retired & pensioned teacher Small farming on dry fields Trading in drums & ropes & grass (used for thatching) Female patient used to work as community teacher, then at a guesthouse in town before sick Man patient used to work as a groom in town before sick	Poor Village – 8 km from main road Food insecure Both TB patients relocated
HH 4A	25-year-old man	9	Hoh divorced 54 yrs (woman) Son 25 yrs (TB patient) Wife of patient 27 yrs Son of patient 9 months Son of hoh 18 yrs Son of hoh 15 yrs Son of hoh 13 yrs 2 Grandsons (both 18 yrs)	Owens 1 burnt brick & thatched house & outside kitchen. No grain bin. Hoh petty trader at market & small farmer & does piecework Patient used to sell videotapes in town before sick One adult son sells tomatoes at roadside	Very poor Township – 1 km from the main road and the market. Food insecure TB patient relocated

(continued)

Table 3 (continued)

	TB Patient Profile	HH members	HH Composition	SES	Wealth Ranking, Area & Food Security
HH 5A	30-year-old woman	7	Hoh 34 yrs m First Wife 32 yrs Second Wife 30 yrs (TB patient) Son 14 yrs Son 11 yrs Daughter 4 yrs Son 1 yr	Owens two burnt brick houses (1 thatched, 1 with iron roofing sheets) & outside kitchen Hoh runs beer business, small farmer & does piecework First wife does piecework Second wife used to work at bar before sick	Poor Village: on main road, 3 km from township Food insecure
HH 6A	21-year-old woman	11	Hoh 63 yrs divorced Sister 70 yrs Niece 35 yrs Daughter 29 yrs Niece 21 yrs (TB patient) Nephew 32 yrs Grandson 9 yrs Granddaughter 4 yrs Great granddaughter 3 yrs Grandson 1 yr Grandson 4 months	Owens three burnt brick & thatched houses & outside kitchen Hoh small farmer & makes baskets 3 other adult children & grandchildren do piecework & one sister makes baskets	Poor Village – 8 km from main road Food insecure TB patient relocated
HH 7A	41-year-old man Head of Household	9	Hoh 41 yrs (TB patient) Wife 36 yrs Brother in law 42 yrs Son 18 yrs Daughter 15yrs Son 13 yrs Daughter 6 yrs Son 4 yrs Daughter 1 yr	Owens 3 burnt brick houses (2 thatched, 1 has iron roofing sheets) & outside kitchen Patient a builder Wife small farmer Brother-in-law does piecework	Poor Village: 7 km from main road Food insecure
HH 8A	55-year-old woman	8	Hoh 55 f (TB patient, widow) Daughter 36 yrs Son 31 yrs Daughter 29 yrs Son 22 yrs Son 12 yrs Granddaughter 4 yrs Granddaughter 2 months	Owens 2 burnt brick & thatched houses & outside kitchen Hoh small farming before sick One adult daughter does piecework and selling at the market; the others are dependents due to handicap (night blindness & dumb)	Very poor Village: 9 km from main road Food insecure

Notes: HH = household; yrs = years; hoh = head of household; SES = Social Economic Status

Table 4: Profile of affected households in South Africa

	TB Patient Profile	HH members	HH Composition	SES	Wealth Ranking, Section & Food Security
HH 1A	46-year-old woman Head of Household (Hoh)	5	Hoh 46 yrs (TB patient) Brother 57 yrs (recently had TB) Daughter 27 yrs Daughter 10 yrs Grandson 7 yrs	Received land restitution No employment. Earns money from shack rental, craft work for PLWH Patient received disability grant for HIV + status since 2002 Brother received disability grant for TB, piece meal jobs Lives in own row house	Better Off Well off area Food Secure
HH 2A	31-year-old woman	5	Hoh 51 yrs (woman) Daughter 31 yrs (TB patient) Daughter Granddaughter 12 yrs Granddaughter 9 yrs (Daughters of the patient)	Hoh works full time at a fast food restaurant Patient receives child support for 2 children, stopped work after TB & received a disability grant Live in rented shack	Poor Mixed area: poor & well off Food Insecure
HH 3A	24-year-old man	4	Hoh 33 yrs (woman) separated from husband Brother 23 yrs (TB patient) Daughter 13 yrs Daughter 4 yrs	Hoh full-time domestic worker and receives child support for 2 children Earns money from shack rental Patient received disability grant (stopped farm work after TB) Live in own RDP house	Poor Poor area Food insecure
HH 4A	36-year-old man	3	Hoh 40 yrs (woman) Partner 36 yrs (TB patient) Girlfriend's son 18 yrs	Patient self-employed repairing cars, TVs & radios and receives disability grant Partner farm seasonal work Live in partner's RDP house	Poor Poor area Food insecure
HH 5A	Hoh 61-year-old man	2	61 yrs (TB patient) Partner 55 yrs (woman)	Lives in shack No employment Patient receives disability grant Patients sells & grows traditional herbs Partner collects rubbish	Poor Poor area Food secure
HH 6A	50-year-old man	11	Hoh 74 yrs (woman) Son 50 yrs (TB patient) Daughter 39 yrs Daughter 35 yrs Son 37 yrs Daughter 31 yrs Granddaughter 20 yrs 4 Grandsons (16 yrs, 14 yrs, 5 yrs, 2 months)	Received land restitution in 2005 Hoh received old-age grant 2 daughters do farm seasonal work Son receives disability grant (psychiatric problems) 2 children receive child support Earns money from shack rental Patient did seasonal farm work but stopped after TB Patient did not receive disability grant Live in own row house	Poor Mixed area: poor & well off Food insecure
					(continued)

	TB Patient Profile	HH members	HH Composition	SES	Wealth Ranking, Section & Food Security
HH 7A	39-year-old woman	8	Hoh 83 yrs widower (died during fieldwork) Daughter 39 yrs (TB patient) Granddaughter 29 yrs Granddaughter 8 yrs 3 Grandsons (18 yrs, 14 yrs, 4 yrs) 3 Granddaughters (29 yrs, 12 yrs, 8 yrs)	Received land restitution No employment Hoh received old-age grant 3 children receive child support grant Partner to patient gives financial support Earn money from shack rental Lives in own row house	Poor Mixed area: poor & well off Food insecure
HH 8A	50-year-old man	7	Hoh 56 yrs (man) Wife 43 yrs Brother 50 yrs (TB patient) Daughter 22 yrs Son 19 yrs Daughter 13 yrs Son 13 yrs	Hoh in full-time employment (for Municipality) Wife does seasonal farm work Daughter work in a pharmacy Patient works in construction before TB, died in process of applying for disability grant House in Eastern Cape Family dwelling, in process of building own house	Better off Mixed area: poor & well off Food secure
HH 9A	30-year-old man	7	Hoh 58 yrs (man) Son 30 yrs (TB patient) Son 22 yrs Daughter 25 yrs Nephew 40 yrs Daughter 10 yrs Granddaughter 6 yrs	Hoh in full-time employment in construction Patient employed (general worker) & receives disability grant House in Eastern Cape Live in former hostels: will get own family unit	Better off Housing becoming better off Food secure
HH 10	32-year-old woman	8	Hoh 66 yrs (man) Wife 71 yrs Daughter 32 yrs Daughter 36 yrs 2 Granddaughters (11 yrs, 10 yrs) 3 Grandsons (15 yrs, 9 yrs, 7 yrs)	No full-time employment Hoh and wife receive old-age grants 4 children receive child support Wife and daughter do seasonal work Patient used to do seasonal work & received disability grant House in Eastern Cape Live in own RDP house	Poor Poor area Food insecure

Study Settings (see Table 1)

Pemba/Batoka, Choma District, Southern Province

Pemba/Batoka is predominantly a rural area, strung along the plateau in Choma District, Southern Province, along the line of rail and a main road leading to Livingstone in the south and Kafue town in the east (Figure 1). Pemba/Batoka residents live mainly in scattered villages. Pemba and Batoka are the names of two small townships on the main road, which lie about 20 km apart.

Pemba township feels like a ‘has been’ place, with rows of old buildings, half of them seemingly deserted, a few dark shops, guesthouses and churches, a police station, a primary school, and a government clinic and secondary school. Batoka is less formal and more spread out—with most activity focused on a roadside market and an informal settlement called ‘Cars’ near the railway and a road junction. It also has a primary school and a clinic near the road. There are two other small health centres—one lying between Batoka and Pemba (Muzoka) and one lying 11 km to the north-west of Pemba (Kasiya). Housing in these small townships is a mixture of concrete houses with tin roofs, and mud, brick, and thatched houses. In the villages, people reside in mostly mud, brick, and thatched houses with family groups in compounds consisting of a cluster of huts, an outside kitchen, a maize barn, groundnut granaries, chicken houses, and (for better-off houses) goat and cattle kraals.

The population of roughly 65,000 is relatively homogenous and mostly Tonga—an ethnic group who have resided in Southern Province at least since Livingstone first trekked through there in 1853 (Colson 1958a:7). Chiefs and headmen maintain some control over the allocation of customary land. There was a brief period of prosperity from the late 1940s to early 1970s based on agricultural⁶ and educational development, and improved access to transport and markets. Since the late 1970s, social disorder and fragmentation have become more pronounced and the local economy has become progressively more fragile. Based on small farming and petty trading with very limited formal employment on commercial farms or in government, livelihoods are undermined by HIV/AIDS, recurrent droughts, poor soils, cattle diseases (especially East Coast fever), poor access to fertiliser, seeds, and other farming inputs, and poorly resourced agricultural and veterinary extension services (see Siamwiza 1998, Waller 1997, Bangwe 1997, Foster 1993). The population has also steadily increased, with people moving in from the Gwembe Valley, the West, and other provinces to take up land or to be employed as labour on commercial farms. By the 1990s, most farmers had lost most of their cattle and some were once again using hoe cultivation. Kin and other connections in town remain essential to survival. Beer brewing and sexual exchange are common strategies to get by. Although not that evident in this study, other research indicates that violence and crime are escalating in Pemba/Batoka (Colson 2000, 2008; Scudder 1983, 1984).

⁶ Crop rotation, contour ridges and plough agriculture were successfully promoted in this period (Elizabeth Colson, Personal Communication, 18 August 2008).

Some people were seen as caught in a poverty trap—unable to buy seeds and/or fertiliser, unable to plant and grow their own food and dependent on piecework and other strategies to survive. Others were said to slide from wealth to poverty through chronic illness, animal diseases, careless spending, having too many girlfriends, too many dependents, and *'juju wealth'* (using witchcraft to get rich).

Most groups were quick to point out that poverty was not new—*"it was there a long time ago and it is still here"*, one man from Kasiya explained. Seasonal charts reflected that the food shortage is worse from October through to February or March, in the lead up to the rains and planting and during the rains when the crops are ripening. Selling off assets, such as livestock, bicycles, and beddings, and stealing were said to be more common during this period. Food is also less available to buy at this time of year.

Asked what caused current food shortages, the groups listed drought, lack of fertiliser, poor soils, water shortages, drinking, laziness, poor planning, too many wives⁷ and children, illness (especially chronic or a short illness), and death (especially the costs of funerals and property grabbing).

Mbekweni, Paarl District, Western Cape

Mbekweni is a peri-urban area, which lies in a valley partially enclosed by hills about 60 km outside Cape Town metropole, close to Paarl town, a wine farming area, two other smaller townships, and a high security prison (Figure 2). A railway line and a main road link Mbekweni with Paarl and Wellington towns, and with Cape Town metropole. The history of the township dates back to 1951 when four hostels and 30 houses were built to house seasonal farm labourers and their families and other labour for the rapidly developing industries in Paarl District (Lodge 1982). This labour had previously been squatting on the fringes of farmland (Lodge 1982). *'Mbekweni'* is a Xhosa word that denotes 'a place of respect'; given the history of exploitation and current poverty, one respondent wryly commented that *"the name only seems fit for Mbekweni railway station"*.

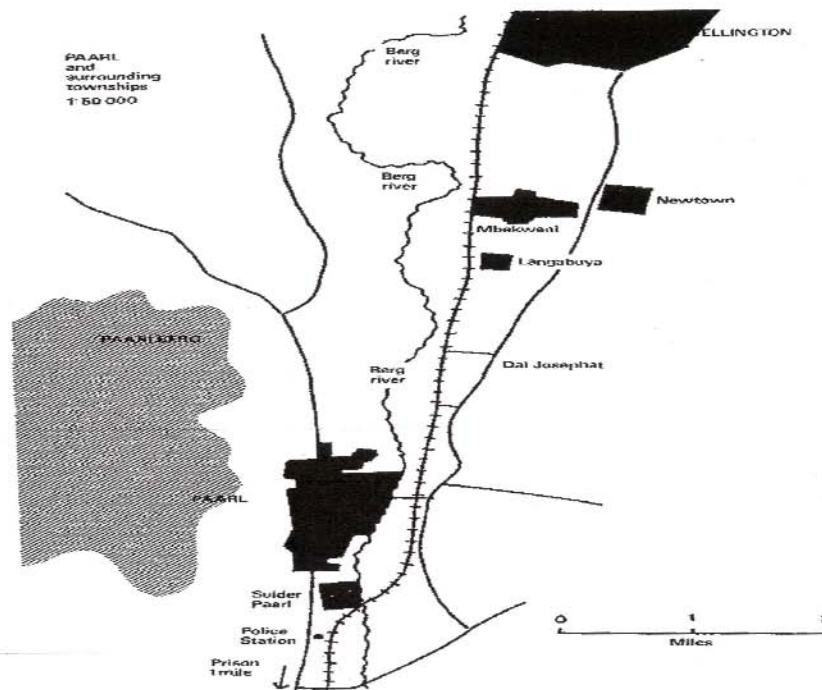
Today, it is a sprawling township with a variety of formal, informal, and hostel housing. Some formal housing is privately owned and considered middle-class, but most are row houses, currently being subdivided into family units and transferred to registered families, as part of the democratic government Residential Development Plan (RDP). Some hostels are undergoing the same transformation. Informal areas are a mix of RDP houses, self-built brick houses, and shacks; and housing, sanitation, and water supply are extremely poor in the largest informal settlement along the railway line. There are two clinics, Mbekweni and Phola Park (a newer clinic opened in 1999), three primary schools, and one secondary school.

Numbering close to 32,000, the majority of residents are Xhosa-speaking, and a minority are Sotho- and Afrikaans-speaking. Following a pattern entrenched by colonial and apartheid laws of segregation, links with a rural base in Eastern Cape are strongly maintained, with many people going back to Eastern Cape for holidays, rituals, initiations, and burial of kin. Newcomers—who were not born in Mbekweni

⁷ The Tonga practice polygamy (see Colson 1958).

but elsewhere in Western Cape or elsewhere in Africa—are resented and blamed for rising crime. Politically, Mbekweni is ANC-dominated, although there is growing disillusionment about the role of the ANC and councillors regarding service delivery and employment prospects.

Figure 2: Mbekweni, Paarl District, Western Cape



Despite the relative wealth of Paarl District, and due in part to recent retrenchment and re-employment on a casual basis in textiles and canned food-producing industries, livelihood options are limited for most residents to seasonal, unskilled contract work on farms. There is some informal trading (clothing, fruit and vegetables, meat, *spaza* shop,⁸ shebeens, home brewed beer) and some work available in textile, plastic, canned food, and construction industries, as well as in shops and private houses, and there are a small number of people in professional employment working as nurses, teachers, librarians, and administrators. However, the bulk of residents were identified as living on less than R800 a month, six times lower than the average income in the region (Integrated Development Program Report 2005/2006).

⁸ Small or medium grocery stores operating from peoples' homes.

Poverty was matched to residential area in Mbekweni—usually with each section corresponding to a particular wealth group and a particular type of housing. Talking of one informal area, one peace committee member said, “*Owu! There is no direction there; it’s tough in that place. It’s where an axe sinks with its stalk,⁹ where everything is difficult; there is crime and a lot of poverty*”. Inadequate housing was strongly linked to poor health, in particular diarrhoea and TB (especially in the winter, when houses get damp).

Pivotal to survival is the welfare state. One woman in the sewing group said that many people rely on a social grant—“*I don’t know how would people survive if there was no social grant...ngesisifa—we would be dying of hunger*”. But due to debt and needs, a grant gets finished quickly—one peace committee member exclaimed, “*It gets finished the same day, it’s the same as nothing*”. For example, one elderly woman explained she spends her grant on settling her debts, burial society payments, church fees, school fees, school transport, rent, electricity, and buying a hamper (food in bulk).

An elder from the Dutch Reformed Church was emphatic that “*hunger is the main problem in this community to an extent that when you go to some houses where there are elderly people, there is no smell of cooked food, you only smell water. You will notice that the children are sick because there is no income except for the old-age grant*”. Elderly people complained that they carry the burden of supporting their unemployed children, despite having spent money on educating them. “*Now our children are depending on us, on our old-age grant. We just get paid for them to pay for tuition fees, to buy food, and buy uniforms. Siyalamba akukho nto intle—we are hungry, there is nothing good*”. One went as far to say they are “*victims*” of their own children—“*they rob us of our money and groceries*”.

Seasonal charts reflected that seasonal work is mostly available on farms from September through April. Both earnings and expenditure are highest in December when informal saving clubs and bonuses are paid out and used to cover visits and ceremonies in Eastern Cape. After this expenditure, payment of school fees in January was often extremely difficult. During the winter months, expenditure rises due to increased costs on heating, food, and health care (there are more illnesses in the cold, wet winter months), yet work is hard to come by at this time of year, and other hardships like floods and fire are more common.

Hardship is also associated with sickness and a lack of nutritious food—one elderly woman said “*All our children have TB because of malnutrition—we don’t have fruits, vegetables, or even an egg in our houses*”. Sicknesses was said to lead to poverty—forcing people to spend money on a doctor,¹⁰ leaving nothing to buy food with. Being poor was also thought to cause disease—“*once a person gets poor there is always a disease*” (man, Phola Park Garden group). “*Our children are consumed by TB*”, an elderly woman in Mbekweni lamented, “*There is no money coming into the house while you are sitting with death*”. But with sicknesses also came the possibility of obtaining an additional grant, although a disability grant took some time to process and was not always successful.

⁹ This metaphor refers to disorder and ruptured boundaries.

¹⁰ This is an indication of the pattern to pay to visit private doctors and traditional healers, played out in the case-study data.

Alcohol abuse was mentioned as running across all wealth groups, but also seen as being a reason for sliding from wealth to poverty and resorted to because of hardship, for example, by those retrenched. In the case studies, there was a pattern of drinking among men and women (two of the female TB patients liked to hang out and drink in shebeens). Alcohol abuse was often accompanied by domestic violence. This was evident in both affected and comparative households.

Another aspect of poverty in Mbekweni is violence. The group discussions spoke of robberies (both armed and unarmed), stabbings, rapes, and killings—more prevalent in some areas than others. One man in the garden committee said, “*We don’t sleep in my street*”, recalling how “*boys and girls come with bottles and break them and they fight*”. Another man who said he lived near an open area talked of how “*they burn each other*”. Violence and crime were apparent in the case-study material. Murder, fighting, robbery, and stealing are mentioned often; three households have or have had household members in prison and two household recently had a close family member murdered. Households are fearful to open their doors at night because of fighting and crime, and one household was subjected to an armed robbery, during which two people were shot, during fieldwork.

Data Collection

In the field, Magazi and Chileshe each worked closely with a local woman research assistant throughout—these two women were selected for their knowledge of the area and of the language, and because they had extensive home-based care experience and some research training.¹¹ Although Magazi was fluent in isiXhosa, Chileshe was not fluent in Tonga, so the research assistant also helped with translation. Both research assistants would also help with the transcription of taped interviews if necessary. In Zambia, Chileshe lived in the field site with the local research assistant for 10 months; in South Africa, Magazi did not stay in the field site, but travelled there during weekdays and resided there over a few weekends.

Data Analysis

Data analysis was initially conducted separately in Zambia and South Africa, due to MPhil requirements and different time frames (fieldwork finished a bit later in South Africa). After reading through all the raw data, Bond, Magazi, and Chileshe discussed the case studies on an individual basis then pulled out themes for each country, with guidance from Levine (particularly for the South African material). Magazi and Chileshe then wrote up the data for their MPhil, and Bond, with some support from Sullivan, worked on the comparative analysis that is presented in this thesis. No qualitative data management programme was used.

Study Limitations

This study has a number of limitations:

- First, the comparison of rural Zambia with peri-urban South Africa is not ideal. It was not possible to select a rural site in Eastern Cape, which would

¹¹ Florence Moyo in Zambia and Florence Njila in South Africa.

- have been a sharper comparison, due to the confines of the trial (which is not being carried out in any rural sites in the Cape).
- Second, in Pemba, there were a limited number of TB patients, so all newly diagnosed TB patients who were eligible were approached by this study and asked to participate, whereas in Mbekweni, there were many more TB patients and therefore this study had more scope to recruit a range of household types in Mbekweni.
 - Third, the data were collected by different researchers in two very different contexts who inevitably, and necessarily, did not always collect equivalent data. For example, in Mbekweni, there is more data on the wider context and less on access to ART, anthropometric measurements, and the role of religion. And the detail on farming activities from Pemba/Batoka is not comparative with livelihood patterns in Mbekweni. Magazi also stopped recording and conducting more formal interviews quite early on in fieldwork, opting instead for making detailed field notes on more informal conversations in each household and about the area, whereas Chileshe continued to conduct and record more formal interviews, whilst maintaining a fieldwork diary. These two different approaches produced different detail. For example, Chileshe has more quantitative data on expenditure and Magazi has more contextual data on the setting. Whilst this was useful, and necessary, for their independent enquiry and development—and critically for their MPhils—it made the comparative analysis harder and more limited. Chileshe also confronted the difficulties of distance in rural Zambia; dropping in on households, some of which required catching transport there and back. Magazi was more easily able to drop by because distances were much less.
 - Fourth, the material from comparative households was of limited use. The researchers ended up visiting affected households much more intensely and the value of the comparison lay mainly in the comparison of individual and household productivity, diet, and nutrition in rural Zambia, and in throwing further light on the weight of problems other than TB and HIV faced by poor peri-urban households in South Africa.

REFLEXIVITY

Before fieldwork started, although both researchers anticipated that this type of fieldwork might be emotionally taxing, they felt that their previous fieldwork for the ZAMSTAR trial (in the selected communities as well as other sites) prepared them for the sadness they expected to encounter. However, they both underestimated the pain and suffering they would witness in the households. Through interviewing TB patients and their families in the privacy of their own homes—as opposed to in the clinic (a public place)—and over time, they got to know the patients and their families

in a space where patients tended to be more open and where their observations of suffering were not just one-off but often continued from one visit to the next,

“This work gave me a chance to know the patients, so they became part of me, so I not only knew their pain, I also felt their pain...It was very taxing...I also got to see the caregivers’ pain and the children’s pain. And the funny thing is, you don’t get used to it” [Chileshe, 2008].

particularly in the first months of TB treatment. They also observed the efforts the families went through to make the patient better and how the families were adversely affected. Chileshe wryly remarked, *“I realized that in dealing with ill persons, a researcher cannot have a complete guide on how to act or behave or carry out research”*.

Faced with physical pain and frailty, they both felt sad and sometimes shocked and scared—particularly when patients were bedridden and extremely frail. Magazi describes such patients as *“too weak, their eyes wide open, and faces pale”*; Chileshe describes them as *“in a terrible state...they were failing to breathe properly, talk properly, their hair was falling off”*. It was difficult to conduct interviews in such circumstances. They tried to remain composed and coped with the encounters using silence, prayer, encouragement, practical advice, and referral (sometimes to the ZAMSTAR team who could even, on occasion, visit the patients at home to administer advice and medication). They worried about extremely sick patients dying before the next visit. When patients did die—on three occasions during fieldwork—it always came as a shock and it felt as though they had lost someone close to them. They also wished they had known these individuals for a longer time and when they were not sick. A member of a comparative household in South Africa also died. On all occasions, they contacted the family to offer condolences, either by phone, by visiting them, or attending the funeral, and maintained contact with the family after the death. Another dimension of the death in Zambia that saddened Chileshe was the amount of resources spent on the patient and on the funeral and the future impact of all of this on the household economy; *“they were losing much more than an individual”*, she reflected. In Zambia, the researchers also felt angry that the deaths could have been avoided if both patients had started ART earlier. Both patients wished to start ART but faced delays caused by not having money for transport and by the ART procedures. The loss of the two patients prompted discussions about transport costs with both the local district health authorities and the NGO implementing the roll-out of ART in Southern Province.

“It was difficult to engage them in a long talk. I felt like I was making their condition worse, so there were moments of long silence, not that I was distancing myself but to respect their private space – any thoughts they must have had during silent moments” [Magazi, 2008].

The researchers frequently observed patients and other family members crying. There were many reasons why people broke down into tears, including pain, humiliation and frustration at their physical weakness, fears about living with HIV, unpaid bills, rejection and concern about the wayward behaviour of family members—including violence, verbal abuse, and alcohol abuse. Often the researchers felt disturbed by the crying, particularly in men, and sometimes felt like crying themselves. But they felt it was

important to remain composed and *“to stay strong”*. They were both empathetic in such situations and drew on their skills as a social worker (Magazi) and counsellor (Chileshe), exploring other sources of support that the families could call upon to help, asking about the problems in subsequent visits and referring to other counsellors if they felt it necessary. They also said they distanced themselves from the situation, recognising they didn’t own the problem.

“When we were about to start the process [have sex], I asked my husband for condoms but he got upset. He shouted at me and told me that we were not supposed to use condoms when stopping a child breast-feeding because it was a traditional process, not a modern process. I told my husband, you have been sleeping with someone who has HIV but I am negative. Don’t you think I could catch HIV from you? He answered by saying, ‘who told you I was HIV-positive? I am not! You should wait for us to go for VCT before you accuse me!’” [Co-wife, HH5A]

Neither researcher encountered any acts of physical violence against women, but the vulnerability and powerlessness of women and sexual violence in certain situations perturbed them. For example, Magazi felt sorry for the mother of one female TB patient, and found herself questioning the behaviour of the husband who had a drinking problem and did not bother himself to support his family financially, amid family hardship. There was one TB patient who consistently used vulgar language and made sexual innuendos, which made her feel uncomfortable. Magazi also had to support her woman research assistant whose teenage daughter was questioned during fieldwork by the police for being a witness in a gang rape and murder. The research assistant herself was almost a victim of mob justice related to the same murder. Magazi drew on the support of the ZAMSTAR team to give the research assistant protection and to accompany her to the police station. She said that this case deeply affected her and her research assistant. Safety issues were a constant concern in South Africa, where Magazi was privy to hearing about numerous violent and/or criminal incidents either in the recruited households or the wider community, which included stealing and other clandestine activities, the gang rape and murder of a 15-year-old girl, domestic violence, and armed robberies.

“At times it was easy for me to deal with the here and now – crisis, to deal with respondents feelings about the situation and to offer support. And I have somewhat distanced myself from offering long-term solutions to their problems” [Magazi, 2008].

In Zambia, Chileshe recalled the powerless of two wives—one was HIV-negative and unable to refuse to have unprotected sex with her husband who was living with HIV. And the other wife was widowed and had to allow her husband’s relatives to determine whether she should be sexually cleansed. Luckily for her, her mother-in-law refused to allow sexual cleansing—the widow told Chileshe, *“I did not feel like having sex with another man. I was happy with my husband and thought of another man touching me did not feel right. I was glad my mother-in-law refused”*.

Alcohol abuse was less evident in Zambia—Chileshe could only recall one household where the wife complained about the husband resuming drinking beer after he had finished TB treatment. But in South Africa, Magazi could see how alcohol abuse could have a negative impact on family relations and the allocation of money and, especially at the weekends, she witnessed heavy drinking in the households and the community. On one occasion, the sons of a respondent had been drinking all night and Magazi said when the mother agreed to buy him cigarettes, *“I had my moral*

judgement that she had lost control but also thought she had no choice because her son was supporting her financially”.

Child abuse was not documented in either fieldwork, although Magazi had her suspicions about the relationship between a grandfather and his six-year-old granddaughter because the granddaughter would throw herself upon her grandfather in an inappropriate manner. This made Magazi feel anxious and uncomfortable. Chileshe witnessed children being neglected, especially when a household fractured. For example, when a father abandoned his wife for a year, when the wife was four months pregnant, she felt the children were adversely affected.

Asking about food in some detail but not being in the position to give food assistance quickly proved awkward for both researchers. This issue was raised by Stellenbosch’s Ethics Committee, who initially recommended that Magazi give food parcels to all the households in the study at the end of fieldwork and finally agreed that instead, she would provide snacks during the interview and would refer households in need of welfare assistance to relevant NGOs. In practice, Magazi was successful in leaning on other organisations to deliver food parcels on occasion to affected households who were short of food in the study, but a similar referral approach in Zambia was ineffective and Chileshe was not allowed to give snacks during interviews due to the links with ZAMSTAR. Both researchers found it hard to witness hunger, and were careful to carry lunch and to eat it away from the households since they did not have enough to share. Being attached to the ZAMSTAR trial also constrained their response to need; in order not to confuse the purpose of the trial, in Zambia Chileshe was not supposed to give any food to the households. Chileshe said food shortage was almost the most painful experience to document because it never went away and she found it frustrating that she couldn’t give snacks to everyone and that despite the efforts of the households, food was always short. She said she was shocked by the extent of food shortage—recalling watching one TB patient cooking a small amount of wild vegetables with no cooking oil that was blatantly inadequate for the family, and, that she personally would find hard to eat. Many of the affected households would ask her for food—eggs, kapenta, cooking oil, breakfast meal—and on occasion, she would bring them something. Indeed, one of her regrets is that she didn’t buy eggs for the male TB patient who died—he would always greet her by asking, “*So, where are my eggs?*”

“It was very disturbing to see the hunger written over their faces, and I again felt like an intruder, that they would feel uncomfortable with me around to see their suffering. There were times when I felt like I didn’t want to hear their suffering. On one occasion, D had a terrible headache because of hunger and she wanted to sleep. So I just stayed with her and joined her in bed” [Magazi 2008].

There was some pressure sporadically put on researchers to reveal the HIV status of their participants to others in the community, or to gossip about their household visits with others. Both researchers responded to this pressure by reiterating the importance of confidentiality.

Misuse of disability grants was another tricky situation for Magazi. When respondents gave her details of how they spent their grants, they worried she would

report them for misusing their grants. Magazi, in turn, found it hard to talk to them about it, particularly if they were older than her.

A further issue of concern in both settings, but especially in South Africa, was the risk of researchers themselves developing TB. In South Africa, the higher TB incidence rates increase this risk. Both researchers said that they had dealt with their fears about falling sick with TB through fieldwork when working in earlier ZAMSTAR studies and that in this particular study, they did not worry about it. The South African research assistant fell sick with TB towards the end of this study; she has now completed treatment and is cured.

Being linked to the ZAMSTAR trial gave both researchers practical and moral support, in particular from the team based in the sites where they did their fieldwork. Because the trial was doing interventions, this also meant that the researchers were part of a team who were actually seen by the community as trying to ‘do’ something to enhance the management of TB and HIV, although this excluded material support. Their research assistants, counselling and social work skills, their own strength, the value of listening and caring, friends, and supervisors also helped them cope. And there were more rewarding experiences in the field. These included getting to know how people live; learning new things about relationships and support, the trust of the households; seeing that people were happy to be visited, good communication; the opportunity to disseminate findings to respondents; and watching some patients recover, complete treatment, and resume livelihood activities.

Providing practical and financial support to households whilst conducting ethnography on poverty and infectious disease is often regarded as beyond the remit of ethnography. In addition, being privy to suffering induced by illness and food shortage can be distressing for researchers. Establishing better preparation before fieldwork, better linkages with organizations in a position to give practical and financial support (if present), and psychosocial debriefing and support for researchers would help address these ethical dilemmas.

Table 5: Wealth ranking in Pemba/Batoka

Poorest	Very Poor	Poor	Rich
Those with almost nothing – no relatives, no food, hardly any housing, forced to beg with their bowls.	Those with no livestock, poor housing, and a small piece of land, whose <i>butala</i> (food barn) is empty and who survive mainly through working as casual farm labour ('piecework') for others. Only able to afford one meal a day, children do not go to school and are more likely to die, clothes are shabby, belongings (including pots and plates) are few, there is no soap and the environment is dirty. Cannot afford to send a patient to a hospital or buy a coffin for a funeral. One group said that very poor people are usually referred to as dogs – <i>babwa</i> ("they are treated like dogs and no-one respects them", Kasiya NHC).	Own a small amount of livestock (chickens), a medium piece of land, and children go to school.	Those with large houses with iron roofing sheets, a large piece of land, and livestock (cattle and goats), who have the ability to buy farm implements and hire labour, and who have a salary or their own business (like a shop), are able to support others and are able to have three nutritious meals a day and snacks in-between meals.

Table 6: Wealth ranking in Mbekweni

Very Poor	Poor	Better Off	Wealthy
<p>Those who have many children and live in poor housing – either a shack (prone to fires) or a small house, with dilapidated floor carpets, sparse, wooden furniture (<i>“not a set”</i>) and no bed (sleeping on a mattress on the floor). Depend on seasonal work, child support grants, and handouts, selling home-brewed sorghum beer and sheep heads, and doing laundry for other people in the township. Short of food, and sometimes resort to selling clothing, stealing groceries, or going to bed without eating. Teenage girls from these very poor households are reputed to have sex with older men to get money for food or alcohol (known as <i>kura</i> – meaning sex and alcohol for money), or to run away. Those who don’t have any state welfare grant belong in this very poor category.</p>	<p>Those who live on welfare grants, live in a RDP house, and earn less than R1,500/US\$250 a month. One member of the Phola Park Peace Committee defined poor people as <i>“people who live on grant money without anything else being received”</i>.</p>	<p>Those with employed household members, their own car, furniture, and house, and getting rentals from foreigners.</p>	<p>Those who have household members formally employed (as teachers, nurses, police officers, doctors, and other types of government employees), receive land restitution payments^a, live in brick <i>“beautiful”</i>, double storey houses with secured gates, have good furniture and televisions, and have a car. These wealthy households were likely to move out of Mbekweni to another suburb.</p>

^a Monetary compensation for ancestral land misappropriated by the apartheid government under the Land Act of 1913.

FINDINGS

We follow the journey taken by TB patients and their households, describing both how TB is experienced and the implications of each stage for the patient and the household and food security. In addition, since most TB patients in this study are co-infected with HIV, more long-term and extra dimensions around treatment, disclosure, stigma, and food security are documented.

TB symptoms

The 19 TB patients recalled how they first began to experience TB symptoms. The majority of patients in both Zambia and South African experienced loss of appetite and weight loss as their primary symptom. In Zambia, a cough was more prevalent at the beginning; in South Africa, the cough was often reported as a later symptom. Other symptoms included pains in the chest and legs, dizziness, night sweats, and general weakness. One 24-year-old man working on grape farms in Mbekweni described a stomachache and sore throat as his first set of symptoms.

For most, the onset of illness was gradual, but by the time they were diagnosed, they were unable to work and were bedridden.

Gradual Onset of Illness, 40-year-old man, bricklayer, Zambia

For four months he treated a cough, body pains, and loss of appetite with ‘African herbs’ and three courses of antibiotics from the clinic. Then he started feeling very ill with bad chest pains and took sputum to the clinic but never received the results. “*I continued working because I had to feed the family, but it was not easy because my chest was really paining and I was not breathing well. After work I used to cough the whole night and my chest was in pain, so it was difficult for me to sleep*”. Once diagnosed and on TB treatment, he was so ill he ended up spending two weeks in the district hospital and another two weeks at the local clinic before being discharged.

For a few, the onset of illness was more severe and sudden; one 50-year-old man who worked on a grape farm in Mbekweni was brought home by his employer feeling dizzy and weak and within one week, was critically ill. Another 38-year-old man who worked as a groom in the Zambian Copperbelt woke up early one morning and “*found that I had real pain on my left side. I forced myself to walk outside....At that time, I was really forcing myself to walk; I had to be strong like a man... that was the beginning of my illness*”. Within a few weeks, he was transported home over 500 km by taxi (paid for by his employer) and arrived close to death at his parents’ house.

Close to Death and Keeping Vigil, Mother to 38-year old TB patient, Zambia

His mother recalls the arrival of her son and how the family kept vigil. *“I found him lying on a mattress; he was not able to talk or stand. You can imagine, his body was stiff, his legs and jaw were not moving. He was very sick, I tell you this, he was very sick. I told the boys to prepare warm water to bath him and his brother said they had already washed him. We prepared porridge for him to drink and in the evening we prepared warm water to wash him. No one used to help him in the Copperbelt. After washing his mouth and massaging it so hard, he finally started to talk but we could not get what he was saying - we would only hear him say ‘Mum’. We prepared a bed for him to sleep. On that day we did not sleep, we sat outside his room waiting for morning.”*

Dreaming

A symptom of TB illness documented in this study was vivid dreams. Three TB patients and the sister-in-law and nephew of one TB patient who died recalled experiencing vivid dreams early on in their illness and in treatment and after a patient died.

Early on in her treatment, a 31-year-old South African female TB patient had a dream about her uncle telling her to wear *isiyaca* (a necklace which signifies puberty and womanhood) so that she could be healed; when she related the dream to an uncle living in Mbekweni, he agreed that it should be performed. The mother mustered the money to pay and her daughter went to Eastern Cape for the ritual. Late into treatment, Magazi noticed that this woman was no longer wearing the necklace and the bracelet from the *isiyaca*. The woman explained that the bracelet had broken up by itself and the cow, whose skin had made the necklace, had slipped into the river and broken its legs and had to be slaughtered. This signalled misfortune to the family and the *isayaca* was no longer trusted to bring healing. She did not think she would get sick again not wearing the *isiyaca*. Unfortunately, she died in July 2008.

Two Zambian male TB patients had terrible dreams in the early stages of their illness and early into taking TB treatment and, for one, when starting ART.

Dreaming, 25-year-old man TB patient, Zambia

He persistently had dreams about being given meat. *“I used to have these dreams about people who used to come and take me to places I have never been before. We used to kill animals and then eat them raw. In the morning, when I woke up, I would be vomiting and experiencing general body pains”*. His mother consulted elders and friends at the market about his dreams; then, when the herbs they gave her did not work, she went to a traditional healer in Choma who blamed the father of the young man of wanting to kill her son because of his success in business. The medicine from this healer was *“very powerful”* and her son’s dreams stopped.

Physical Debility

Implicit in the details of their symptoms is the physical pain and degeneration brought on by their illness. One 36-year-old South African man patient talked of severe headache and pelvic pains that made it difficult for him to walk and sit up for a long time. Another 54-year-old Zambian man patient was unable to walk due to his swollen legs prior to diagnosis and had to be taken to the hospital by taxi (further adding to treatment costs). Other patients in both countries particularly mentioned pains in their legs; a 50-year-old South African woman describes how she *"used to feel like the pains were in the bone marrow. When I am sleeping I will feel a funny sensation in my feet and wake up"*.

When TB patients were regaining health, they and their family referred back to the pain of the frailty experienced—talking in detail of extreme weakness and weight loss, and of being unable to carry out the most menial of tasks—like bathing, going to the toilet, fetching water, washing clothes or carrying out other household chores. Being so weak could be frightening, frustrating, and humiliating. Men in particular found it hard not being able to provide for their households. Emotionally stretched by their illness experience, three men in Zambia would often break down and cry whilst being interviewed early on in their illness, reiterating how they felt *"like a child"*, having everything done for them by others. In South Africa, a 30-year-old man, who was sometimes alone at home during the day, said there were times when he wanted to get something that was out of reach and with no one to ask and too weak to get up, he would have to give up. A 50-year-old South African man referring both to his appearance and to his inability to help out in the house, said shortly before he died, *"I am like a dead person"*. A 50-year-old South African woman and a 30-year-old Zambian woman, both co-infected with TB and HIV, told of their humiliation when their diarrhoea got so bad and they got so weak that they *"soiled"* themselves.

The physical debility that patients experienced captures the severity of TB. A 32-year-old South African woman said she looked like death and that the doctor said *"there is no disease that I don't have"*. A father of a 24-year-old man said that when he first saw his son's condition on his return from Eastern Cape, he thought he would die, describing him as

Physical Debility and TB

"I feel crushed by TB" [50-year-old male TB patient, SA].

"I look like death and the doctor says there is no disease I do not have" [32-year-old female TB patient, SA].

"My son was thin, bony and like a thin rod; I thought he would die" [father to a 24-year-old male TB patient, SA].

"His TB had crippled him and made his knees weak" [mother to a 50-year-old male TB patient, SA].

"I was sad. I have seen how TB patients suffer and I did not want my husband to go through the same. Our neighbours have suffered from TB before; one of them used to have swollen legs all the time; his legs are still swollen and he cannot walk" [wife of a 41-year-old male TB patient, Zambia].

“thin, bony, and like a thin rod”. The mother of a 50-year-old South African man said his TB had *“crippled him and made his knees weak”*; her son described himself as *“crushed by TB”*.

In Zambia, two patients were physically very debilitated and bedridden before they died; the 54-year-old man had bedsores, a swollen stomach and face, and the 30-year-old woman was experiencing blackouts and had a ‘shaky, cold, and weak body’ (Chileshe Fieldnotes 14th May 2007).

For caregivers, family, and, indeed, researchers, observing TB patients when critically ill was alarming and upsetting.

Causes of TB

Healing Rites

“I am not saying it is a cure for her illnesses but I suspect she is infected because her blood is weak as a result of certain rites that we have not performed for her, according to Xhosa tradition...we might blame the doctors for failing to cure the diseases while we have also failed to do what is necessary” [mother to a 31-year-old female TB patient, SA].

TB was thought to be mainly caused by exposure to dust and tar, smoking cigarettes and marijuana, drinking, inheriting TB from the family, and improper sex. Three patients in South Africa and two patients in Zambia considered their TB to be linked to witchcraft, considering themselves vulnerable to witchcraft because other people were envious about various successes in their own, or their families, lives. As a 25-year-old male TB patient in Zambia explained, *“There are certain illnesses and problems that modern medicines cannot heal. You cannot find modern medicine for people who come to fight with your spirit at night”*. In Zambia, recent deaths in the household further underscored the link between TB and witchcraft. For example, a 30-year-old male TB patient had recently lost two adult sisters—his mother attributed this chain of illnesses and deaths to

witchcraft. In South Africa, TB was attributed by three patients to *idiliso*, a medicine or poison fabricated by an expert hand with secret knowledge and sent by magic, to achieve, in these cases, witchcraft, bringing illness, misfortune, and/or death to others or illicit wealth and power to the witch (Ashforth 2005). Illness in South Africa was also related to failing to perform certain rites of passage. Witchcraft and poisoning fears and accusations were also documented in the comparative households, either in connection with success, illness, or other calamities.

There were some conspiracy theories about TB in both countries. For example, a 32-year-old South African female TB patient was advised by a friend to go to a crusade with a white preacher to get cured, but she was immediately suspicious and refused, saying *“are these white people not going to bring us diseases?”* Similar feelings about mistrust were levelled at the ZAMSTAR project in Zambia, especially when the project first started and was conducting a Tuberculin Skin Test (TST) survey. The project was accused of being Satanic and out to steal blood, and although the fears have ebbed over time, they still persist in pockets and in one area meant that this study was unable to recruit a comparative household.

Conspiracy Fears

“Photos are prohibited! I have heard that Satanists now have become very sophisticated and can take a photo from Africa to London. While in London all they have to do is poke my photo and then when I sleep everything will happen in my dream and my blood will be gone” [30-year-old male TB patient refusing to have his photo taken by visiting IFPRI director, June 2007, Zambia].

Treatment Options

With the onset of symptoms, five of the nine TB patients in Zambia first treated themselves—one bought painkillers from a market stall and four used herbs (either known by them or given to them by family or neighbours). Three of the others went to a clinic thinking they had malaria and were duly given malaria medication. And one was in Lusaka and was admitted into a clinic after an epileptic fit a few days after her symptoms started. In South Africa, four patients went to a clinic, three went to private doctors, two went straight to a hospital, and one went to a traditional healer.

Failing to get better, patients then ‘ping-ponged’ between the various treatment options before being diagnosed; journeys back and forth from government health services were the most frequent. Private doctors did not feature in the therapeutic journeys of any of the Zambian patients (a reflection of the rural setting and lacking funds to pay), but in Mbekweni, four patients visited a private doctor at some stage—most opting for a local private doctor but some going to private doctors outside the Paarl area. Some other patients wished to visit private doctors but did not have the funds.

Five TB patients in both Zambia and South Africa went to traditional healers; sometimes these healers resided some distance away. Treatment from traditional healers was sought either just for symptoms and/or because patients feared they were bewitched. In South Africa, treatment from traditional healers involved prescribing herbs and purification baths. Use of traditional healers for afflictions other than TB was common in affected and comparative households in both countries.

Faith healing was another treatment option in Mbekweni. Two patients went to an apostolic church that heals people with holy water. The latter is known as *isiwasho* (wash), and treats people through a ‘purification’ process that induces vomiting, enemas, steaming, and bathing. One of the patients, a 31-year-old woman, found the purging and vomiting induced by the holy water made her so weak that after one week she had to be treated at the hospital. The other patient, a 24-year-old man, found the church so full the day he went that he left without being treated.

It was common for patients in both countries to purchase painkillers from hawkers or market stalls. In Zambia, TB patients often took herbal medicine, which was either bought from healers or either foraged by themselves, family, or neighbours from the bush around them. In South Africa, herbal medicine was mostly bought off hawkers

or healers. This included Chinese herbal medication. In South Africa, a few patients were reluctant to take any form of alternative medication.

Relocation

Relocation was a feature of the therapeutic search, especially in Zambia and during the period before TB was diagnosed. Six of the nine TB patients in Zambia relocated from the town to the village whilst sick and before diagnosed, all moving back to their mother's household to be cared for. Two of the 10 South African TB patients fell sick whilst in Eastern Cape over Christmas, moving back to Mbekweni (one to his father's, the other to her mother's household) to seek treatment and care. Relocation contributed to both delayed diagnosis and to costs.

Delayed Diagnosis

Two women—one in South Africa and one in Zambia—experienced symptoms for 18 and 20 months, respectively, before getting diagnosed with TB. Both were co-infected with HIV. In Zambia, the other TB patients were ill for between two and ten months before being diagnosed. In South Africa, five were diagnosed with TB within three months (two of whom were diagnosed within two weeks); the other four took between three and nine months to be diagnosed. In both countries, 12 of the TB patients were admitted to the hospital or the local clinic for at least two weeks prior to TB diagnosis; in South Africa, patients seemed to spend longer in the hospital (from one to two months).

In South Africa, patients were more proactive in pushing for tests and a diagnosis than in Zambia and found the process of diagnosis frustrating. One 30-year-old man described his travelling to the clinic on two occasions to provide a sputum sample and collect his result only to find the clinic closed. One 46-year-old woman living with HIV, who had had TB before, recalled how when she started losing weight, she asked the clinic to test her for TB, but they refused. It was only when she saw the doctor at the ART clinic, some three months later, that she was sent for an X-ray and asked to give sputum, and finally (from her sputum results) was diagnosed with TB. She related, "...before I was told I have TB, I was telling my daughter that I am losing more and more weight and I don't understand when they are telling me that I don't have TB".

Patient Agency in SA

"A few days after falling ill, I went to the clinic to check my sputum results, but they said they were not there yet. And I was feeling like ndiyaphela ngoku – finished and emaciated. I came back home and told my sister that I was going to the hospital now. She said, 'No – the nurses told you to wait for your results'. I said, 'No – I am the one who is suffering!' and she agreed to take me to the hospital. We took a taxi to the hospital and I was treated very well there. They took me for X-ray and said I had ichaphaza le TB – TB spot" [50-year-old male TB patient, SA].

The health system in South Africa was, on the whole, quicker to suspect and test for TB; and to refer suspect TB patients with negative sputum results to the hospital for further investigation. It was less common in South Africa than in Zambia to be

diagnosed first with other illnesses; many of the TB patients in Zambia were initially treated for malaria. In both countries, negative sputum results and co-infection with HIV led to a more protracted diagnostic search, with TB diagnosis often confirmed by x-rays at a hospital.

Cost of Therapeutic Search

In both countries, repeated trips to clinics and hospitals both before and after diagnosis involved travel costs. The cost is higher early on during illness and treatment if the patient relocated and as the patient often needed to be accompanied by another member of the household (usually the primary caregiver), particularly if very ill or if the patient was trying to start ART (see next section). Travel costs were significantly higher in Zambia because of the rural setting, but costs were also not insignificant in South Africa, especially when going to Paarl East Hospital. One 74-year-old mother talked of “being up and about, going to the hospital repeatedly” accompanying her 50-year-old son. One 21-year-old Zambian female TB patient, from a very poor household, would either walk or borrow a bicycle to reach the clinic. In one South African household, the 39-year-old patient had no money to travel to the clinic so had to walk, but said “that killed me because I come back tired”. Seeking treatment from private doctors, traditional healers, and spiritual healers often proved expensive. In two South African households patients made costly trips back and forth to Eastern Cape for healing rituals; one household spent R2,400/US\$400 and the other R1,200/US\$200 (close to one month’s or half a month’s income).

Burden of Costs

“I am suffering! Before my son got sick, I used to have enough food but this year has been full of hunger. From the time I started trying to find out what was wrong with my son, I have been using money to take him to the hospital and to get food for him, but it has been a problem to find money. So far I have used more than K140,000/US\$35. I also sold some chickens to help me care for my son with the hope that he will get better but there is no sign of improvement. Where will I get the money because now I have nothing. I am really suffering!”
[mother to 25-year-old male TB patient, Zambia].

Comparative cost of trip to hospital by public transport

Mbekweni (10 km): R20/US\$3
Pemba/Batoka (40-60 km):
Between K12,000/US\$3 and
K30,000/US\$7.50

Zambian affected households reported having spent not less than K200,000/US\$50 before being diagnosed, and any periods when patients were admitted in a hospital were expensive, since food had to be provided for the patient by a household member (who would either try to stay with a relative or travel to and from home). In both countries, there was a limit to this outlay on treatment. A 74-year-old mother threatened to give up supporting her 50-year-old son on TB treatment and ART in South Africa, exasperated

by his heavy drinking and failure to keep up funeral plan contributions or contribute to household costs. She said emphatically, “I have spent a lot of money caring for him, hiring cars to hospital but he is not taking his health serious. If he gets sick again, I am not taking any action”.

Contracted Space

As a result of both the physical toll of the disease and not wishing to be seen by others whilst very frail, all patients experienced a marked contraction of their space. Unable to work and too weak to venture far, patients were essentially confined to the house. Some spoke of the loneliness of the disease as friends fell away; a 50-year-old South African male TB patient (prior to contracting TB a very sociable person who hung out drinking in shebeens) complained, *“My friends stopped visiting me. I sometimes see them walking from afar now”*. One 30-year-old South African male TB patient was often at home all day alone, whilst everyone else in the household was out and about.

The relocation of six of the Zambian TB patients from the town to the village further increased the isolation that the patients felt, as a 25-year-old woman, who had moved from town back to her mother in the village, expressed, *“Even if I want to go and visit, I cannot, because I hardly know anyone...I have no social life”*.

The case of a 30-year-old male patient illustrates this contraction of space. During the first month of TB diagnosis, he could not move unaided and was limited to moving between his house, the toilet and bathroom, and under a tree where he laid for fresh air. No friends visited him during this period. After two months of treatment, he was able to walk unaided around the family compound, to the market (a kilometre away), and could eat his meals without help. He also occasionally went to church, to the clinic, and to a farm nearby to pursue a compensation claim and to the bush to strip trees in order to make ropes. These limited activities were a marked contrast to his mobility before getting sick, when he used to go to work on a farm and to drink beer in the evenings on a daily basis, travelling further away during the weekend to drink with friends or to buy goats for his mother. When drawing the charts (see Figures 3 and 4), he said he felt *“sad”* since he used to move around much more. The charts of a 25-year-old female patient convey a similar patten of reduced mobility during illness.

Contraction of Space

“I don’t go out. I don’t even think about going out. I am always at home” [31-year-old female TB patient, SA].

“My life has changed. I stay at home more unlike the time I was well. Those days I used to move around but now I cannot” [38-year-old male TB patient, Zambia].

Figure 3: Mobility of a 30-year-old Zambian male TB patient before and during illness

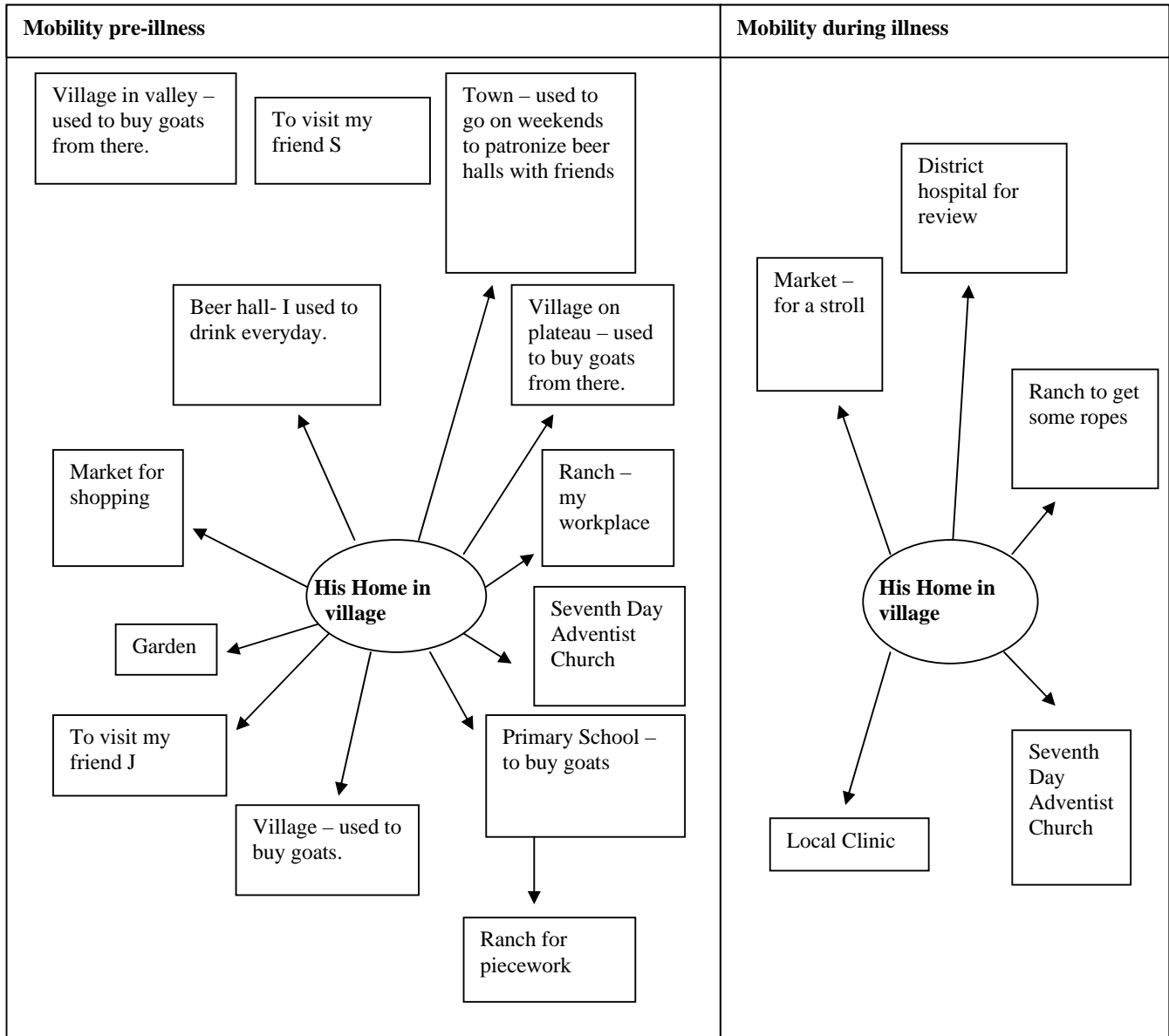
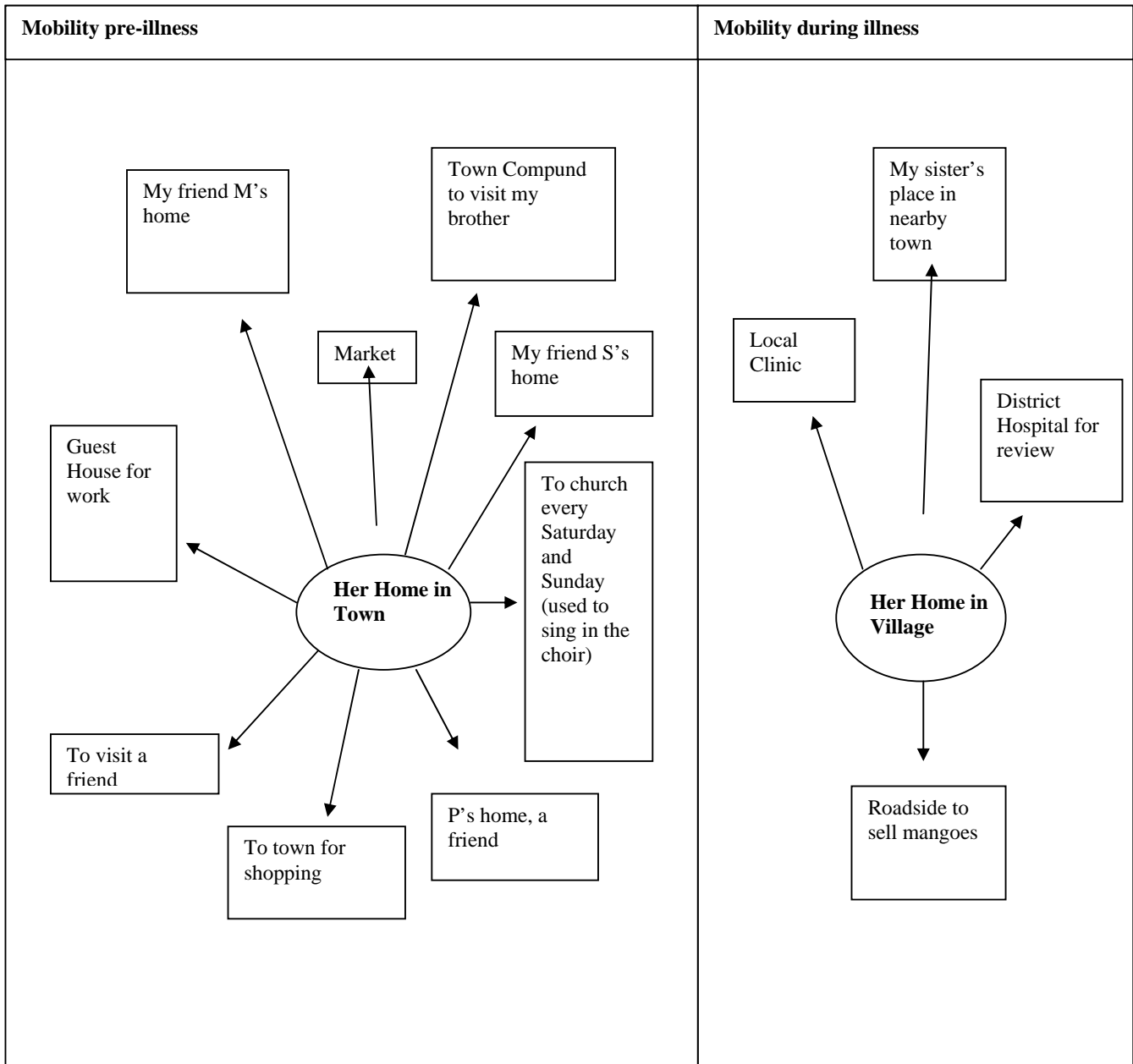


Figure 4: Mobility of a 25-year-old Zambian female patient before and during illness



Loss of Livelihood and Productivity

Patient Livelihood

All of the TB patients were contributing to household living before they fell sick, and with the exception of two South African TB patients, had to stop their normal livelihoods when they fell ill. In Zambia, accounts of daily activities from both TB patients and an adult of the same sex and equivalent age in comparative households reflected a loss in productive activities amongst TB patients compared to their adult counterparts in comparative households. TB patients, especially early on in their illness, spent time resting and eating, compared to their counterparts, who were working in the fields, doing household chores (if women), and socialising. About three months after diagnosis, most patients were beginning to recover and female TB patients often resumed household chores such as cooking, washing, and sweeping, but were still not able to do heavy chores like drawing water or farming. Similarly, men were not able to engage in farming.

Unable to Farm

“My biggest problem is that I have no money to use. The rains are about to start but I cannot farm and this means that my children will starve next year. If I had money, I would have paid other people to farm for me so that by the time I get well my children will have something to eat. I feel very bad because my family is now affected” [54-year-old male TB patient, Zambia].

“I have fallen, my sister, I have fallen! I am the breadwinner; everyone looks up to me but now things are tough. My sisters are married...I used to care for my mother - as you can see she has not even started farming (he points to the field next to the house); it is because there is no money” [25-year-old male TB patient, Zambia].

All except three households in South African were low income, and the loss of livelihood was a blow particularly in the long term. In the short term, all except two managed to obtain a disability grant.

Not Strong Enough to Return to Previous Livelihood

“I am scared of losing blood again because of hard work” [50-year-old male TB patient, SA, who used to work in construction].

“I feel very weak at times so I can only manage to work half day. I am lucky my boss is very understanding” [38-year-old male TB patient, Zambia, returning to work as a groom].

“My daughter cannot return to seasonal farm work because she has not yet returned to her normal body” [mother to 31-year-old female TB patient, SA].

Only 7 of the 19 TB patients were to resume their previous livelihoods when they recovered. The majority (n = 12) either didn’t feel physically strong enough to return to their previous job or they no longer had the capital to start up or run a small business.

Household Livelihood

The livelihoods of caregivers in peri-urban South Africa were more diverse than in rural Zambia and were derived from a range of sources including welfare grants, formal employment (construction, domestic, fast food), seasonal farm work, the combined income of the household, and support from partners and relatives. This diversity—combined with a sharing of caregiving tasks and a stronger economic base—made the household economy less vulnerable to the impact of TB than the household economy in rural Zambia, which was largely dependent on small farming and trading.

Seven out of the eight affected households in Zambia complained of having less time on their hands to work in the fields because of having to care for the TB patient. The one household that did not complain was a large household with many adults, so whilst the grandmother cared for the patient, they were busy in the fields. Sickness—either short or long term—during planting or of a breadwinner was experienced as particularly disruptive.

From December to February it is unusual to find people at home in Pemba/Batoka; they spend the whole day in the fields, breaking off only for lunch. In this study, the comparative households followed this typical pattern

Disrupted Caregivers, Zambia

“I am disturbed; all my programs are disturbed. I fear going far. I am the only older man around and if anything happens to him, I have to take charge” [brother to 54-year-old male TB patient, Zambia].

“My life has changed! It has changed so much because I cannot do the business I used to. When my mother was not suffering from TB, I used to sell vegetables and fruit at the market, but after she fell ill with TB, I started spending my time with her and I found myself doing more piece work” [29-year-old daughter to 55-year-old female TB patient, Zambia].

but the patient and one or more adults in affected households would be found at home at this time, unless they had gone to the clinic for review or to other people's farms for piecework. Most caregivers were loath to leave the patient alone, and—depending on the condition of the patient—other adult household members would also stick around to give support. In four affected households, crops were planted closer to the house (sometimes on an anthill, which is considered more fertile), and a smaller area than previous years was cultivated. Four affected households also sent adults to do piecework in other people's fields, usually being paid in kind or earning US\$1 or less a day. This meant they spent more time away from their own fields or from their usual livelihood. Affected households also relied on children's labour. In one household, a 12-year-old grandson ploughed the fields in 2006, whilst his grandparents ran up and down caring and raising money for two patients.

Empty Granary

“We have no food and we fear that we might starve. Because of caring for two patients, we did not put much effort in our field. All our resources were spent on money to the hospital and nice food for the patients. We were scared of losing two children at once. Now that they are fine we are happy but we do not know how we will survive the rest of the year because we hardly have any food” [father to two TB patients, Zambia].

Pemba/Batoka households generally have one harvest per year and aim to use the maize over the whole year and sell surplus. The adverse impact on food production in Pemba/Batoka is reflected in the comparison between household records of 2005/6 maize harvests and 2006/7 harvests in both affected and comparative households. The amount of maize harvest in the 2005/2006 farming season was more than the maize harvest in the 2006/2007 for seven out of eight affected households.¹² Although 2005/2006 was a better season, none of the unaffected households registered a drop in the maize harvested when the two farming seasons were compared (see Tables 7 and 8).

A drop in maize harvest meant a shortage of food sooner than expected. Many of the affected households as compared to no affected households had no maize in the *butala* by June 2007. Indeed, two had no harvest at all in 2007. These affected households were also worried about how they were going to survive throughout the rest of the farming year.

¹² Measurements differ depending on the household. Some households measure their harvest using kilograms while others measure using an ox-cart. These measurements were collected in March 2007, the same month the maize was harvested.

Table 7: Household production before and after TB

Affected household	2005/2006 harvest	2006/2007 harvest
HH1A	Eight 50-kg bags	Two 90-kg bags
HH2A	3 ox-carts plus six 90-kg bags	2 ox-carts
HH 3A	3 ox-carts	½ ox-cart
HH4A	1 ox-cart	Nil
HH5A	Nil	Nil
HH6A	4 ox-carts	4 ox-carts
HH7A	3 ½ ox-carts	2 ox-carts
HH8A	2 ox-carts	1 ox-carts
Notes: The above table is a comparison of 2005/06 and 2006/07 maize harvest for affected households. The table reveals that apart from one household, there was a drop in maize harvested during the time that the households had a patient. One's household's production was stagnant.		

Table 8: Comparative household harvest for 2005/6 and 2006/7

Non-affected household	2005/2006 harvest	2006/2007 harvest
HH1B	1 ox-cart	3 ox-carts
HH2B	60 ox-carts	80 ox-carts
HH4B	1 ox-cart	1 ox-cart
HH5B	Eight 50-kg bags	During this farming season he worked on his father-in-law's farm
HH6B	5 ox-carts	5 ox-carts
HH7B	2 ox-carts	3 ox-carts
HH8B	1 ox-cart	2 ½ ox-carts
Notes: The table is a comparison of 2005/06 and 2006/07 maize harvest for non-affected households. Apart from two households that were stagnant, the rest of the households recorded an increase.		

TB Medication—Adherence, Side Effects, Hunger

All patients experienced side effects during their TB treatment. The majority in both countries spoke of increased drowsiness. One South African patient had to switch to a different treatment after getting an itchy rash. Several patients remarked on the large size of the tablets but no one reported difficulties in swallowing them. One South African patient considered stopping taking his tablets due to side effects, but knew he was putting his health at greater risk if he did. Only two TB patients, both South African men, were known to interrupt TB treatment. One 25-year-old man stopped TB treatment because he was feeling too “*lazy*” to go to the clinic for two weeks—he then felt “*guilty*”, so he went to get his drugs. And the other 50-year-old man stopped treatment for a month due to excessive drinking.

A few patients in South Africa, once on TB medication and/or ART, did not take any other herbal medication; one 30-year-old male patient described mixing TB medication with herbs as “*suicidal*”, although he said he would continue taking herbs once he had completed TB treatment. Three women living with HIV and on ART said they were explicitly told not to use any other medications with ART, and were told to notify the ART clinic if they were prescribed any other pharmaceutical medication by another clinic. They appeared to adhere to this advice, and one woman told a story of a member of the support group who died after taking African potatoes. In Zambia, at least four of the TB patients took herbs alongside TB treatment to treat illnesses other than TB.

All TB patients co-infected with HIV and on ART reported experiencing side effects to ART. In Zambia, one said they made him “*itchy*”; another said he had experienced “*a black out*” after taking drugs on an empty stomach. In South Africa, patients reported getting drowsy, and having blurred vision, a skin rash, and pains in their legs. In both countries, side effects were more marked the first few months of treatment.

The most common side effect to TB treatment experienced by all patients was increased or renewed hunger.

TB, Food, and Hunger—*Igazi alihlanga*— “The spoilt blood that needs nourishment”

This isiXhosa metaphor conveys the connection between the presence of disease and poor nutrition. The metaphor, used frequently by South African caregivers when discussing how they managed TB, reflects how patients in both countries were instructed to always take medication with food and were often told by the clinic and hospital what types of foods to eat.

TB Medication and Hunger

“Now that I am taking the TB drugs, I feel very hungry and I have never had such hunger...from the time I started the medicine, I eat all the time”,
[50-year-old male TB patient, Zambia].

“Before taking the tables, no, I couldn’t even finish a plate before I got sick...I got appetite now that I’m taking the tablets”
[50-year-old male TB patient, South Africa].

“Taking tablets without eating can make you drunk, knock you down, and could even kill you”
[30-year-old male TB patient, South Africa].

Special foods could also be a motivation to eat, especially when TB patients were very sick and/or had lost their appetite. In South Africa, patients reported being told by the clinic to eat vegetables, meat, and fruit. For example, the mother of a 31-year-old female TB patient says she was told by the clinic that her daughter “*must eat nutritious foods, so I buy meat, vegetables, cereals, canned fish, and so on, as I was told, because I want her to get better*”. In Zambia, patients recalled being told about what food was prohibited as well as what food was recommended. TB patients were told to avoid okra and *kapenta* (small dried fish) and to eat beans, vegetables with groundnuts and oil, and fruits.

All the patients said they felt much hungrier on medication. A 50-year-old South African male TB patient explained, “*I eat a lot now—I can finish two plates of food a day and I wake up at night and search for food. My family knows there must be some food left in the plate*”. Patients in both countries talked about craving for food that their families could not afford to buy. And in the group discussions, nutritious foods were deemed necessary for those with TB but were also said to be “*scarce*”.

This put households and TB patients in a terrible quandary—they needed to buy food they couldn’t afford. In Zambia, patients often demanded food high in protein, particularly fish, eggs, meat, and sausage as well as soft drinks, and fruit. This was in contrast to the

Extraordinary Hunger

“The difference is that before TB, whenever I felt hungry I would still go without eating anything - that is if I had no food – but the TB hunger is worse. When you feel hungry, you need to eat; you just have to find food, otherwise your body shakes and you feel generally weak. TB hunger can cause you to steal!” [55-year-old female TB patient, Zambia]

Struggling to Provide TB Patients with Special Foods

“I have a child who has TB. He cannot ask for special foods because he is not working. He must accept what I am offering him, because he is not even getting the grant. If he was..he would buy himself those morvite (wheat meal), carrots, and all the special foods...he does not ask (for special foods) but I sometimes feel for him and buy him fruits, cabbages, but we don’t have them at the moment. I do buy those things when I have the money” [elderly woman, group discussion, SA].

“I tell you it is a problem. Their food desires changed all the time. Today they want this; the other day they want that. I do not know how I managed. Sometimes one would have the appetite and the other one would not. On other days, they both wanted to eat too much. There were days when one wanted eggs and the other one wanted fish or chicken. It meant me cooking eggs, then fish...Then also I had to cook for the rest of the family” [mother to two TB patients, Zambia].

usual diet of vegetables and maize-meal (*insima*). Indeed, in some cases, TB patients refused to eat vegetables and many of them felt entitled to special food. In one Zambian household, the 21-year-old female patient asked for sour milk and meat but the household was unable to provide these. *“I cannot manage her demands because I do not know where to start from, I have no money”*, said her grandmother. And in South Africa, a 32-year-old daughter with TB infuriated her mother by asking her to buy chicken portions, mayonnaise, tomato sauce, aromat (seasoning), cabbage, potatoes, and liquor (alcohol) on grant pay-out day. Again such items contrasted with the staple foods, sugar, and cooking oil usually bought in bulk on a monthly basis on grant pay-out day.

All affected households would try to buy special food for the patient if and when they could. Indeed, comparing food consumption in affected and comparative households over a seven-day period in February 2007 in Zambia revealed that the affected households were trying to meet the nutritional demands of TB patients by having a more varied diet and by preparing more frequent meals. The comparative household’s food consumption pattern is more typical of a Tonga diet in the village; normally chicken, fish, milk, or soya pieces would only be eaten a few days a week—and often not at all during February (a hunger month).

Comparison of Household Diet over 7 Days, February 2007, Zambia

	Food type	Sources	Frequency of meals
TB patient household	Chicken, milk, dry meat, soya pieces, eggs, fish, vegetables, bread, maize-meal	Bought from market, gifts from relatives	At least twice a day
Comparative household	Vegetables, maize-meal.	Mostly from own garden, a few bought from market	Usually once a day

In Zambia, the patient was frequently served first, and sometimes the special food would be reserved only for the patient. The caregiver might kill a chicken and cook a small piece for the patient and the rest would be roasted or smoked on wood to preserve it for a week or so until the patient had finished the whole chicken. Other members of the household, especially children, found this hard. In one household, the children once pretended to be sick so that that they, too, could have a chicken to themselves! In South Africa, patients were not served first, but households did try to reserve special food (for example, eggs, soup, meat) for the patient.

For those co-infected and on ART, needing to eat and take treatment was a more long-term problem. One 25-year-old Zambian man said, *“I tell you suffering from TB and taking ART but no food is torture”*, and a 25-year-old Zambian woman said that she had lost a lot of weight but could not afford the *“balanced diet”* of fruits, groundnuts, *“relish”* that the ART clinic recommended since they were expensive—*“We can only afford vegetables, so I will never gain weight”*, she said. All three, some months after completing TB treatment, were complaining about being short of food.

The Nutritional Impact of TB on Households

Findings from anthropometric measurements in children under the age of five in both the affected and comparative households in Zambia show that both have a poorer nutritional status at the time of the second measurement (May/June/July 2007) compared to the first measurement (October/November 2006). In the affected households, 13 children's measurements were analysed and in comparative households, 11 children's measurements were analysed.

The findings show that both affected household and comparative households have a poorer nutritional status at the time of the second measurement (May/June/July 2007). Although the 2006/7 farming season was better than the previous year, the harvest and effects of this improved season had not yet kicked in nutritionally for all the households—their worsened nutritional status in May/June/July 2007 was therefore a reflection of the previous 2005/6 season. On average, affected households exhibited greater losses of weight and arm circumference¹³ at the second measurement than comparative households and some affected households exhibited large weight losses. Arm circumference is a measure of fat stores, and reduction in fat stores indicates loss of nutritional status in the immediate term.

The Cost of Special Food

The increased demand for food as well as trying to provide the specific foods required often proved a strain on household finances. Using the local wealth ranking categories, 15 of the 18 affected households were food insecure (see Tables 3, 4, 5, and 6). Five of the seven affected South African households who were food insecure consistently did not have enough food and another two (both larger households) had no food at certain times, particularly in the days running up to grant pay-out day.

Food Insecure Household, SA

“I also lack a lot because even my father's grant is not enough – it's no money. Look now the small one was looking for porridge! There's no sugar, no maize-meal, there's nothing – we only have maize...sometimes we cook samp and they eat it when going to school and that becomes their meal for the day....I am not right. I always think of what are my children going to eat. Now that makes me sick; it causes me stress” [39-year-old female TB patient, large household, SA].

In Zambia, all the affected households were food insecure. For four of them, this meant sometimes not having any food; during the peak months of April, May, June, and July 2007, two of these households had no maize in their *butala*—a sign of being very poor, and the other two had run out of maize by May and June. For the other four, it meant being short of food and having to reduce the number of meals. All affected households in Zambia relied on produce from subsistence farming, livestock, foraging, and wild foods to feed the household—whereas only two South African affected households picked wild greens to eat.

In Zambia, monthly expenditure accounts from

¹³ This measurement is referred to as the upper arm circumference Z-score or MUACZ.

comparative households showed—with the exception of January, October, and November, when expenditure was pushed up by school fees and agricultural costs—that households spent, on average, around K50,000/US\$12.50, mostly on food and soap. Expenditure accounts from one affected household during a period of critical illness reflected a monthly expenditure four times higher than this average. In this household, the mother of the 54-year-old male TB patient said the total of K235,200/US\$60 was the most money she had ever spent on household food and this was largely due to buying sugar, bread, milk, rice, juice, and sausage for her son. In addition, her elder brother slaughtered one goat and six chickens for the patient and the rest of the household.

In peri-urban South Africa, households were mainly reliant on having cash to buy food, and most would buy in bulk on a monthly basis at a local supermarket after receiving their state grants and/or salaries. This bulk buy would be supplemented with additional purchases (vegetables, fruit, meat, soft drinks) through the month; some of these purchases—especially meat or *braai* meat¹⁴—could be obtained on credit. Whether households managed to buy sufficient food until the next round of payments depended on the size of households (larger households struggled more), contributions of any employed household member, number of state grants, the number of debts to settle, and any family emergencies that required contributions in cash or in kind.

Monthly 'Hamper', SA

- 10 kg of maize meal
- 10 kg samp
- 10 kg flour
- 10 kg potatoes
- 10 kg dry beans
- 10 kg sugar
- 2 litre of cooking oil

Cost: between R169/US\$28 - R200/US\$33.

Faced with providing food required by the TB patient, in most cases, the smaller South African households were able to provide the majority of food required by the patient, bolstered by state grants, NGO support, employment, and support from relatives. The

Content of Food Parcels, SA

Samp, maize-meal, flour, sugar, cabbage, soya mince soup, coffee creamer, dry beans, tinned fish, cooking oil, yeast, tea bags, sunlight soap, and a packet of beef stock cubes.

more expensive food items requested by TB patients were bought when money was available or on credit. Money and sometimes food were also borrowed from friends and neighbours as families struggled to meet patient needs. Clinics in South Africa also provided patients with porridge and milkshakes so that they would always take their medication on a full stomach. One 50-year-old male TB patient said he liked the instant porridge he received from the clinic and was unhappy when it was not available. Four households also received food aid (called food 'parcels') from local religious groups and NGOs.

No affected household in Zambia was able to consistently provide the food required and requested by the TB patient, and used various strategies to cope with the shortage

¹⁴ Meat cooked on a bar-b-que and sold by the piece. *Braais* are found throughout South African townships.

or absence of food. No affected household received food aid or any form of state welfare. Similar to South Africa, borrowing money to get food or to pay for other needs was a common practice by all the affected households. By the end of the study, all of the eight households were in debt, some more than others. The money borrowed came from neighbours, friends, a church, and better-off households in the community, and only the church did not ask for interest. Households were often charged 50% interest on money borrowed—this type of informal borrowing is known as *kaloba* and is widespread in Zambia. In South Africa, four households were also in debt, which they were struggling to pay off after grant pay-out day or at months end.

During TB treatment, five of the Zambian TB patients actually relocated (one permanently, four temporarily), specifically to find more food, whereas in South Africa, only one TB patient moved briefly to her sister’s household in order to get better food. This could be humiliating and was not always successful. A 38-year-old male TB patient moved to his sister’s house in town in order to get more food, but moved back to his parents after a few weeks, seeking better care.

It was often the primary caregiver that would go to ask for food from their relatives. Three households borrowed food from relatives, friends, and neighbours. “When we run out of food, I go to my parents to ask for food and they give me two buckets of maize or so. Sometimes my parents send word for me to collect food. I tell my son not to go to school on that day so that we can go and collect the food”, related the co-wife to a 30-year-old female TB patient.

Five of the eight Zambian households sold off assets and livestock, partly to buy food and partly to pay for other costs related to TB. One very poor household sold all its livestock; at recruitment, they had one chicken and two pigeons and during the course of the study, the chicken and the pigeons were sold off. After that, they started selling clothes; the TB patient sold a pair of shoes and some trousers and his mother sold some of her *chitenges*.¹⁵

Relocating to Find Food, Zambia

“We had no food at all so my mother thought it is would be best for us to go and live with her sister for a few days. We stayed a week with my aunt. The food was a lot and we did not have any problems in terms of food. I had forgotten how good it feels to have everything that you need. I have suffered a lot. It is embarrassing to go and beg for food in someone else’s home. I have no option; I have to beg because if I do not, I might die”
[25-year-old male TB patient].

¹⁵ A one-and-a-half metre piece of cloth worn by Zambian women, wrapped around their waist. Colson recalls Gwembe Tonga women saying that in the 1992 drought, they would tighten their *chitenges* to stop them from feeling hungry and work in the fields until “everything went black” and they fainted (Elizabeth Colson, personal communication, June 2007).

Co-Infection with HIV

All except one of the 19 TB patients had been tested for HIV and 13 (7 out of 9 in Zambia; 5 out of 10 in South Africa) were co-infected with HIV; out of these, most of them (n = 8) found out that they were living with HIV after being diagnosed with TB (see Tables 9 and 10). The four TB patients (one in Zambia, three in South Africa) who knew they were living with HIV prior to having TB had found out by being seriously ill. Two co-infected Zambian patients and one HIV-negative South African patient died before completing TB treatment; another two co-infected South African patients died after completing TB treatment.

Living in countries with high HIV prevalence, affected households were familiar with HIV/AIDS. Seven of the 13 co-infected TB patients shared with the researchers that they had other household members who knew they were living with HIV (including a wife, children, siblings, and a niece); and two shared that they had, in the previous two years, lost other household members to HIV.

Out of 13 co-infected TB patients in this study, by the end of TB treatment, all five in Mbekweni and four of the seven in Pemba/Batoka had started ART. Two of the nine co-infected TB patients (both South African) had started ART before falling ill with TB; the other seven co-infected TB patients started ART after finding out they had TB.

“Where does this TB these children have come from? No, it seems that my children are going to die now that they are grown-ups, although they never got sick when they were young....Is it still TB alone? What kind of TB is at the back?” [head of a Comparative Household, SA]

“I suspected I might have this common disease [HIV] that is out there. I thought I might have TB, but it might not be TB alone” [31-year-old female TB patient, co-infected with HIV, SA].

“I was scared of going to the clinic to get tested because I did not want to find out that I have HIV. I suspected but I did not want to know my status” [50-year-old male TB patient, co-infected with HIV, SA].

Hurdles in Accessing ART

Despite the provision of free ART, there were various hurdles confronted by TB patients trying to access ART, particularly in rural Zambia. During the study, the ART clinics were at district or mission hospitals in Zambia and at the local clinics or district hospital in South Africa. Therefore the first hurdle for co-infected patients referred to ART clinics was distance and to muster funds to pay for public transport with each trip (there and back). If the TB patient was still quite sick, he or she would be accompanied and this would double the transport costs. In addition, a number of visits were needed in order to be started on ART; in Zambia, a system had been set up that required at least four trips to the ART clinic within a period of two months. In Mbekweni, there were fewer visits to start ART and distances were shorter. It was feasible for some to walk to the ART clinics within

Mbekweni but some were getting ART from either Paarl East Hospital or elsewhere. One co-infected woman and another woman LWH said they struggled to find the money to attend an ART clinic. The one 39-year-old woman said she would sometimes walk the 10 km to the ART clinic at Paarl East Hospital and ask the doctors for her return fare. The other 32-year-old woman chose to attend an ART clinic in Cape Town, because she did not wish to be seen attending a clinic in Mbekweni, but struggled to find the money to reach the ART clinic.

Steps to Commencing ART, District Hospital, Rural Zambia

At two week intervals:

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

Survey of 49 PLWH, District Hospital ART Clinic, Zambia

- 32/49 lived outside town
- To reach clinic, 7/49 cycled, 13/49 walked, and 29/49 came by bus
- 24/49 spent K10,000/US\$2.50 – K30,000/US\$7.50
- 10/49 spent over K30,000/US\$7.50
- 40/49 took over two hours to reach clinic
- 29/49 spent more than 3 hours at clinic on last visit

All the Zambian co-infected patients lived between 40 and 60 km from an ART clinic and, as mentioned earlier, it cost between K12,000/US\$3 and K30,000/US\$7.50 a trip (there and back). This amount was a hurdle for all of them. A questionnaire administered to 49 clients at the district hospital ART clinic in February 2007 revealed that most of them also had to pay to reach the clinic. One 25-year-old woman said her parents had spent about K100,000/US\$25 on transport by the time she started ART. Her parents had to spend roughly the same amount on her 38-year-old brother. The parents said that “*money was not easy to come by*” and they had borrowed some of the transport money from friends and another daughter, urged on by the experience they had had the previous year when their daughter-in-law died. A 25-year-old man raised money for the trips to the ART clinic by selling his clothes and by his mother

borrowing money from friends. But on two occasions, he was forced to miss review days at the ART clinic.

Lacking Transport Money

“Last year my daughter-in-law passed away because we did not take her to the hospital in good time. I do not want that to happen to my two children. People die because they have no money to go to the hospital. Others also default due to lack of transport money to the hospital, so my husband and I are doing the best we can so that the patients can manage to go for their reviews” [Mother to two co-infected TB patients, Zambia].

“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 the 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!” [25-year-old co-infected man, Zambia].

“My husband does not want to give me money to go to hospital to collect ARVs. The other day I asked him for transport money to hospital, he refused....My husband does not want me to start taking ARV drugs” [30-year-old co-wife co-infected with TB and HIV. With the help of friends, she managed to start ART in April 2007, but died a month later.]

And often in practice in Zambia, the four steps took at least five visits, which increased transport costs. Additional visits were caused by congestion, lack of power, losing blood, faulty equipment, and the administrative procedures. In some cases the queues are too long; as one 35-year-old co-infected woman in this study related—*“The ART clinic is a long process. You go early in the morning and get back late at night”*. She had experienced having to queue and not managing to get seen at all. She reflects on the congestion at the ART clinic, *“Hey! It is 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”*. Her 38-year-old brother said his blood was taken but repeatedly lost. And a 54-year-old man reached the ART clinic to find the CD4 machine broken; his health rapidly deteriorated and he never managed to make it to the clinic again, dying a month later.

Repeated Visits to the ART Clinic, Zambia

“There were many problems. When I first went to the ARV clinic, I was told to give blood so that tests would be done. When I went back for my results, I was told that the results were lost. Before I left, I gave them more blood. When I went back the second time, I was told that my blood 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 ARV drugs” [38-year-old co-infected man, Zambia].

During one observation, lack of food combined with long waiting times caused frayed tempers at the ART clinic. Most people attending the clinic had not eaten before leaving home and by mid-afternoon were tired and hungry. One man shouted at the staff, “*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?*” Clients also complained about sometimes being given fewer pills than what is written on the container and that the staffs running the ART clinic were “*lazy*” and not concerned about their welfare. The staff, in turn, explained that they were short staffed and that the process required spending time with each client, explaining the importance of adherence and what side effects to expect. They also said that clients needed food supplements, because most of them are very poor.

Denial remains a hurdle to accessing ART. Two other co-infected patients in Zambia—a 30-year-old man and a 21-year-old woman—refused to go to the ART clinic during the period of the study.

In June 2007, Pemba clinic became an ART delivery centre. One of the TB patients in the study said when she heard, “*That is a wonderful thing! I think I will change to be seen there. It is nearer to home*”. But she still has about 20 km to travel to the clinic.

Disclosure of TB

Being diagnosed with TB was “*disturbing*” to most of the 19 TB patients, due to fears about physical frailty, death, and stigma, and the possibility of co-infection with HIV. Most of the 13 co-infected with HIV and the 6 who were not co-infected with TB were cautious about disclosing that they had TB. One 40-year-old Zambian man said he never imagined he would suffer from TB. His parents had had TB and he was scared of being as sick as they were and of “*looking as bad as they looked before they died*”. He was open about having TB once he discovered he was HIV-negative, but two other South African men who tested HIV-negative did not inform their girlfriends that they had TB. Precarious relationships and marginality undermined disclosure of TB. A 25-year-old Zambian woman in a marginal position in her household hid her TB diagnosis from others, retorting, “*Why should I tell people about my TB? They only gossip. I hide that I am a TB patient; I do not share with anyone*”. In contrast, one 50-year-old man in South Africa, well supported by his family, explained that his family were not shocked when they heard he had TB and said he didn’t have a problem that others in the community knew he had TB—“*TB is known. People with TB are known. I hear from people about other people....They say you recover, just use treatment*”.

Disclosure of HIV

In this study, there was more openness and acceptance about living with HIV in South Africa. Out of the five co-infected TB patients in South Africa, one was public about her status, three were relatively open—disclosing to children, partners, families, and close friends—and one 31-year-old woman had only disclosed to her mother and boyfriend, fearing gossip and abandonment. Indeed, her boyfriend later left her,

accusing her of being unfaithful, and she recalls people pointing fingers at her in the street saying, “*You see that one has that thing; she has won the LOTTO*”¹⁶.

Those who had recently found out their status said that they had accepted it and were “*fine*”, but brushed off any in-depth conversations about living with HIV, disclosed to a very limited circle, avoided contact with the VCT counsellors, and in reality seemed to be struggling.

The narrative of the 46-year-old South African woman living with HIV for some years reflects a deeper acceptance. In 2002, when she fell extremely ill, she decided to test for HIV—“*I did not just want to sit not knowing what is wrong with me...I want to be around to see my children grow up*”.

Once diagnosed with HIV, she first told two good women friends and then her daughters. Her elder daughter reacted with understanding and compassion. Both her children now help remind her to take her medication (both ART and TB). Slowly, over the coming years, she told other relatives and some of her tenants about her HIV status, on two occasions travelling to Eastern Cape to tell uncles (her mother’s brothers). Sometimes she would disclose to strangers at the clinic or other people in her network, if the situation suggested it might be helpful. People thought she was joking on occasions; others responded with compassion. Although she had been

Reluctant to Disclose HIV status

“I feel it is not 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, Zambia].

Acceptance of HIV status

“That’s why your weight has gone down like this, I noticed your weight and I had my suspicions but I was cautious to ask you because you are my mother. Don’t worry; nothing is going to change our relationship. You are still my mother!”
[Reaction of 17-year-old daughter to her mother’s disclosure about HIV, SA]

a member of the Treatment Action Campaign and attended a support group for PLWH since being diagnosed, it was only after taking part in marches and after being on ART for over a year that—in response to a request from her support group—she decided to go public. “*Some people knew I was HIV-positive but I was not comfortable to stand up in public gatherings and disclose. I started doing it at the funeral of a friend’s relative....I felt confident after I disclosed*”. She went public first at a funeral and then on World AIDS Day (December 1st).

In the accounts of all of these five co-infected South African TB patients, it is evident that the clinic, relatives, and patients themselves use the high prevalence of HIV and the availability of treatment to normalise HIV and to both challenge and reassure fears and stigma related to HIV.

¹⁶ LOTTO comes from winning the lottery; there is both irony and a play on ‘four words for AIDS’ in this label, even though ‘lotto’ is five letters. ‘Four words’ and ‘three words’ are popular terms for AIDS and HIV in South Africa.

Normalising HIV in South Africa

“I was told by the staff at the clinic that nowadays, people don’t get HIV through sexual intercourse; HIV is something you get from the air....She said she could not say I got it from my sexual partner because there are so many people in Mbekweni who are infected with HIV, you are not alone. Everyone who comes out of this door has an HIV test and the results are positive” [31-year-old co-infected woman, SA].

“I tell people not to be scared when we drink from the same glass and they don’t believe me and say I am lying because I am looking fat. I tell them I treat my HIV” [39-year-old co-infected woman, SA].

“it is silly to ridicule people living with HIV. This thing is in everyone; it is just going to appear at a later stage when people get sick and confined to bed” [mother to 32-year-old co-infected woman, SA].

In Zambia, there emerges a different pattern of HIV disclosure. In this study, Zambian TB patients were less open, less pragmatic, and more scared about co-infection with HIV, and without the household counselling intervention, it is likely that disclosure would have been even more limited. One man and one woman out of the seven co-infected TB patients did not share their HIV status with anyone other than the household counsellors. The man also shared his status with the researcher and research assistant. The latter was in denial and fearing gossip; and the woman was also in denial, having been abandoned by her husband, lost her only child to HIV and having relocated to the village to stay with her grandmother who she did not know well.

Four other co-infected patients told some family members (two told their mother and wife, one only told his wife, and one told both her parents—all with support from the household counsellors) but did not share their status with any other relatives or anyone else outside the household. The three who told their wife did so within the context of couple counselling, conducted by the household counsellors. One of these—a 30-year-old Zambian man—was confused and resentful about this wife’s HIV negative status, and has continued to struggle with accepting he has HIV, despite some continued counselling support.

The only co-infected patient in Zambia who disclosed to anyone outside the household was a 30-year-old Zambian woman, who speaks to the real risks of disclosure. She found out she had HIV when she, her husband and her co-wife tested for HIV in the context of household counselling. Although she and her husband had HIV, her co-wife was HIV-negative. She disclosed to a good friend who subsequently gossiped to others about it and before long, the researcher came across women gossiping in a salon about the woman's HIV status. In addition, her husband blamed her for infecting him with HIV, and the co-wife stopped helping her with any chores, bathing her or her clothes, and refused to eat with her. This corresponded with her getting increasingly ill. The co-wife, who had cared for her for the previous year and a half with some compassion, confirmed that she was scared of her children being infected with HIV, protesting about the TB patient not wearing gloves when she washed her clothes and that she ate with bare hands. This behaviour would appear as a deflection of her anger at her husband's own HIV status and his relationship with the other wife, as well as her own fear about becoming infected with HIV, since he was forcing her to have unprotected sex with him.

Rejection

"She [the co-wife] has been giving me food separately from the time I started getting worse. She is scared I might infect her and the children....She refuses to help me. She refuses to come near me and when it is time to eat, she leaves the food by the door. She tries to avoid any contact with me. I feel very bad"
[30-year-old co-infected woman, Zambia].

Stigma Related to TB and HIV

The fears and experiences around disclosure of TB and HIV indicate the stigma related to TB and HIV. A common form of stigma in both countries was verbal stigma—gossip and name-calling. Such remarks are usually instigated because of the physical frailty, especially weight loss—Goffman (1963) labels this type of stigma as 'abominations of the body'. According to the home-based caregivers in Zambia, in some households, TB patients—like poor people—are resented and "treated more like dogs...some are actually called dogs".

Another common form of stigma was social exclusion; many patients talked about friends and relatives no longer visiting and children in the affected households were also visited less by friends. In South Africa, neighbours

Name-Calling

"Whenever I entered the bus, everyone would look at me and some would move away from me...I used to feel uncomfortable because everywhere I went, people used to stare at me" [25-year-old male TB patient, Zambia].

"A young man, my neighbour, started shouting at the top of his voice that a TB patient had stolen a chicken! He called me all sorts of names. He called me an AIDS patient. He called me a dog. He told me it was not his fault that I was promiscuous and had landed myself a disease. I felt very bad. I still feel very bad. That young boy has no respect. He insulted me in front of my children" [30-year-old male TB patient, Zambia].

were less likely to stop visiting than in Zambia. There were often a number of reasons for not visiting TB patients, including fear of transmission, moral judgments about TB, and avoiding requests for assistance, but the subsequent exclusion was hurtful for the patient and the household.

There were more fears around the transmission of TB in Zambia, which led to more physical exclusion—all Zambian TB patients used separate utensils and were moved out of the main sleeping area to sleep separately, whereas in South Africa, patients shared utensils and, when very sick, were brought into the main sleeping area to be cared for. A 54-year-old Zambian male patient said his brother and sons feared catching TB from him and they would only bathe him if they had gloves to put on. He found this demeaning. In general, South African patients and their households seemed to be more familiar and less scared of TB.

“I am usually isolated – they bathe me with gloves on, and when they do not have gloves, they either wear plastics or skip my bath” [54-year-old co-infected man, Zambia].

Rejection

“She is annoyed with me and she does not want anything to do with me because I do not have money and she cannot have the kind of life she wants. There is no marriage between us. From the time I came to learn about my HIV status, there has been no marriage” [25-year-old co-infected man, talking about the relationship with his wife, Zambia].

There were many examples of TB patients and people living with HIV (in both affected and comparative households) facing rejection. Five TB patients’ relationships with their spouses or partners broke up when they were sick with TB and two other relationships were in jeopardy. In Zambia, women seemed particularly vulnerable to this—three retreated to their mother’s house when sick, after their relationships with their husbands broke down. Sometimes there was a history of problems in the relationships, but sometimes it appeared to be the disease itself—combined with a downturn in household economy brought about by TB—that led to the break up. This is illustrated by the experience of a 25-year-old Zambian male TB patient who, previous to TB, was a successful trader. He said his wife left him because he was no longer able to earn a living. He shunted between houses seeking care—first staying with his mother, then his mother-in-law,

then his brother-in-law, and then ending up back with his mother. He faced various forms of neglect—his mother left him alone without a bath or water for drinking four months into his TB treatment. And he faced rejection—his wife rejected him, his mother-in-law threw him out of the house in the middle of the night, and his brother-in-law made him sleep under a table and would not allow the children to go near him.

Emotional Impact of TB on Households

Although often households were initially compassionate and supportive when TB patients were ill, over time, relationships in the household became more stressed. The strain that TB imposed on households, and especially primary caregivers, became increasingly more apparent three or four months into TB treatment as caregivers got progressively more tired, household resources dwindled, and other priorities emerged. In both countries, these tensions erupted into open conflicts, usually between the primary caregivers (mostly mothers) and patients, although ultimately, relative to other relationships, mother's love was recognised as more guaranteed. In Zambia, the worse conflicts were between co-wives and between mothers and adult children. In South Africa, the worse conflicts were between siblings. Many caregivers fell sick themselves towards the end of the period of TB treatment.

Conflict between Mother and TB Patient, Zambia

"I quarrelled with my mother over cooking oil. On Saturday I was left home to cook and when my father came home and found me cooking, he told my mother not to leave the cooking for me, because he fears I might burn myself since I am still weak. My mother got upset and when it was time to cook, she complained that I had put too much oil in the food. She said that I was wasteful and was not going to have any cooking oil for a week. She said so many things about my illness, accusing me of having acquired the disease because of my carelessness. The words she used were too much for me so I failed to eat my food. I went to bed without eating. The next morning I decided to move to that hut in the bush, because I did not want to face my mother. She is a demon... Sometimes she says nasty things to my brother and he, too, runs away. One day I found him in the bush sleeping under a treeI asked him why he was sleeping under a tree and he answered by saying he was running away from my mother's big mouth" [25-year-old female TB patient, Zambia].

Stress of Caregiver

"I used to be so stressed and I would cry when I was alone. I ended up shouting at every one and it made me sad that I would not handle my emotions. I know my children well and I can handle them, but I was failing. Caring for the sick is not an easy task" [mother to two TB patients, including a 25-year-old woman, Zambia].

The three mothers who were primary caregivers in South Africa were worn down by caring and juggling expenditure of their old-age grant—they were also older (57, 74, and 77 years). But, unlike in Zambia, they did at least have the benefit of the old-age grant. One 30-year-old male TB patient in South Africa was cared for by his father,

since his mother lives in Eastern Cape with her younger children and his father works for a construction company in Mbekweni. His father also seemed a bit strained by caring for his son and gets fed up with his son not doing household chores, accusing him on one occasion of being “*lazy*”, although his son was quite ill at the time.

Most prominent in South Africa was a pattern of tensions between adult sisters and brothers in the households, usually arising over alcohol abuse and household income, ironically escalating if the TB patient received a disability grant. Once the grant was received—usually two to four months into treatment—the household and any kin outside the household, who had helped the TB patient out, expected their share. A 32-year-old woman, recognising this expectation, was careful to buy food for the house and pay R300/US\$73 for her sister’s trip to Eastern Cape when she received her grant. She also started doing household chores. The researcher asked why she was washing her sister’s clothes during a visit, and she replied, “*Yho, they talk too much. They would say we took care of you while you were sick and now you are healed and don’t want to help us*”. In three other households, a history of tensions between siblings erupted when two male TB patients and one man living with HIV received their disability grants. They all lived in shacks in their sisters’ yard. The sisters expected the grant to help them buy food at the very least. Although one brother did contribute part of the grant to food, all three brothers spent part of the grant on liquor, often entertaining friends, much to the fury of their sisters. All of the sisters either used direct confrontation (in the form of verbal insults and physical fights) or, in one case, imposed restriction orders (with the support of the police) to redress what they regarded as abuse of the grant. When two of the TB patients returned to work, the tensions dissipated. Likewise, when the other TB patient allowed his sister’s daughter (and his favourite niece) to collect his disability grant for him and to buy food and make funeral plan payments on his behalf, the tensions fell away.

This study does not have many insights into the emotional impact of TB on children in the household. During periods of critical illness or relocation, children at times seemed neglected. One son in Zambia said he found his task of bathing his father inappropriate. Another 12-year-old in South Africa “*did not show any emotions*” when her mother disclosed that she (the mother) was living with HIV. Some children in affected households in Zambia resented the special food that TB patients received. And in South Africa, children were putting other demands on household income that competed with the needs of TB patients. An example is the 77-year-old mother of a 32-year-old female TB patient, who after receiving her old-age grant, had to balance the demands of her daughter for specific food with demands from teenage girls in the household; she bemoaned, “*I am really burdened. Can you imagine all this responsibility; the girls are growing up and the demands are getting more—they want to look smart. The youngest one says she wants to have braids on*”.

Presence and Absence of Support

Primary Caregivers

The primary caregivers for the TB patients were usually women (see Tables 3 and 4), mostly mothers—eight mothers in total, five in Zambia and three in South Africa. The other women caregivers were sisters, daughters¹⁷, girlfriends, a sister-in-law, a grandmother, a niece, a wife, and a co-wife. In two South African households, fathers were caregivers. Both fathers shared the care of their daughters with another person in the household; this pattern of spreading the care of the TB patient across more than one person was found in two other South African households as well. Indeed, initially it was sometimes hard to identify the primary caregiver in the South African households, and it was only after some observation of events that it became apparent who took a lead in caregiving. In two cases, it was the TB patient themselves who was sometimes responsible primarily for their care (one a tenacious female head of household, and the other a younger man whose family were out at work all day and whose father was the primary caregiver). In Zambia this pattern was not observed and the care of a TB patient always fell on the shoulders of one woman in the household. Overall, it was close women kin, as well as two girlfriends, who proportionately spent time and energy on caregiving. If patients recovered, they often expressed the appreciation of the care they had received from their mothers and siblings.

A Mother's Care

"I don't want him to be alone in the shack; he might say he has taken his tablets and eaten his food when he has not. I want to make sure he takes his medication" [74-year-old mother's explanation for moving her 50-year-old son into her house when he is diagnosed with TB, SA].

A Child's Appreciation

"The illness has taught me a lot about my family. I have come to appreciate my mother and siblings" [38-year-old male TB patient, Zambia].

Close and Extended Kin

In three Zambian and five South African households where women were caregivers, there were men¹⁸ in the household, and men kin and boyfriends outside the household, who played a critical role in caring for the TB patient—most often in the form of giving or sourcing financial support for treatment, transport and food, and, in one case in South Africa, it was a mother's brother who oversaw rites that aimed to heal the TB patient. In Zambia, men kin came to the forefront of decision-making at the two funerals. Children had to sometimes take up the role of secondary caregiver; younger brothers or older sons also helped to bathe male TB patients in Zambia, as well as assist them to the toilet, when they were too weak to do this by themselves. And

¹⁷ One of the daughters was 12 years old; the other young women were aged 29 and 21 years.

¹⁸ In Zambia, these men were an elder brother and a father in the household and a co-wife's father outside the household. In South Africa, these men were the mother's brothers outside the household, boyfriends outside the household, and a brother-in-law, a brother, and a father in the household.

daughters in one South African household played a key role in reminding their mother to take ART.

In Zambia, support outside the close kin in the household—including support that runs along marriage unions—appeared to have largely fallen away for poor affected households in this study. Affected households received fewer visits from extended family members compared to the comparative households. One elder from a comparative household remarked that some households had fewer visitors than others because “*No one would like to visit a poor man*”. As a sister—who frequently visited her mother’s house to see her 25-year-old brother—remarked, “*I wish I could do more to help my mother but I do not have much. I also depend on my husband*”.

But in South Africa, mothers, siblings, fathers, and partners (girlfriends and boyfriends) either within or closely tied to the household, as well as matrilineal kin in Eastern Cape, come to the forefront in the event of TB. The presence of elders and, critically, their old-age grant, links with Eastern Cape, and rights to land restitution¹⁹ and/or housing help hold the household and close kin together. Child support grants also help close kin stick together. The evident reliance on a mother’s brother during TB, and the absence of marital unions, suggests a breakdown of bride-wealth payments and patriliney, with a de facto matrilineal system in place.

Disability Grants

There is no functioning state welfare system in Zambia. This made a striking contrast to the South African affected households, which, bar one better-off household with three formally employed household members, were all in receipt of at least one welfare grant. Nine of the 10 South African TB patients received a disability grant of R870/US\$137 a month. This was usually received two to four months into TB treatment. The 50-year-old man who did not receive a disability grant had lost his identity documents whilst in the hospital and could not apply without them—he returned to work whilst still ill. One other 50-year-old died in the process of applying for a grant, but his family was to receive one month’s payment after his death, because the application had been submitted before he died.

A disability grant was regarded as an entitlement for those diagnosed with TB and other chronic diseases, such as diabetes and high blood pressure. Disability grants for those living with HIV were dependent on low CD4 counts and poor health. One 46-year-old woman co-infected with TB and HIV, and in receipt of a disability grant for four years, said she was careful at the ART clinic to avoid seeing a particular doctor who had a reputation for striking people off the grant, although she is looking for a job and generates an income from a bead-making project run by her PLWH support group. The same woman said that

A TB Patient’s Entitlement

“I am going to be patient until the grant is sorted out, because as a sick person, my brother-in-law is supposed to be getting some money” [sister-in-law to 50-year-old male TB patient, SA. The day before her brother-in-law died, she had spent half the day at the welfare office submitting his application.]

¹⁹ Three affected households had received land restitution payments.

she regarded her disability grant as “*getting paid*” for being HIV-positive. All five co-infected South African patients in this study continued to receive the grant beyond TB treatment, unlike the TB patients who did not have HIV. Applying for a disability grant was a barrier for getting employment; a 30-year-old male TB patient in South Africa was refused a job once the prospective employer learned that he was in the process of applying for a grant. He did later receive the grant, and once better, found a job.

Partly because the grant was initially received in a lump sum, covering two and more months, the grant was used not only on food, but, in all cases, on other expenses.

Many of the affected households were also in receipt of other welfare grants; six of the ten had one or more child support grants (R190/US\$32 a month for each grant); and three had one or more old-age grants (R890/US\$48 a month for each grant). For three affected households, the disability grant was their only welfare grant. The affected household with the most grants received a disability grant for the TB patient, one old-age grant, and four child support grants; but combined, this amounted to an income of R2,540 for a household of eight, with no one in full-time employment and the household was food insecure. This is still way below the average income of R5,495 for Paarl District. It should be noted that all the comparative households were also in receipt of at least one grant—indeed, four had one or more disability grants for other health problems.

Grant pay-out day was known as “*Imini Yoncumo*”—“*a day of smiles*”. The 83-year-old head of an affected household said, on a visit that coincided with grant pay-out day, “*this is a lovely day because it is grant pay-out day*”. On this day, as one 32-year-old female TB patient said, “*You eat meat*”.

In earlier research conducted by the ZAMSTAR social science team in Mbekweni in 2005, one young man commented, “*TB is money*”. Rumours that people purposively wanted to get TB in order to access a disability grant (even to the extent of sharing sputum that was positive) emerged in this earlier research in eight Western Cape sites. However, in this more intensive study, there was no evidence that this was actually occurring in Mbekweni. A woman in a poor comparative household recalled that when her late daughter was diagnosed with TB and received a disability grant, some people—aware that she was poor and struggling—gossiped about her daughter and asked what she would do when her daughter died and she no longer had the grant—“*As if my daughter was enjoying her illness*”, she remarked.

Disability Grant Expenditure, SA

Food
Clothing
Transport (including travel to Eastern Cape)
Debts
School fees, uniforms, and stationary
House or shack maintenance
Alcohol
Funeral plans
Cell phone
Bed*
Furniture instalments*
Electricity bill*
Savings*
Remittances to Eastern Cape*

* = less common.

Government Health Services

Although not always quick to diagnose TB, in both countries, the government health system provided consistent support to TB patients in the study, providing them with medical care and free treatment. The TB patients did not complain about the health staff once diagnosed. ZAMSTAR project staffs were based within the TB services at the government clinics, and especially in rural Zambia, their relationship with patients was strengthened by seeing them both at home and in the clinic. In South Africa, TB patients received one packet of milkshake and instant porridge from the clinic in the first two months of treatment and when their weight was low. There was no food aid administered by the government health services in Zambia during the period of the study.

NGOs and Churches

In Zambia, none of the 12 NGOs working with HIV and/or TB in Pemba/Batoka gave any material support to the affected households in this study. This contrasted with Mbekweni, where, in addition to the food aid from the clinic, some affected households received material support. Two South African TB patients received additional food aid from a local NGO. A 46-year-old woman also living with HIV received food parcels every month for her participation in a support group for PLWH coordinated by the Catholic Welfare Development (CWD). A 50-year-old man, egged on by his mother, attended the same support group reluctantly (he was not very open about living with HIV and disliked the in-fighting at the support group) in order to get food parcels, clothing, and a mattress. And another affected household received food aid from CWD and another NGO (Area Development Programme) for household members who were old and living with HIV. On three occasions, Magazi asked local NGOs to give food parcels to two TB patients and one comparative household.

In Zambia, affected households did receive valuable emotional support from some local organisations. This included household counselling from the ZAMSTAR study—each of them was visited at home at least three times during TB treatment. This appeared to have helped the TB patients and their spouses (and, in one case, a mother and young children) decide to test for HIV, as well as giving them the opportunity to learn more about both TB and HIV and allowing them to develop new associations. During the local dissemination for this study in April 2008, some household members said initially they were suspicious of the ZAMSTAR study, seeing it as Satanic, but they later saw the value because they felt “*supported*” and “*encouraged*”. One of the TB patients said at the meeting, “*If it wasn’t for ZAMSTAR I would be dead*”, describing how he couldn’t walk when he first met the counsellors.

Support from churches was more apparent in Zambia. Seven of the nine TB patients in Zambia were also visited at home by church members. Since many of them had relocated, leaving any church networks behind, the visits from church members occurred because of other members of their household attending a particular church. Occasionally, church members would bring a small amount of food from their own home, but usually they came to offer spiritual support. One 25-year-old female TB

patient was suspicious of their visits—saying their visits were voyeuristic and not genuine, and, despite being an active church member in town where she lived before, she told them she preferred to pray alone. When critically ill, and when making sense of their illness, the TB patients would sometimes pray or explain their situation as “*part of God’s plan*”, and as they recovered, some of them started to attend church more regularly, developing a new network. They belonged to a range of churches—Seventh Day Adventist (n = 4), Roman Catholic (n = 3), and Protestant (n = 1). One household attending the SDA church had been banned from attending church services because they had been visiting traditional healers. This greatly upset the mother, who was herself sick with HIV and in need of help and support.

In South Africa, Magazi did not establish the churches that all the TB patients belonged to and none of them went to church regularly. One of them belonged to the Zionist Christian Church, and one belonged to the Children of Peace Apostolic church choir but only attended choir practice once during TB treatment—although the other choir members often came to the house to visit him when he was ill. The TB patients did not tend to emphasise religion in their quest for better health, which was dominated rather by state and NGO assistance and Xhosa culture. Neither did they use God much in their discourse. Other than the Apostolic church choir members, the Catholic Church and a Pentecostal church emerged as sources of support through the activities of CWD and the healing rituals conducted by St John’s church.

Two South African TB patients were visited by the local HBC organisation, but in Zambia, none of the affected households received visits from either of two local HBC organisations. When the researcher held group discussions with both, they said that lack of commitment amongst members, their own poverty, transport problems, the lack of food aid, and stigma associated with their visits curtailed their work. One explained, “*Most people would rather go out to look for food for their own families than visit patients*”. The home-based caregivers explained that they offer spiritual help and practical assistance to households they visit, but “*when you reach the household, they will ask you what type of food you have brought for them*”. The Catholic HBC organisation did occasionally get food aid (maize, beans, cowpeas, and sun hemp) donated by Church Health Association of Zambia, but this was sporadic and when they last received it, it was only enough for 97 households—they had over 300 on their register. Chileshe’s own observations were that both visits and food aid only reached a few households and always those close to Pemba Township. She also noted that approaching the Catholic priest directly was a more effective approach than going through the HBC organisation.

Support Groups

Support groups for PLWH existed both in Pemba and Choma, and in Mbekweni. There was a sense of empowerment that two Zambian women living with HIV who started ART gained through starting to engage with PLWH support groups in Choma town, through which they made new friends, shared their experiences, and encountered some income-generating opportunities. This empowerment was the most evident in the 46-year-old South African woman who had known her HIV status and had belonged to a support group for five years. Other than enjoying sharing experiences with others living with HIV, she was able to generate an income from beadwork with the group, and, once she had gone public with her status, there were

opportunities to earn money for making testimonies and doing outreach education. Other co-infected patients in South Africa had less affirmative experiences with support groups. One man had joined but disliked it because of in fighting and his own reticence around his status, and two other women were reluctant to join a support group for a number of reasons. They both worried that their participation would publicise their HIV status and one said she was not talkative and would not fit in the group whilst the other said she did not know what support groups were.

OUTCOME

The study followed the TB patients and their households intensively during the period of treatment (for eight months in Zambia and six months in South Africa), the last visit being conducted close to the end of treatment. After this, some sporadic contact has been maintained—through the ZAMSTAR teams and through the local disseminations in April 2008 and November 2008, which most of the affected households and comparative households attended. Therefore, the outcomes discussed in this section are confined mostly to how TB patients and their households were at the end of TB treatment—with some scattered but incomplete data about their predicaments beyond this point.

The outcomes are summarised in Tables 9 and 10, and were distributed as follows:

- Death—5/19 (2 in Zambia, 3 in South Africa) by June 2008
- Co-infected with HIV and on ART—6/19 (3 in Zambia, 3 in South Africa)
- Co-infected with HIV and not on ART—2/19 (both in Zambia)
- HIV-negative and completed TB treatment—4/19 (2 in Zambia, 2 in South Africa)
- HIV-negative and on TB treatment for Relapse TB—1/19 (South Africa)
- Unknown HIV status and completed TB treatment—1/19 (South Africa)

Table 9: TB and HIV profile in Zambian affected households

	Sex and age of TB patient	Length of time to diagnose TB	TB outcome	Primary caregiver	HIV status	ART
HH 1A	30-year-old man	4 months	Cured	Mother	LWH	No
HH 2A	54-year-old man	9 months	Died, October 2007	Mother	LWH	No
HH 3A	25-year-old woman AND 38-year-old man	10 months (woman) 2 months (man)	Cured	Mother	LWH	On ART
HH 4A	25-year-old man	20 months	Cured	Mother	LWH	On ART
HH 5A	30-year-old woman	4 months	Died, April 2007	Co-wife	LWH	On ART
HH 6A	21-year-old woman	10 months	Cured	Grandmother	LWH	No
HH 7A	41-year-old man	3 months	Cured	Wife	HIV-	N/A
HH 8A	55-year-old woman	9 months	Cured	Daughter	HIV-	N/A

Table 10: TB and HIV profile in South African affected households

	Sex and age of TB patient	Length of time to diagnose TB	TB outcome	Primary caregiver	HIV status	ART
HH 1A	46-year-old woman	3 months	Cured	Self and daughters	LWH	On ART
HH 2A	31-year-old woman	9 months	Cured	Mother	LWH	On ART
HH 3A	24-year-old man	1 week	Completed, still coughing	Sister	HIV-negative	n/a
HH 4A	36-year-old man	2 weeks	Completed, still coughing	Girlfriend	Unknown	n/a
HH 5A	61-year-old man	Never clear	Re- treated (relapse)	Sister and girlfriend	HIV-negative	n/a
HH 6A	50-year-old man	1 week	Completed, still coughing, died March 2008	Mother	LWH	On ART
HH 7A	39-year-old woman	18 months	Completed, still coughing	Sisters and father	LWH	On ART
HH 8A	50-year-old man	1 month	Died, April 2007	Sister-in-law and sister	HIV-negative	n/a
HH 9	30-year-old man	1 month	Cured	Self and father	HIV-negative	n/a
HH 10	32-year-old woman	1 month	Cured, but later died in June 2008	Mother and sister	LWH	On ART

Table 11: Deaths during TB treatment and funeral costs

Details of death	Material resources used on funeral	Household economic recovery after funeral
<p>SA: 50-year-old man, HIV-negative, single, staying with brother. Died in Paarl East Hospital, 4 months into TB treatment at the end of month. Body had to be transported to Eastern Cape, ‘washing of spades’ ritual in Eastern Cape and cleansing ritual had to be performed later. Brother devastated by death and off work sick for some months after death due to grief.</p>	<p>Funeral cost R12000/US\$2000. No funeral plan (payments not kept up). Costs were met from employer donation (R800/US\$130), brother selling two old cars (R5,500/US\$900), brother’s household savings (meant for building a house in Eastern Cape), sister who paid for transport.</p>	<p>Immediately after the funeral, short of food – borrowed money from a relative to buy food. In long term, recovered quickly due to savings club payout, one month’s disability grant paid to patient after death, inheriting small house in Eastern Cape, combined salaries. Busy renovating shack for daughter, bought a car, and spent R1000/US\$170 on bedding.</p>
<p>Zambia: 54-year-old man, living with HIV, married, staying with mother. Died in Mission Hospital six months into TB treatment in the planting season; body had to be transported back to mother’s house for burial. His wife and children were staying with her mother in Central Province and had to travel to funeral.</p>	<p>Funeral cost K850,000/US\$210. Costs met by brother borrowing money from neighbours and friends, contributions from mother’s brother, brother contributing two goats, neighbour contributing two goats, mother’s household used all maize left in granary.</p>	<p>Household unable to concentrate or spend resources on planting because of funeral. By May 2007, six months after the death and following a poor harvest, the household’s main diet was pumpkin leaves. Wife and children moved back to house in Pemba Township, but the wife could not afford to send the children to school and was considering relocating to mother’s house in Central Province.</p>
<p>Zambia: 30-year-old woman, living with HIV, married, second wife, staying with husband and co-wife. She died at the local clinic and her family insisted on having the funeral at their house, 40 km from the clinic. Burial delayed by her family holding her body as ransom until the husband paid them for the marriage. When body started to smell, and husband had made one-sixth of the amount they had asked for, they buried her, but then detained him until his other father-in-law intervened, and he was released to raise the remainder of the money.</p>	<p>Funeral cost K736,000/US\$184. Cost met by co-wife’s father contributing cash and maize, husband borrowing money from friends, husband’s brother and nephews contributed a goat, two chickens, and some beef. Additional costs for marriage were K600,000/US\$150, but husband only paid half - K300,000/US\$75.</p>	<p>Household in heavy debt, surviving off piecework.</p>

Death (n = 5)

Out of the 19 TB patients, three died during treatment (two co-infected and one HIV-negative) and two died after they had completed TB treatment and when they were on ART.

In both countries, accompanying the trauma of the deaths was the immediate costs of the funeral. Details of the funeral costs of the death of three of the TB patients who died during TB treatment (and during fieldwork) reveal that funeral costs in both countries were astronomical. In Zambia, there is no culture of funeral plans or saving for funerals despite the high costs of funerals. In this study, the costs of two funerals for TB patients were close to 16 times as much as the average monthly income. South African households were mostly careful to contribute to a funeral plan, although these contributions were an added financial burden that sometimes seemed hard to maintain during the event of TB. Funeral or burial plans are informal savings for burial costs, and contributions range between R50/US\$85 and R100/US\$15 a month and are saved in a bank or contributions are made when a member dies. In four households, sisters and mothers fretted about funeral plan payments of TB patients, if the patients themselves either did not have one or did not keep up payments when they fell sick with TB. Some households had in the past struggled to bury relatives who did not have funeral plans, and would therefore try to make the payments if they could manage, sometimes using the disability grant or other strategies. But not all households managed to keep up funeral plans.

Two other South African TB patients living with HIV and on ART died four and seven months after completing TB treatment. The 50-year-old man had returned to work still coughing, having failed to obtain a disability grant, and had also resumed drinking and smoking. He got progressively sicker and was admitted into the district hospital. His family struggled to find the money to cover transport costs to visit him in the hospital. When he eventually died in the hospital in March 2008, it was only when the police came to the house to report his death a few days later that the family found out. His 74-year-old mother had previously complained that she could not afford to pay his funeral plan when he had TB, because she was already paying her own and another son's plans. She had said, "*He is not taking his health serious, he is going to die and he thinks there is a chance to rise from his death. He is not even paying his burial plan*". Without a funeral plan, and given the high costs of funerals and the food insecurity of the household, this household must have struggled to pay for the funeral and accompanying rites, although Moya was buried in Paarl and not in Eastern Cape. which would have reduced costs.

The 32-year-old woman, who died in July 2008, had remarked that she wished to return to work—"*I want to go to the farms; I'm tired of staying here in this township; I am tired now of doing nothing. I could feel now in my body, I'm no longer weak, I'm fresh*". But her mother discouraged her, saying she needed to fully recover. She died in July 2008 in the district hospital and her body was transported to Eastern Cape for burial. She had a funeral plan that would have helped considerably with costs (depending on the plan, payments of between R3,000/US\$500 and R10,000/US\$1,667 were made).

In addition to the TB patient deaths, affected households in both countries were more likely to have a history of recent deaths. Five of the eight affected households in Zambia and four of the affected households in South Africa had experienced one or more deaths within the last two years, whereas none of the comparative households in Zambia and only one comparative household in South Africa had had a household member die in the last two years.

Co-infected with HIV and on ART (n = 6)

The outcome of starting ART was more transformative in Zambia than in South Africa. For the three co-infected Zambian TB patients who had started ART, there was a transformation in their physical appearance that, in turn, allowed livelihoods and networks to rekindle and even expand. One 38-year-old man talked with both humour and pride of his physical transformation, thinking back to the beginning of his illness, when he arrived at his mother's house in a taxi close to death, and then recalling how the household counsellor had failed to recognise him on a recent visit because he had gained weight. Another 25-year-old patient didn't at first believe that ART would make the swellings in his neck subside, but some months into treatment, he had started

to believe that he could indeed get better. Both these men had also resolved not to resume drinking—both having drunk heavily previous to having TB. One of them and his 25-year-old sister had struck up a new church network whilst ill from which they drew strength. His sister was also delighted with her physical regeneration.

The transformation after ART was less marked in the three co-infected South African TB patients, although all of them remarked about an increase in energy and no longer being in pain.

Only one South African woman had managed to retain her livelihood during TB treatment—she had an income from renting shacks and from the disability grant, and also made a living making crafts and increasingly through outreach HIV education. The other two in South Africa both had disability grants and one was supported by her partner. In Zambia, although the three all managed initially to either return to old livelihoods or identify new livelihood opportunities, both men said they were unable to work as before—and a year later had both returned to their mother's houses relatively healthy but having failed to resume their previous livelihoods successfully and, in one case, having failed to reunite with his wife. Their mothers' households were struggling to recover from the impact of TB, having gotten heavily into debt and having missed out on crucial farming activities in this period, and had ironically hoped that their children would send money to help them repay debts rather than return home empty-handed. The woman continued to try her hand at making tablecloths and to stay with her sister in town.

Physical Transformation on ART

"I was in a very bad state when I first came 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 again. He will think that he has seen a ghost! I remember how terrible I looked...but here I am very fit. I never thought that I would get well and look the way I am looking today. It is a miracle! The medicine has done wonders".

[38-year-old man on ART, Zambia]

Co-Infected with HIV and Not on ART (n = 2)

Only two of the TB patients living with HIV were not on ART—both were Zambian. One was a young 21-year-old woman in a very marginal position—having been divorced, having lost her young baby son, and staying with her mother’s mother whom she did not know well. She was always in denial about living with HIV and as soon as TB treatment was completed, she returned to her brother’s household in Lusaka. Her grandmother’s household was poor but the young woman was not a long-term member of the household and with five generations in the household and six adults. Although food insecure, it was relatively robust; after the young female TB patient left, it appeared to have recovered. But the young woman’s predicament was more uncertain. The other patient was a 30-year-old man whose 53-year-old mother was also living with HIV. By the end of his TB treatment, she had bad herpes zoster and was quite ill, being cared for by her daughter-in-law and unable to continue trading in goats and second-hand clothes. Her son felt “*fit*” and was happy to have recovered and some of his old social networks were beginning to regenerate, but he was not able to find employment and didn’t feel fit enough to farm. The household was surviving off what small harvest they had produced—his wife’s trade in vegetables and goats and his wife’s piecework jobs. He managed one visit to the ART clinic in Choma, but, even after the Pemba clinic started ART, by July 2008, he had not yet gone there, partly due to the lack of funds for transport but also due to his confusion over his wife’s HIV-negative status. His mother also had not started ART. This household had fallen into deeper poverty and isolation since he had had TB, and with his mother’s illness, was vulnerable to falling further.

Proud to Provide

“I am now able to bring some money home, but, like I said, I have lost most clients during my illness, so the money that I am generating at the moment is not much. But I am happy because I can provide for my family” [41-year-old builder, Zambia].

HIV-Negative and Completed TB Treatment (n = 4)

In Zambia, the two TB patients without HIV resumed both their livelihoods and social networks once the TB treatment was completed. The 41-year-old builder slowly started to win contracts back six months into treatment. By the end of the TB treatment, he was rarely found at home—either working or, in the evenings, spending time in bars with friends. His wife was not happy about him resuming drinking. Although he had acquired debts during illness, he was confident he would pay them back and had regained his self-esteem, happy that he could take care of his family once more. He remained cautious about his own and his wife’s HIV-negative results, explaining they could be in the “*window period*”. They have continued to repeat their HIV tests at regular intervals.

The other Zambian TB patient without HIV—a 55-year-old widow with a history of epilepsy and four disabled adult children in her household—had never faced the same degree of isolation as others and had been helped by both friends and relatives throughout treatment with visits and food. By the end of TB treatment, she was back

selling fruits and vegetables at the market, but her epilepsy continued to be a chronic health problem; indeed, she suffered an attack in July 2007 and could not continue trading for a while after that. In addition, her 29-year-old adult daughter felt very much overstretched by her TB illness, and had lost out on a relationship because of her mother's TB illness. The same daughter wished to attend night school, but the household could not afford either to do this or to send her disabled siblings back to a special needs school.

Of the two South African TB patients who did not have HIV and completed TB treatment, one—a young 24-year-old man—returned to work on the farms but continued to be unwell. He also resumed heavy drinking and smoking. His formidable sister, also living with HIV, was busy renovating her house by the end of treatment and the plan was to rebuild her brother's shack against the extension. Buffered by welfare grants and his sister's strong personality and networks (including boyfriends), this household bounced back in the short term from his TB illness; but with two other sisters also living with HIV, mounting credit, and the brother's poor health, the more long-term future looks more shaky. The other patient, a 30-year-old man who had been dependent on his father during his sickness and had also been quite lonely, managed to get a job doing shift work as a general assistant in a hardware store. This work, combined with his father's permanent employment, the disability grant, the future ownership of a house in a converted hostel, a strong base in Eastern Cape, and his reflective personality, meant that the household recovered from the impact of his TB illness, although he also resumed drinking and smoking, which was of concern.

HIV-Negative and on TB Treatment for Relapse TB (n = 1)

The 61-year-old man with a history of mental health problems was not cured of TB and was put on relapse treatment, so his disability grant continued, and he also received visits from a local NGO that observed his treatment. In addition, he had been referred for further psychiatric assessments and there was a possibility that he would in the future receive a disability grant for his mental health condition. He commented wryly, *"It was okay (to be referred) if that was the way I should benefit from the welfare. It was okay; many people have benefited from government. Who can refuse such a fortune?"* His livelihood was marginal—he grew medicinal herbs and did piecework on and off, and was locked into (although not necessarily part of) a clandestine drug and stolen goods network. He lived with his girlfriend in a shack in a notorious, informal settlement. She was referred to as a *"red woman"* (a Xhosa woman who wore traditional clothes and make-up and was thought of as primitive) and she collected rubbish and wild greens, and could be quite abusive to him when drunk. Despite their marginality, both the system and his family were supportive and, if this continues, the 61-year-old would appear to be relatively well protected. Indeed, TB could have precipitated a more stable future for him if he obtains a more long-term disability grant.

HIV Status Unknown and Completed TB Treatment (n = 1)

The 36-year-old man, whose HIV status was unknown, lived with his girlfriend and her 18-year-old son. He was locked into a clandestine network of stolen goods and was arrested for stealing during TB treatment. He received his disability grant at the

end of 6 months treatment and this was a great boost to the household, because his girlfriend had stopped doing seasonal work and they were struggling to buy food before receiving the grant. His girlfriend owned the RDP house they stayed in and the grant allowed them to recover from the impact of his TB illness. But he was not well—still coughing and losing weight—and this, coupled with his clandestine lifestyle, cast a shadow over the future.

DISCUSSION

Comparative Poverty

Because of the established association between TB and the poorest communities (Porter et al. 1999), the two settings in this study were chosen to demonstrate and compare how the event of TB unfolds for households in a poor peri-urban setting in South Africa and in a poor rural setting in Zambia and—critically—in the context of high HIV and TB prevalence.

People living in both sites experience disease alongside desperate inequities (Pronyk 1999). Common to both sites are limited and seasonal livelihood opportunities, alcohol abuse, gender-based violence, witchcraft fears, disillusionment of youth, and a relocation pattern when ill. In South Africa, inequities are also rooted in the legacy of apartheid manifest in the unequal burden of disease on the black population. Peri-urban poverty in Mbekweni is characterised by retrenchment, unemployment, pronounced alcohol and drug abuse, violence, crime, xenophobic trends, and overcrowding, poor housing, and ‘shack’ fires. In Zambia, inequities also reflect the growing chasm between rich and poor as well as rural poverty—manifested in poor infrastructure, food insecurity, limited access to health services, and the absence of government and NGO welfare support.

Overall, the degree of poverty and vulnerability is greater in rural Zambia—before households have to deal with TB and HIV. Compared to peri-urban South Africa, food is less affordable, accessible, and available, assets are fewer, capital accumulation is less, the rural economy is less robust (and less supported by urban kin), and income levels are lower. Peri-urban South Africa is not, by any means, without hardship, but the provision of welfare grants, land restitution payments, the UIF and credit opportunities, coupled with a stronger advocacy and active NGO base, are (combined) a buffer to absolute poverty, proving to be an effective, if limited, form of social protection. Amongst the small number of households in this study, the possibility to buy in bulk, have savings, and make plans (for example, for funerals) in Mbekweni contrasts with the more hand-to-mouth existence led by households in Pemba/Batoka. The contrast lies not only in peri-urban versus rural poverty—but also in different systems (state and culture), different historical legacies, and in the actual use of the systems. When dealing with TB in South Africa, TB patients and their households relied on the state and NGO system much more than in Zambia, where, other than government health facilities, the state and NGOs seemed quite removed and households were forced to be self-reliant.

The TB Trajectory

Symptoms, Frailty, and Dreaming

Charting the experiences of TB patients from the onset of symptoms reveals that most patients got gradually sick. The most common symptoms were a loss of appetite, weight loss, and cough. But by the time they started the TB treatment, most patients were extremely frail and ill. The severe physical debility of TB is frightening, painful, and stigmatizing for TB patients and their households. An unusual symptom was dreaming. With the exception of streptomycin used for relapse TB, TB medication is not normally known to induce dreams (Helen Ayles, Personal Communication, July 2008). The dreams, therefore, signify a wider psychosis related to the experience of having TB. In the South African dreams, the influence of Eastern Cape and Xhosa culture is evident. In the Zambian dreams, the burden of other deaths in the household, limited support, and the shortage of food are evident. And apparent in the dreams of patients in both countries are the importance of witchcraft explanations and traditional medicine, the role of ancestors, grief surrounding deaths, and the fears surrounding TB.

Causes of TB—Witchcraft and Conspiracy Fears

Five TB patients in both South Africa and Zambia attributed their TB, in part, to witchcraft. As Peters, Kambewa, and Walker (2007:47) write for Malawi, witchcraft competes with other interpretations for any one incident (including HIV and TB), although people may use more than one interpretation when assessing illness or death. Thus witchcraft does not exclude other causes of TB. Any rise or trend in witchcraft is an indication of fragmentation—or what Scudder (1983, 1984) labelled “community unravelling”. One TB patient in Zambia was told by a witchfinder that his father was trying to kill him because of his success in business. This echoes Colson (2000) who has documented a new trend of accusing fathers of witchcraft amongst the Gwembe Tonga. She interprets this trend as a reflection of wider grievances about exploitation of the young by elders, as well as a reflection of general unhappiness and vulnerability (Colson 2000:354). Failure to perform rites of passage was also seen as a cause of TB in two cases in South Africa.

Fears about “whites” purposively introducing diseases and about Satanism and blood stealing documented in this study correspond with conspiracy theories documented in Malawi (Peters, Kambewa, and Walker 2007; Probst 1999) and West Africa (Fairhead et al. 2006). These fears both reflect a history of exploitation and represent a form of protest (Schumaker and Bond 2008; Fairhead et al. 2006).

“Therapeutic Misadventures” (Farmer 2000:183)—Treatment Seeking, Treatment Options, Delayed Diagnosis, and Costs

Symptoms were often first self-treated with drugs or herbs, especially in Zambia. As symptoms continued, consultation and treatment was commonly sought at traditional healers—where patients would seek both treatments and/or investigate the cause of their illness—and at government health services. Private doctors were consulted by some patients in peri-urban South Africa. Seven patients relocated back to their

mother's household, and one to his father's household, while seeking treatment. In Zambia, patients (n = 6) relocated from urban areas to Pemba/Batoka, and in South Africa, patients (n = 2) relocated from rural Eastern Cape to Mbekweni. Most patients (n = 12) were admitted into a hospital for at least two weeks before diagnosis. In both countries, diagnosis of TB was always made within government health services and journeys back and forth from government health services were the most frequent. In Zambia, both patients and health staff often first diagnosed malaria, and, despite the evidence that patients were coughing, patients were often not subjected to further examination in their initial visits.

It took between 2 weeks and 10 months for most patients to be diagnosed with TB, with patients both more proactive and TB more quickly suspected and tested for in South Africa. Two women patients (one Zambian, one South African)—both co-infected with HIV—took 18 and 20 months to get diagnosed. This protracted diagnostic search was fed by the often slow onset of illness, misdiagnoses of other illnesses (in particular malaria) and inadequate consultations in Zambia, other treatment options, relocation during the therapeutic search (more notable in Zambia), poverty, sputum-negative results, and co-infection with HIV.

Transport costs for the TB patient and the caregiver during the entire therapeutic search was both considerable and prohibitive in rural Zambia, and also proved difficult for some South African households until they received a disability grant. In both countries, government TB and HIV services provide free consultation and treatment, but seeking alternative treatment—including more traditional forms of healing in both countries and private health care in South Africa—and the distance to health services (particularly in rural Zambia) proved more costly. In this study, rural Zambian households had spent not less than four times their average monthly income by the time TB patients were diagnosed—over a period that varied from two to 10 months. A recent cost analysis of TB patient diagnostic and treatment costs in urban Zambia concurred with these high associated costs, revealing that the median total patient costs were equivalent to 47.8% of patients' median monthly income (Aspler et al. 2008). The latter research also pointed out the roll of delays in adding to costs. More prompt diagnosis is critical not only for patient's health and outcome, but also for the household economy and recovery.

Contracted Space and Loss of Livelihood and Productivity

Although during treatment-seeking TB patients were often more mobile than normal, once diagnosed with TB, all TB patients experienced a contraction in space due to the illness reducing their mobility and due to poverty and the isolation that accompanies TB. Contracted space reduced both livelihood opportunities and the degree to which assistance could be accessed and shared across government, NGOs, and a dispersed network of kin and friends. The mobility of caregivers was also restricted, particularly during periods of critical illness, when they dare not move too far away. Often unable to reciprocate in the short term, TB patients and caregivers were also not in a strong position to engage in "give-and-take" relations, which further deepened their isolation.

In addition to contracted space, both the TB patients and their primary caregivers were often unable to make a living during the diagnostic search and early in

treatment. Ogden et al. (1999:855) refer to the situation of TB patients needing money for treatment yet unable to earn a living as being “doubly impoverished”. All the 19 TB patients used to earn a living before falling ill with TB and all their livelihoods were adversely affected by having TB, both during their protracted diagnostic search and for at least four months into TB treatment. Only 7 out of 19 were to try to resume their previous livelihoods by the end of TB treatment. Most of those who survived were unable to resume their livelihoods in the short term because they lacked the physical strength or the capital, either remaining unemployed or doing other less taxing work.

The farming economy in Pemba/Batoka proved to be especially vulnerable in periods of critical illnesses, especially if they occurred between October and March, when fields had to be cleared, planted, weeded, and harvested. Scudder observed in his earlier research on the Tonga that disease, among many other factors (irregular rainfall, animal and plant pests), caused variation in crop yield between households. “Each time a gardener is stricken and confined to his hut, valuable time is taken away from essential agricultural activities” (1962:240). This observation corresponds with findings in this study. The loss of patient and caregiver productivity during critical farming months led to severe food shortage in half (n = 4) the affected Pemba/Batoka households in the 2006/7 season, which would stretch into and have a negative impact on following farming season. In South Africa, in the short term, the impact of the loss of or change in livelihood was buffered by the provision of the disability grant in all but one household, but in the long term, the loss of livelihood is of concern.

In both countries, common strategies to meet costs associated with TB, and to overcome the dip in household income, were asset stripping (in Zambia, livestock and clothes; in South Africa, household goods and cars); and borrowing money (often with interest) and food (from neighbours, relatives, friends). Additional strategies in rural Zambia were “piecemeal” (casual daily labour), trading, relocating (the patient or children) and begging; and in South Africa, applications to secure a disability grant, drawing down on capital and accessing other forms of welfare support, including other welfare grants and assistance (food, mattresses, and clothes) from the clinic and a local NGO. It is notable that coping strategies were more extreme and more likely to be irreversible in rural Zambia.

TB Medication—Adherence, Side Effects, and Hunger

Only two TB patients, both South African men, interrupted treatment and both resumed treatment relatively quickly (within two weeks and one month). Adherence to TB medication did not emerge as an issue in this study, despite medication side effects that were experienced by all patients. In South Africa, but not Zambia, patients co-infected with HIV and also on ART advocated that neither TB medication nor ART should be combined with other herbal medications. The most common side effects to TB medication were drowsiness and “hunger”.

TB, Food, and Hunger—Nutrition and the Cost of “Special” Food

In a recent review on the role of nutrition in TB disease, weight loss was a common occurrence amongst TB patients, with some experiencing vitamin and mineral deficiencies (USAID 2008). This was worse among those with TB/HIV co infection

(USAID 2008). The nutritional status of TB patients was not measured in this study, but weight loss (often severe) was observed in all patients. In addition, nutritional jeopardy in the affected Zambian households is evident in anthropometric measurements collected at eight-month intervals. Both affected and comparative households in Pemba/Batoka experienced seasonality losses in nutritional status between October/November and May/June/July the following year, but, on average, affected households are in far greater nutritional jeopardy at the end than comparative households. Although the numbers are small, this suggests the negative impact of TB on the nutritional status of a household.

In both countries, similar food needs and desires accompany TB—namely vegetables, fruit, and meat. These are prescribed by the government health staff and a wider culture of nourishment during illness and taking medication with food, and ascribed to by health providers, households, and patients. In all affected households, taking medication without food was considered unwise and dangerous.

However, according to the Food and Agriculture Organization of the United Nations' (FAO) definition of food security, before falling ill with TB and having to deal with the added burden of special nutritional requirements coupled with a loss of income, most households (n = 15) in this study were food insecure. During TB illness, their struggle to satisfy the “*hunger*” of the TB patient and provide “*special foods*” threw many affected households into jeopardy and sharpened desires, food insecurity, and tensions. Although all affected households tried to meet the added nutritional requirements, particularly in the first four months of TB treatment and/or when the patient was extremely sick, and sometimes to the nutritional detriment and resentment of others in the household, it was not always possible. The poignancy of being hungry in the context of poverty and disease was not lost on households.

The change in household diet brought about by TB was more notable in Zambia, where diet was more limited and where food insecurity was proportionately greater in number and degree. Although, in both countries, households would try to purchase fruit, meat, and soft drinks for the TB patients, in Zambia, their presence in the household diet were more unusual and households would often reserve such food items for TB patients. Households would also eat more frequently and spend proportionately much more on food than comparative households. Strategies to cope with a shortage or an absence of food included moving elsewhere to live with other relatives, slaughtering livestock to eat, borrowing, and begging.

Many households in South Africa spoke of the demand for special food as being hard to meet, and there was evidence, particularly in larger households and towards month's end, of both a food shortage and being unable to purchase special foods without using credit or borrowing from others. But all affected South African households accessed food aid from government clinics early in the TB treatment and

Definition of Food Security

“Food security, at the individual, household, national, regional and global levels...exists when all people, at all times, have physical and economic access to sufficient, safe and nutritious food to meet their dietary needs and food preferences for an active and healthy life” (FAO 1996:3).

three also accessed substantial food parcels from a local NGO. In addition, disability grants, once received, were used to purchase food. In Zambia, no affected households received food aid.

Those TB patients co-infected with HIV and on ART spoke about their hunger and the need to have good nutrition. The struggle to prioritize special nutritional needs over other households' needs extends indefinitely for them and their households, and already other evidence shows that adherence to ART and its efficacy are significantly influenced by access to adequate food and nutrition (ODI 2006; PlusNews 2008). A review by the Academy of Science in South Africa concluded that nutrition could neither prevent nor cure TB and HIV, but that better nutrition did result in better outcomes on medication (Ncayiyana and Daniel 2007). Even without the longitudinal evidence, this study suggests that in both settings, both the health of PLWH and households as a whole will be compromised by the struggle to access "special food".

Co-Infection with HIV

For the TB patients, part of the experience of having TB in both countries was the strong possibility that they were also co-infected with HIV. This study implies that the health services in both counties are successfully encouraging TB patients to test for HIV, since only one of the 19 TB patients had not tested for HIV. However, it should be noted that the presence of the ZAMSTAR trial in both sites enhanced the likelihood of TB patients undergoing HIV testing. Thirteen of the 19 TB patients were co-infected; most (n = 8) tested for HIV after being diagnosed with TB. This reflects the trend in both countries that people mostly only test for HIV when they fall very sick. Four of the co-infected TB patients died after starting ART; three after completing TB treatment. Mortality rates are higher in co-infected TB patients (Zachariah et al. 2007).

Hurdles in Accessing ART

Co-infected patients faced various hurdles to access ART. Costs associated with ART had to be met by households that were already stretched by a period of managing TB. Indeed, distance and transport costs were insurmountable for some patients in rural Zambia, either leading to a delay or failure to start ART, or missed review appointments. Accessing ART was much more feasible for poor households in peri-urban South Africa, due to the shorter distances, the disability grant, and less absolute poverty. Interruptions to ART were documented in two South African and one Zambian PLWH. In South Africa, interruptions were due to travelling to rural Eastern Cape (implying that accessing ART in rural South Africa would be more problematic) and due to work hours. In Zambia, interruptions were due to a lack of funds for transport.

Observed only in rural Zambia were other hurdles to accessing ART, namely, denial of HIV infection; lack of support from close kin; the requirement to visit the ART clinic at least four times before being started on ART (including one visit when someone else had to accompany you as a "buddy"); congestion at the clinic, leading to long waiting periods often without food; lengthy administrative procedures; a shortage of staff; and inefficiencies of the health services (losing blood, having no power, the CD4 machine breaking down). In July, 2007, the Pemba clinic became an

ART delivery centre, as part of the roll-out of ART to more peripheral centres. The shortage of staff, delays in CD4 results, and congestion are already becoming an issue, although the presence of additional ZAMSTAR staff at the clinic does help. By July, 2008, 268 people living with HIV had started ART through the Pemba clinic, but most are struggling to come on time for review appointments (when they collect their drugs).

Disclosure and “TB/HIV Stigma”

In areas of high HIV prevalence, the stigma related to TB has deepened and a new stigma has emerged—namely “TB/HIV Stigma” (Bond and Nyblade 2006). This is evident in much of this material; central to the experience of TB—and of co-infection with HIV—is both anticipated and enacted stigma. This is a thread that runs through patient journeys. TB patients all experienced verbal stigma (gossip and name-calling) and social exclusion. Rejection was another common form of stigma; five relationships with spouses or partners broke up during TB illness. It is unsurprising that disclosure both of TB and HIV remained limited, especially in rural Zambia, where disclosure remained risky, increasing the chances of rejection and exclusion. In peri-urban South Africa, disclosure was wider and safer for those who were older, in a stronger position in the households, in good health and accessing ART, in contact with support groups, and aware of their HIV status for some time.

Overall, in Zambia, stigma related to both TB and HIV seemed to be more marked. There were more fears about being diagnosed with TB and around the disclosure of HIV. Social and physical exclusion of TB patients was patently more evident in Zambia. All Zambian TB patients used separate utensils and were moved out of the main sleeping area, whereas no South African patients used separate utensils, and patients were conversely moved into the main sleeping area to be cared for when they were very ill. Physical exclusion of TB patients is actively encouraged in Zambia and elsewhere as a public health strategy (Bond and Nyblade 2006) and fears about casual transmission are a main cause of TB-related stigma (Van Rie et al. 2008; Bond and Nyblade 2006). This study implies that public health messages in South Africa do not advocate isolating TB patients within the household. The lower level of TB stigma in peri-urban South Africa is also a reflection, in part, of the long history of TB in Western Cape, which has resulted in a strong public health focus on TB. It is possible that the rise in multi-drug-resistant (MDR) TB, including the outbreak of extra-drug-resistant (XDR) TB in KwaZulu-Natal Province in 2006²⁰, could heighten both TB and TB/HIV stigma, but this was not yet evident in this study. However, TB stigma was still evident in South Africa, as testified by the cases of the two men who did not wish to disclose their TB diagnosis to their girlfriends.

The lower level of HIV stigma in peri-urban South Africa in this material, as demonstrated by a more open disclosure pattern, is less about history—since Zambia has a longer history of high HIV prevalence than South Africa—and more about more accessible HIV services (both government and NGO), HIV advocacy, and less absolute poverty. Research conducted on HIV stigma in Zambia in 2002 argued that lower levels of stigma in an urban setting were partly due to the presence of HIV

²⁰ In 2006, 52 people co-infected with TB and HIV with XDR-TB died in KwaZulu Natal. More cases of XDR-TB have been reported recently in Western Cape and Eastern Cape (MSF 2006; Stop TB 2007).

services and wider livelihood options, which enhanced household management of HIV/AIDS by reducing household stress (Bond et al. 2003). But lower levels of stigma, although significant, should not mask the persistence of HIV stigma in South Africa, as evident in other literature (Deacon et al. 2005) and in this study.

Emotional Impact of TB on Households

Emotionally TB patients experienced fears about frailty and dying and fears around co-infection with HIV. They also struggled with their inability to work and provide for their children and household. For men, in particular, the transition whilst sick from being a provider to being a patient was particularly hard and resulted in a loss of self-esteem. This was especially evident when patients were critically ill at the beginning of treatment; patients would often cry when interviewed at this stage. These findings tie in with a multi-country study conducted on gender and TB (Weiss et al. 2008).

Primary caregivers became increasingly strained over time. Often initially supportive, as tiredness and resources dwindled, caregivers could turn on patients and open conflicts ensued—between mothers and adult children, a father and adult children, between siblings, and between co-wives ensued. In rural Zambia, these conflicts oscillated around food, and, in peri-urban South African, around expenditure of disability grants and competing needs of other household members. These conflicts would often fall away if patients recovered and contributed to household income. Caregivers also often fell sick themselves. In rural Zambia, there were signs of the emotional impact of TB on children who could be quite neglected during periods of critical illness and who complained about additional caregiver or household tasks, and about the diversion of special foods and additional resources to TB patients.

Presence and Absence of Support

Close matrilineal kin and, once diagnosed, government health services emerged as the most consistent source of support to TB patients and affected households. The core role of women and matrilineal close kin in the household in both countries is clearly demonstrated by the migration of adult children back to their mothers when very ill and the fact that caregiving fell mostly to women—mainly mothers. Only one primary caregiver (in South Africa) was a father, but fathers or brothers were often instrumental in sourcing money and came to the forefront at funerals. Caregivers in both countries were often dealing with TB in the wake of other recent family deaths.

In rural Zambia, outside the household, there was very limited material support from kin, partly because of general poverty and the inability of very poor households to reciprocate any favours. The fragmentation of support from kin is echoed in the ethnography in the same area by Colson (2000, 2008), Cliggett (2005), Bond (1998), Clark et al. (1995), and Scudder (1983, 1984), as well as in research in Uganda (Seeley et al. 1993; Ankrah et al. 1991) and, more recently, in Malawi (Peters, Kambewa, and Walker 2007). The matrilineal family emerges in this study of the impact of HIV/AIDS on rural households in Zomba District as a “bulwark against massive deprivation” (Peters, Kambewa, and Walker 2007:1), but the researchers argue that once the elder generation die, there is a limit to how much the matrilineal family can cope with. In South African affected households, this fragmentation is less

apparent, buffered by the provision of welfare grants, housing development, land compensation, and a straddling of options across Eastern and Western Cape. But given unemployment and the chasm between youth and the older generations, as well as the more limited influx of capital assets in the future, it is possible that the same process of fragmentation will emerge.

Nine of the ten South African TB patients obtained a disability grant, often some months into treatment. Being awarded a disability grant was seen as an entitlement and an income boost, not only to the individual but also to the household. Often received initially in a bulk payment, grant expenditure included food, clothes, school fees, personal and household assets, remittances, settling debts, savings, and alcohol. The disability grant implicitly links illness with money, but there was no evidence from this study that because of the disability grant any patients got purposively infected with TB or that households were pleased when someone got diagnosed with TB. All households, except one better-off household, were also in receipt of other welfare grants (old age, child support, and disability for other conditions).

The evidence from this study is that government health services provide consistent and compassionate TB services, once patients were diagnosed. Despite the five patients who died in this study, the five who are still living testify for the importance of using TB as an entry point for HIV.

Despite the presence of 14 NGOs working with TB and HIV in Pemba/Batoka, affected households only received external support from ZAMSTAR household counsellors and church members. Spiritual support through membership of churches was much more apparent in Zambia. Two PLWH also belonged to a support group, which was effective in providing them with a new social network, access to more information about ART, and the possibility of acquiring new skills. No affected households were in receipt of food aid or other material support. In rural Malawi, Peters, Kambewa, and Walker (2007), amongst a much larger cohort of households, came across the same striking lack of external support. They, like Farmer (1999), argue that this absence of consistent support to households in need stems from the failure to link poverty and HIV from the level of policy to implementation. They pinpoint the three key weaknesses in the HIV response as the lack of experience to manage funds, misappropriation of funds by lead organisers, and the sporadic nature of services (Peters, Kambewa, and Walker 2007).

In Zambia, a shift in HIV policy and a lack of coordination further explain the failure of NGOs to reach households in need. During the local dissemination for this study in Pemba/Batoka (April 2008), the director of the District AIDS Task Force was himself taken to task for the lack of food supplements for TB patients and PLWH. He defended it on the basis that the policy of NGOs was to move away from handouts to a more sustainable approach—based around income-generating activities and requests from communities. But this study reflects that TB patients and primary caregivers could not be expected to take part in income-generating activities for the first four months of TB treatment, so the approach advocated is inappropriate for poor rural households affected by TB. Nor is it appropriate in the case of the Pemba PLWH support group, who related in the dissemination meeting that in order to qualify for these income-generating projects, they needed to open a bank account, but lacked the funds to do so. Others at the meeting pointed out the failure of NGOs to coordinate

amongst themselves or with the clinic; this lack of coordination has been observed in all 16 ZAMSTAR sites across five provinces.

The reach of HBC in rural areas is undermined by distance, the current policy to not provide food aid, and the poverty of caregivers themselves. Peters, Kambewa, and Walker (2007:66), in their recent Malawi study, pointed out that it is unrealistic to expect poor rural small-scale farmers to allocate time and resources to being volunteers. An earlier study in Zambia also pointed out limitations in HBC response, due to the poverty of caregivers (Bond et al. 2005).

Outcomes of 19 TB Patients

- Death (n = 5)
- Co-infected with HIV and on ART (n = 6)
- Co-infected with HIV and not on ART (n = 2)
- HIV-negative and completed TB treatment (n = 4)
- HIV-negative and on TB treatment for relapse TB (n = 1)
- HIV status unknown and completed TB treatment (n = 1)

In peri-urban South Africa, three households were in receipt of sporadic food parcels and visits from three NGOs. In addition, two PLWH attended a support group, from which one drew considerable strength and income-generating opportunities.

Outcome

Across the two countries, there are mixed outcomes. The most distressing are death and co-infected patients not accessing ART. Also worrying are the apparent failure of treatment for some South African TB patients and the resumption of drinking and smoking by some TB patients (mostly in South Africa). Although numbers are small in this study, four South African TB patients were still not well by the end of TB treatment (two were to die, one was to be treated for relapse TB), whereas all the surviving TB patients in rural Zambia were well. The apparently higher cure rate amongst the Zambian patients reflects national trends in both countries; South Africa has a higher re-treatment rate, higher TB incidence rates, and also higher drug resistance rates than Zambia.

Death of patients was accompanied by considerable costs. In rural Zambia, funerals cost 16 times the average monthly income; in peri-urban South Africa, funerals cost around a month's income. In South Africa, there was more planning for burial costs, based on a culture of paying into funeral plans, although conversely, funeral plan payments were a consistent burden for affected households during TB illness.

A much more optimistic short-term outcome is the transformation precipitated by starting ART. This goes beyond regaining physical strength, spilling out to rekindle relationships and livelihood opportunities fractured by illness and poverty. This

transformation is particularly startling in the context of absolute poverty in rural Zambia, but this study was not in the position to assess how sustained this transformation might be. A sense of agency and “therapeutic citizenship” (Nguyen 2005; Nguyen et al. 2007) that emerges around ART, even in a Zambian rural context, is a sharp contrast to TB treatment that historically has both dictated to TB patients what they should and should not do and, at the same time, often blamed them for failures in TB control.

CONCLUSION

Given the urgent need to effectively integrate TB and HIV services in a bid to manage the dual epidemics of TB and HIV, and in the context of overstretched public health services, high rates of poverty, rising food prices, and the roll-out of ART, this study provides timely and early evidence on the practical reality of poor households in two contrasting settings and systems dealing with the converging impact of TB and food insecurity, often alongside HIV.

The study demonstrates that all affected households are adversely affected by the event of TB in an adult household member in the short term, especially if the TB patient has a pivotal role in the household and if the household is in any way poor or very poor. In the short term, only one household in Zambia and half (n = 5) the households in South Africa recover. In the long term, loss of livelihood, and the wider context of rural and peri-urban poverty and, in South Africa, the disillusionment of youth cast shadows over the future of these households, too, and for those also living with HIV, issues of livelihood, food requirements, distance to health services, and transport costs stretch indefinitely. This is particularly critical to the successful uptake of ART in rural Zambia.

This study would concur with Rugalema (2000), who questions the coping strategy approach, since it masks the struggles and suffering of affected households, and implies that they are coping well. In fact, this small number of TB patient households in rural Zambia and peri-urban South Africa all struggle with the emotional, economic, and practical impact of TB and with the more extended HIV pathway. With the striking absence of social protection outside the household in rural Zambia, TB patients and their affected households are reeling from the impact of TB, caught in seemingly relentless poverty, and only just getting by. In contrast, TB patients and their affected households in South Africa are accessing social protection beyond close kin and government health services. This external support from the state and the chequered support from NGOs do effectively buffer the impact of TB in the short term. However, these buffers do not do away with all the struggles around TB, including the emotional toll of TB and more long-term impact of loss of livelihood and the food needs of those on ART.

RECOMMENDATIONS

In both Zambia and South Africa, the following recommendations emerge from this study:

- **Prompt Diagnosis of TB:** More prompt diagnosis of TB by government health services would considerably reduce both the physical and economic impact on

patients and their households and the impact on the health services in the long term. This requires a reduction of both patient and provider delays. Examples of interventions that target delay include:

- Improved diagnostic management of TB within government health services.
 - Outreach education on TB.
 - Anti-stigma education on TB and HIV.
 - Provision of more accessible sputum collection services.
 - Integration of TB and HIV services.
 - Referral from alternative treatment options (implying some partnership with these options).
 - Financial compensation for transport costs during the diagnostic period.
- Nutritional Support for TB patients: In South Africa, nutritional support for TB patients could go beyond the porridge and milkshakes and ad hoc food parcels to households identified to be in need, and in Zambia, beyond the ad hoc provision of soya in a limited number of government health facilities to a more comprehensive nutritional programme that is more integrated into existing TB and HIV programmes as recommended in the recent U.S. Agency for International Development (USAID) review of TB and nutrition (USAID 2008).
 - Effective Integration of TB and HIV services: This study demonstrates the advantages of TB patients knowing their HIV status. The study also demonstrates the advantages of ART for individuals and their households—although a more long-term study is needed to establish how sustained this is. Integration of TB and HIV needs to include:
 - Promotion and improved access to VCT, which emphasises the advantages of knowing one’s HIV status before falling sick.
 - Improved screening of TB in HIV services and improved uptake of TB preventive therapy amongst PLWH and not infected with HIV.
 - Improved referral between TB and HIV services.
 - Integration of TB into HIV initiatives at the community level, including HBC.
 - More effective linkages between HIV and TB organizations and between the state and NGOs. These linkages appeared poor in Pemba/Batoka, but better in Mbekweni. Government health facilities emerge as appropriate for coordinating efforts.
 - Promotion of TB patient empowerment. The emerging ART therapeutic citizenship (Nguyen 2005; Nguyen et al. 2007) present even in a rural Zambian context shows that TB programmes have much to learn from patient empowerment.
 - Access to Counselling for TB patients and their households: Evidence of the emotional toll of TB on patients and their households, coupled with the possibility of co-infection with HIV, suggests that providing more sustained counselling to TB patients and their households would help resolve conflicts, deal with crisis and bereavement, facilitate referral, and could also be supportive to better outcomes, including uptake of TB screening, HIV testing, ART, and TB preventive therapy.

Much of this could be conducted and delivered within the household, possibly using existing community health works and health staff.

- Anti-stigma Education for TB/HIV: Given the evident persistence of TB and HIV stigma, anti-stigma interventions at both clinic and household levels in both countries could help reduce some forms and consequences of stigma. Adjusting TB prevention messages in Zambia, which promote the separation of TB patients within households, would help reduce stigma. Anti-stigma education could draw on effective anti-stigma education strategies and tools (see DFID 2007, UNAIDS 2007, Clay and Kidd 2003) and use a newly developed anti-stigma module for TB (see TB Stigma Module, www.AIDSAlliance.org).

Recommendations that emerge for Zambia alone are:

- Social Protection for TB patients in Zambia: Given the extent of rural poverty in Pemba/Batoka, the implicit link between food and treatment, the loss of patient and household livelihood during TB illness and the converging impact of TB, HIV, and food insecurity, access to effective social protection from the state and/or NGOs during the period of TB treatment (8 months) is critical to allow poor households to recover from the impact of TB. Social protection could follow the South African example—in the form of disability grants administered through the government health services—and include substantial food aid.
- Social Protection for PLWH on ART in Zambia: The majority of TB patients are co-infected with HIV in Zambia and need to access ART, and some form of sustainable social protection is needed for a longer period. This should include transport costs to attend the ART clinic and some form of food aid and access to income-generating opportunities. Currently, disability grants for PLWH in Mbekweni were used to effectively meet transport and food costs.
- More efficient ART services in Zambia: The roll-out of ART in Zambia needs to address current inefficiencies in the ART services in rural areas. It is recommended that steps are taken:
 - To reduce the distance, the number of visits needed to start ART, congestion, and lengthy administrative procedures.
 - To improve management of samples, and the maintenance and availability of equipment.
 - To increase staff and resources.

Recommendations that emerge for South Africa alone are:

- Prompt Payment of Disability Grants in South Africa: In South Africa, more prompt monthly payment of disability grants would help resolve shortfalls in household income brought about by TB more quickly and encourage the grant to stretch over the period of TB, rather than be spent in a lump sum on a range of items and needs.

Recommendations for future research that emerge from this study suggest that the following future interdisciplinary research would be appropriate in both countries:

- Develop and assess more innovative interventions to reduce both provider and patient delays in the diagnosis of TB.
- Research looking at the most effective approaches for treating malnutrition and improving nutritional status amongst TB and TB/HIV co-infected patients, whilst taking account of local food and its availability and cost-effectiveness (USAID 2008:33), as well as state and NGO systems.
- Social science research on co-infected pathways that extends beyond the completion of TB treatment to capture the synergy between the two programmes approaches, including documenting any effect of the emerging ART therapeutic citizenship on TB patients.
- Evaluating the impact of anti-stigma initiatives on TB and HIV stigma at a community level.
- Longitudinal research that investigates the converging impact of food insecurity, TB, and HIV on poor households in urban Zambia and rural South Africa.

Specific to Zambia, operational research that pilots interventions on social protection for TB patients is recommended.

Specific to South Africa, applied research on accessing and using disability grants related to TB and HIV is recommended.

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