

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

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Zambia and South Africa (SA) are two countries that are seriously affected by the dual epidemics of tuberculosis (TB) and HIV. While both are attempting to integrate public TB and HIV services to reach co-infected people, 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 checkered 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 SA 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—characterized 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.

Economic Impact of TB

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. Caregiver livelihoods were also disrupted, further depleting household income. “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.”

It took individuals with TB symptoms between 2 weeks and 12 months to get diagnosed and get treatment. The failure of health services in both countries to diagnose TB promptly added to costs and extended the period of illness.

In their therapeutic search, patients moved between self-treatment, private clinics, government health centers and hospitals, traditional healers, and spiritual healing. Once diagnosed, costs of transport for routine visits to health services and special foods became a priority in affected households. The cost of accessing ART was considerable—due to transport costs and the number of visits. In Zambia, it took on average five visits to start ART and then regular reviews were required. This made ART unaffordable for three TB patients. In some cases, death and funeral costs incurred were an extreme hardship for the family. In Zambia, the death of one TB patient resulted in funeral costs were 16 times higher than the monthly income. In general, costs of illnesses were higher for Zambian rural households since in SA services were usually closer.

TB drugs are perceived as both causing hunger and demanding food intake. In addition, there is a common understanding that the need for nourishment is greater during illness. TB patients wished to eat more frequently and asked for eggs, fruit, instant porridge, soft drinks, meat, fish, 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, usually patients could not access the food they desired. Common strategies to meet additional costs in both countries were asset stripping (in Zambia, livestock and clothes; in SA, household goods and cars) and borrowing money and food (from neighbors, relatives, and friends). Additional strategies in rural Zambia were “piece-work” (casual daily labor), trading, relocating (the patient or children), and begging; and in SA, these were applications to secure a disability grant.

Presence and Absence of Support

Close 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. Only one primary caregiver (in SA) 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. At four months of treatment, caregivers were 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

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SA, tensions, especially between siblings, would ironically escalate when disability grants were awarded to the TB patient.

In Zambia there was very limited support outside the household. Despite the presence of 14 NGOs working with TB and HIV in the area, only one organization was providing counseling and no one was receiving food aid. In SA, three households were receiving sporadic food parcels and visits from three NGOs, and eight managed to access disability grants,¹ and all households received other welfare grants (old age, child support, and disability for other conditions). Disability grants often came some months into treatment, and were used for food, drink, burial plans, personal goods, clothes, remittances, and savings. The grant payout day was referred to as “a day of smiles,” a day when one would “eat meat” and buy food in bulk.

Physical Debility and Reduced Mobility

When TB patients were regaining health, they and the family referred back to the pain of the frailty experienced—talking in detail of their weight loss, of “soiling themselves,” of being close to death, “crushed,” “crippled,” “thin like a bone,” and of “being cared for like a child.” Patients recalled both gossip and verbal insults about their appearance. Patient 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. Some patients, particularly in Zambia and in marginal positions in the household, became isolated also within it—sleeping separately (in one case, under a table), using separate utensils and eating alone. 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.

¹ Of the two that did not access disability grants, one did not have an identity card and the other died before he had the grant approved.

Patient Agency and Transformation

There is a sense of patient agency in the search for TB diagnosis, especially in SA, where the deepened familiarity with TB and the lower levels of TB stigma made patients relatively proactive about getting diagnosed. For those co-infected with TB and HIV, the sense of agency expanded as people embarked on HIV service pathways. The bodily transformation brought about by ART for those that manage to access treatment was accompanied by a social transformation; new networks formed for some through support groups and churches; some resolved not to resume smoking or drinking; others returned to their previous livelihoods. This was more pronounced in Zambia. But access to good nutrition and food remain an issue, and in Zambia, transport costs remain a barrier.

Conclusion and Recommendations

In South Africa and Zambia, inequities increased both vulnerability to infection and disease and likelihood of delayed diagnosis and delayed or interrupted treatment and care for TB and HIV. In Zambia, those in treatment for TB fell deeper into poverty and were in debt and short on food. In SA, 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 are made available to TB patients and PLWH on ART. 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. The converging impact of TB, HIV, and food insecurity also exposes the need to tackle other inequities in these settings. In addition, the government health systems need to try to diagnose TB more promptly and the emerging therapeutic citizenship within HIV services needs to be replicated within TB services.



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About RENEWAL

Facilitated by the International Food Policy Research Institute, RENEWAL is a regional “network-of-networks” in Sub-Saharan Africa. Currently active in five “hub” countries (Malawi, Uganda, Zambia, South Africa, and Kenya), RENEWAL comprises national networks of food and nutrition-relevant organizations (public, private, and nongovernmental) together with partners in AIDS and public health research. RENEWAL aims to enhance understanding of the worsening interactions between HIV, food security, and nutrition, and facilitate a comprehensive response to these interactions. RENEWAL is grateful for support, at present, from Irish Aid, the Swedish International Development Cooperation Agency (SIDA), the International Development Research Centre (IDRC, Canada), and the United States Agency for International Development (USAID).

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