ZAMBART RESEARCH BRIEFING

TARGETS Zambart Project

IMPROVING ACCESS TO TB SERVICES THROUGH COMMUNITY ENGAGEMENT

Recent WHO Global Tuberculosis Reports highlight a growing concern for the burden of undiagnosed TB on a global scale. Research by the Zambia Aids-Related TB Project (ZAMBART) supports the need for intensified TB case-finding in high HIV prevalence settings where existing health systems are over-burdened and limited resources are over-stretched, to ensure early detection and prompt and effective diagnosis and treatment[i]. Research outlined in this briefing illustrates that many TB patients in Zambia remain undiagnosed and that TB suspects with a chronic cough do not seek care at their local health facility, spreading infection within communities where TB is becoming harder to control. Despite the availability of diagnostic tools and treatment for TB, these are inefficient and can be ineffective, and many patients are failing to access them. ZAMBART research aims to address the worrying gap between existing health services and the communities they aim to serve.

Health Systems and TB in Sub Saharan Africa

Tuberculosis is a major cause of morbidity and mortality in Sub-Saharan Africa (SSA). Despite substantial expansions in control efforts in the last decade, progress towards halting and reversing the spread of TB[i] has been slow across many poor countries[ii]. The limited success of TB, and other disease-specific control initiatives has highlighted the weaknesses of existing health systems, limiting their ability to deliver effective services. The converging TB/HIV epidemic has placed an even greater burden on health systems: HIV has led to an increase in TB cases, as the greatest risk factor for TB is HIV infection, and TB is a leading cause of mortality in people living with HIV[iii]. Nevertheless, the true burden of prevalent TB remains undefined across many poor countries as many cases of TB remain undetected and there is limited epidemiological evidence to define this burden[iv]. In Zambia, where HIV prevalence amongst adults is 17%, the prevalence rate of TB/HIV co-infection is the seventh highest in the world. TB notification rates have increased markedly in the last 20 years, largely the result of the HIV epidemic[v]. Of newly diagnosed TB cases, 70% are co-infected with HIV. Consequently, Zambia is experiencing a growing co-infection epidemic that is hampering existing TB control efforts. Prevalence surveys provide a rigorous measure of the success of TB control initiatives and an indication of the true TB burden, however there have been few large-scale TB and HIV prevalence surveys within SSA[vi]. Amongst these few is a large population-based study conducted in South Africa and Zambia by the ZAMSTAR study team, which confirmed high levels of undiagnosed infectious TB in Zambia and South Africa (figure 1), and a high number of TB suspects in South Africa and Zambia with a chronic cough failing to seek care at their local health facility, with those who did access their local facility receiving inadequate investigation (figure 2)[iv].

Figure 1.

HIGH RATES OF UNDIAGNOSED CULTURE POSITIVE TUBERCULOSIS IN PREVALENCE SURVEYS

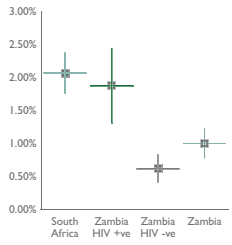
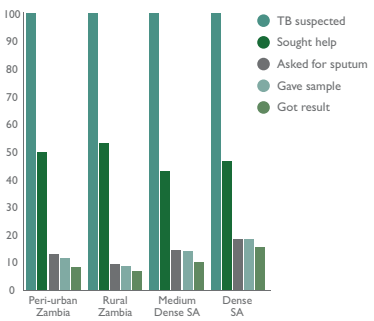


Figure 2.

HEALTH - SEEKING BEHAVIOUR IN ZAMSTAR PREVALENCE SITES



Understanding barriers to accessing TB services

Despite the availability of tools for the diagnosis and treatment of TB, access to them remains inequitable. To understand the barriers to accessing available TB services ZAMBART conducts quantitative and qualitative research on the burden of undiagnosed TB, stigma and other socioeconomic-related barriers to accessing TB services, and is evaluating interventions to improve TB case detection. Current algorithms for TB screening are proving inappropriate and prior to the availability of new diagnostics, alternative TB case-finding methods need to be applied in resource poor settings[vi]. The current approach of passive case-finding advocated through DOTS is failing to prevent TB transmission, particularly in high HIV prevalence settings, leading to growing support for enhanced case-finding (ECF)[vii].

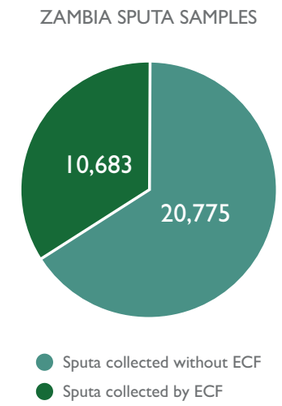
Evaluating ECF through the ZAMSTAR Project

Through ZAMSTAR, a community randomised trial of two interventions delivered to approximately 1.2 million people in South Africa and Zambia while strengthening the existing health systems, ZAMBART in collaboration with the Desmond Tutu TB Centre (DTTC) through the Consortium to Respond Effectively to the AIDS/TB Epidemic (CREATE), is evaluating ECF within high HIV prevalence settings in Zambia and South Africa (results presented here focus primarily on Zambian operational sites). The ECF intervention integrates three strategies: community mobilisation (information, education and sputum collection points), information dissemination and education at schools, and open access sputum collection points at clinics to facilitate diagnostic access; and follows two guiding principles: everyone should be able to provide a sputum sample for diagnosis within a 30 minute walk of their home and results should be available within 48 hours. To date, the ZAMSTAR study has shown that the ECF strategy finds cases (figure 3), with the impact of ECF on TB prevalence and transmission remaining to be ascertained in ongoing prevalence surveys.

The Enhanced Case Finding Intervention: key strategies for success

- **Congestion at the clinic:** open access sputum collection points are easily visible and accessible allowing patients to bypass the busy clinic
- **Delays in obtaining results:** turnaround for results in the ECF intervention is 48 hours
- **Cost of tests:** individuals going through the ECF intervention did not have to pay for tests, encouraging more to come forward for diagnosis
- **Distance to the clinic:** open access collection points were set up in the community so all individuals were able to access a treatment point within 30 minutes walk from their home

Figure 3.



Enhanced Case-Finding in Schools

Within schools, the ECF intervention provided children with key messages relating to TB, HIV and stigma, and encouraged children to disseminate this information and inform their communities and household members about sputum collection points located within their communities and local clinic. Qualitative evaluation of the inclusion of children in ECF activities indicated high levels of TB knowledge and the facilitation of TB-related discussions within their school and homes following the implementation of the intervention. With reports by some children that their knowledge of TB symptoms and diagnosis led to household members seeking TB testing, this research indicates a potential role for children in referral; moreover a role for children in ECF[ix].

School child's drawing of ECF intervention in their community

Targeting Social Barriers to Access

Alongside these studies, qualitative research conducted by the ZAMBART social science team, led by Virginia Bond, has highlighted the increasing role of TB and HIV-related stigma in creating barriers to accessing TB services. To challenge TB/HIV-related stigma, ZAMBART has developed a TB anti-stigma toolkit in collaboration with the International HIV/AIDS Alliance and CARE International[x]. The toolkit was written for and by TB and HIV trainers in Africa and has been designed to help trainers organise educational sessions with community leaders or organised groups to raise awareness and promote practical action to challenge stigma and discrimination. To date over 300 community facilitators have been trained across Zambia.

Working with the anti-stigma toolkit: the story of Mrs. Godfridah Chulu (pseudonym)

The Effects of Isolation

"It was in…1997 when I was found with TB... When my relatives learnt about my condition they did not receive the news well. I was given my own room and feeding utensils.

Though I was in my own room, no one bothered to clean it or even to wash my beddings. During meal times my sisters used to send my children to bring the food to me young as they were, because my sisters did not want… close contact with me for fear of catching TB...

As time went by one of my sisters decided to leave me to go and live with my mother. I remained with one of them who did not nurse me as expected. My sisters' actions led me to think I was very sick and that I was not going to recover at all. I also thought there was no need for me to continue taking the TB pills.

My experience led me to join the local health centre as a volunteer TB treatment supporter and caregiver where I…support TB patients who might be in a similar situation as I was and also to teach the community members not to stigmatise…TB [patients] because it is an airborne and curable disease which can be caught by anyone. I therefore urge everyone to embrace TB patients and support them in every way."

[i] The Global Plan to Stop TB, 2006–2015: actions for life towards a world free of tuberculosis. Geneva, World Health Organization and Stop TB Partnership, 2006

[ii] United Nations (2000) The Millennium Development Goals Report 2008. mdgs.un.org/unsd/mdg/Resources/Static/Products/Progress2008/MDG_Report_2008_En.pdf#page=34

[iii] World Health Organization. Interim Policy on Collaborative TB/HIV Activities. Stop TB Department and Department of HIV/AIDS. 2004. whqlibdoc.who.int/hq/2004/WHO_HTM_TB_2004.330_eng.pdf

[iv] Ayles H, Schaap A, Nota A et al Prevalence of tuberculosis, HIV and respiratory symptoms in two Zambian communities: implications for tuberculosis control in the era of HIV. PLoS One. 2009. 4 (5): e5602

[v] USAID. Infectious Disease: Tuberculosis. Country Profile: Zambia. www.usaid.gov/our_work/global_health/id/tuberculosis/countries/africa/zambia_profile.html

[vi] Corbett E, Bandason T, Cheung Y-B et al Prevalent infectious tuberculosis in Harare, Zimbabwe: burden, risk factors and implications for control. Int Journal of Tuberculosis and Lung Disease. 2009. 13 (10); 1231-1237

[vii] Godfrey-Faussett P, Ayles H. Can we control tuberculosis in high HIV prevalence settings? Tuberculosis. 2003; 83, 68-76

[viii] Building on and enhancing DOTS to meet the TB-related Millennium Development Goals. Geneva, World Health Organization and Stop TB Partnership, 2006

[ix] Bond V, Chilikwela L, Simwinga M et al. Children's role in enhanced case finding in Zambia. In print.

[x] Kidd R, Clay S, Belemu S, Chonta M, Chiiya C, Bond V. Understanding and Challenging TB Stigma, March 2009 www.aidsalliance.org

IMPLICATIONS FOR POLICY AND PRACTICE

International TB control strategies are changing. The second component of the WHO-recommended Stop TB Strategy advocates for intensified TB case-finding in high HIV prevalence settings to ensure early detection and prompt and effective diagnosis and treatment[i] in settings where existing health systems are over-burdened and limited resources are already over-stretched. In addition, the fifth element of the strategy highlights the role of community engagement in interrupting TB transmission: "Engage people with TB and affected communities to demand, and contribute to, effective care".

- **Enhanced case-finding increases access to TB diagnosis and treatment:** Evaluation of ECF interventions in ZAMBART's operational sites has indicated the relevance of this strategy in early detection of undiagnosed TB in HIV settings, with findings illustrating a high proportion of TB cases found as a result of ECF, which in its absence would have gone undetected, spreading TB within their communities.
- **Community mobilisation creates demand for health services:** Included in the ZAMBART ECF intervention is a strong focus on community engagement and mobilisation to generate awareness, knowledge and encourage communities to demand effective TB diagnostic and treatment services from their local health facilities.
- **Update TB control strategies to involve communities in practice:** To achieve the Stop TB and Millennium Development Goal targets for TB in the era of a converging TB/HIV epidemic, it is imperative that TB control strategies are updated, placing greater emphasis on community engagement and mobilisation to increase early TB detection through community case finding.
- **The importance of communication:** Successful implementation of global strategies for TB control requires a sustained and engaged approach to advocacy and community mobilisation: "…ACSM [advocacy, communication and social mobilisation] is essential for achieving a world free of TB and is relevant to all aspects of the Stop TB Strategy"[viii]. ZAMBART research continues to generate support, awareness, knowledge and demand for appropriate TB services in Zambia.

About ZAMBART and TARGETS

The Zambia AIDS Related Tuberculosis (ZAMBART) Project is a Zambian NGO. ZAMBART was formed in 2004 through a collaboration between the University of Zambia's School of Medicine and the London School of Hygiene and Tropical Medicine (LSHTM), which spans more than 20 years. From the initial studies of the impact of HIV on the clinical presentation and outcome of tuberculosis, the scope of the research and the partnerships involved have expanded widely. Based in Lusaka, ZAMBART now collaborates closely with government, non-governmental and academic institutions within Zambia, Africa and the rest of the world. ZAMBART staff form an interdisciplinary team with a range of expertise including epidemiology, clinical science, social science, laboratory, operations research, health systems and services research, health policy analysis, health economics, development communication and counselling.

ZAMBART focuses on the overlap between HIV and TB in order to improve the quality of life of people affected by the dualepidemic. Conducting research within a limited resource setting, ZAMBART is committed to:

- Bridging research and action through operational research and through forging effective collaboration with local stakeholders;
- Providing evidence-based and high quality research;
- Addressing relevant and priority questions;
- Capacity building for Zambian research - scientific and managerial

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ZAMBART is a core member of The Team for Applied Research Generating Effective Tools and Strategies for Communicable Disease Control (TARGETS) led by LSHTM. TARGETS is a Research Programme Consortium funded by the UK Department for International Development (DFID). The Consortium brings together partners in Sub-Saharan Africa, India and Europe working towards better health for the poor and vulnerable through more effective communicable disease control.

www.targetsconsortium.org

TARGETS
Team for Applied Research Generating Effective Tools and Strategies for Communicable Disease Control

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