

## THE ROLE OF SOCIAL SCIENCE RESEARCH IN REDUCING THE BURDEN OF TUBERCULOSIS IN HIGH HIV PREVALENCE SETTINGS

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**Abstract:** Tuberculosis (TB) is a global public health problem. The HIV/AIDS epidemic negatively affects tuberculosis control in many countries. The United Nations has set the Millennium Development Goals (MDGs) aiming to halve TB prevalence and mortality by the year 2015. In this paper, the authors summarize the global situation of TB associated with HIV/AIDS (TB/HIV), WHO's interim policy on TB/HIV, as well as the status and needs of social science research. The authors reviewed two major social interventions which are critical for TB control in HIV high prevalence settings, namely those to reduce stigma and those to promote adherence to TB/HIV medication. The review suggests that more social science research should be implemented in resource limited countries.

**Key words:** tuberculosis, HIV/AIDS, TB/HIV, social science research, social interventions

*"The battle against AIDS will not be won unless the international community does more to fight TB as well".*

Nelson Mandela, former president of South Africa and former tuberculosis patient

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### Why does fighting AIDS need to involve fighting TB?

HIV/AIDS and tuberculosis (TB) are the world's first and second leading causes of death from infectious diseases. If there had been no HIV epidemic, TB would have been controlled. In 2005, it is estimated that about 40.3 million adults and children were living with HIV and about 3.1 million have died from AIDS [1]. About 8.8 million new cases of TB occurred in 2003 with an estimated 1.7 million dying from the disease. In the same year, about 674,000 new cases of TB were associated with HIV (TB/HIV), and 229,000 people with HIV/AIDS (PHA) died from TB [2]. Tuberculosis is the leading cause of morbidity and mortality among PHA. At least one in three will develop TB [3]. The alarming global crisis of HIV/AIDS and TB has prompted the United Nations and the international community to set a global target to reduce these priority diseases. The Millennium Development Goals (MDGs) aim to reverse the incidence and halve the mortality of these two diseases by the year 2015 [4].

Biologically, it is well known that TB enhances HIV replication and accelerates HIV progression, thereby shortening the life expectancy of PHA [5]. The close interaction between TB and HIV/AIDS indicates the need to reduce the burden of both HIV/AIDS and TB. Most Sub-Saharan African countries with high HIV prevalence have suffered the negative impact of the interaction between HIV/AIDS and TB for more than a decade. WHO recently published the first interim policy on collaborative TB/HIV activities to tackle the dual epidemics [6]. Table 1 presents the WHO's recommended interventions to reduce the burden of TB and HIV/AIDS. The biomedical interventions to reduce TB and HIV burden include antiretroviral therapy (ARV) and cotrimoxazole preventive therapy (CPT) for HIV-positive TB patients and isoniazid (INH) to prevent TB among PHA. The results of clinical research show that CPT can prolong lives and ARV can reduce death among HIV-positive TB patients [7-10]. INH can reduce the risk of developing TB among PHA [11]. Despite the efficacy of these medical interventions, the task of reducing the TB/HIV burden in resource-limited settings is a great challenge and necessitates interventions suggested by social science research.

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### Why social science research?

To control the epidemic of TB and HIV/AIDS, we must not only deal with the HIV virus and the TB bacteria but also manage patients who carry these germs and educate the health worker who deliver health services to the population. Human behavior and social environments are complicated, and biomedical interventions alone are not sufficient for disease control. It has consistently been proposed that TB and AIDS are social diseases whose patterns of transmission must be understood, not only through the clinical or laboratory studies of bacteria and virus, but also through the study of attitudes, behavior and social organization [12-19]. In particular, HIV/AIDS provides a tragic example of a complex interactions between the disease agent and human behavior, which further complicates the effort to control tuberculosis. How can social science research contribute to TB prevention and care in high HIV prevalence settings?

Based on the social science research in the northern-

most province of Thailand where HIV epidemic fuels the TB epidemic (HIV prevalence among pregnant women was 3.7% and TB incidence was 140/100,000), we summarized the psycho-social interactions between HIV/AIDS and TB and the negative impact on TB and HIV/AIDS prevention and care (table 2) [20]. It is noteworthy that this social science research was carried out before ARV was available to the poor people of Thailand. Increased access to antiretroviral therapy among people with AIDS in Thailand and other resource-limited countries might reduce AIDS related fatalism and stigma [21, 22]. But even though several high HIV prevalence countries in sub-Saharan Africa successfully mobilized free ARV for poor patients, stigma and discrimination, especially among women resulted in a low level of participation in HIV testing and access to ARV. Gender inequality is such that a poor woman is placed in an even worse social situation if her husband or in-laws become aware of her HIV status [1]. These complicated circum-

**Table 1: Interventions to reduce the burden of TB and HIV/AIDS recommended by the World Health Organization [6]**

<p><b>A. Interventions for collaboration between TB and AIDS programs</b></p> <p>A.1. Set up a coordinating body for TB/HIV activities effective at all levels</p> <p>A.2. Conduct surveillance of HIV prevalence among tuberculosis patients</p> <p>A.3. Carry out joint TB/HIV planning</p> <p>A.4. Conduct monitoring and evaluation</p> <p><b>B. Interventions to decrease the burden of tuberculosis in people living with HIV/AIDS</b></p> <p>B.1. Establish intensified tuberculosis case-finding</p> <p>B.2. Introduce isoniazid preventive therapy</p> <p>B.3. Ensure tuberculosis infection control in health care and congregate settings</p> <p><b>C. Interventions to decrease the burden of HIV in tuberculosis patients</b></p> <p>C.1. Provide HIV counseling and testing</p> <p>C.2. Introduce HIV prevention methods</p> <p>C.3. Introduce co-trimoxazole preventive therapy</p> <p>C.4. Ensure HIV/AIDS care and support</p> <p>C.5. Introduce antiretroviral therapy</p>
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**Table 2: The psycho-social interactions between HIV/AIDS and TB and the negative impact on TB and HIV/AIDS prevention and care in Thailand (before a launching the government's policy on access to ARV in 2003) [20, 22, 33-35]**

Psycho-social interactions between HIV/AIDS and TB
<ul style="list-style-type: none"> <li>● The social stigma attached to HIV/AIDS is enormous and results in denial of HIV testing and delay in access to TB and HIV care</li> <li>● Serious AIDS stigma and an inadequate knowledge about TB symptoms results in delays in seeking TB care because TB symptoms are comparable to AIDS and people with TB symptoms were afraid of HIV/AIDS</li> <li>● Most HIV negative TB patients were stigmatized as having AIDS.</li> <li>● The high mortality among HIV-positive TB patients during TB treatment discredited the TB treatment efficacy. Health staff had a low motivation to care for the patients because the treatment results were so discouraging.</li> <li>● Fatalism attached to HIV/AIDS hindered the patients access to health care patients felt hopeless and lacked the motivation to adhere to their TB treatment.</li> </ul>

**Table 3: List of some interventions to reduce TB and HIV/AIDS stigma and desired outcomes [36-40]**

Interventions to reduce stigma	Desired outcomes
<p style="text-align: center;"><b>Mass communication interventions</b></p> <p>Television, radio, newspaper or poster presenting the followings:  - photos and news of countries' leaders or popular persons telling about their experiences of having TB or HIV/AIDS; showing close embrace with patients; showing acceptance for HIV blood testing; showing TB is curable or showing that they are surviving from HIV/AIDS  - photos and news of Miss HIV/AIDS stigma contest</p>	- increase public's acceptance and reduce discrimination - promote early HIV testing - reduce delay in seeking care
<p style="text-align: center;"><b>Training/workshop</b></p> <p>-Intensive training course to reduce stigma among health workers  -Community awareness-raising through participatory training  -Involving HIV-positive long-term survivors in education and training</p>	-improve health workers' attitude towards TB and AIDS patients and willingness to care for them. -increase HIV testing and access to care
<p style="text-align: center;"><b>Counseling</b></p> <p>-Individual or family counseling by health workers or by HIV-positive counselor</p>	-reducing self-stigma; reduce anxiety and stress; disclosure HIV to spouse and family members
<p style="text-align: center;"><b>Social mobilization and community participation</b></p> <p>-Establishing network (self-help group) of PHA and motivate PHA to join the network  -Financial assistance to PHA and family  -Involving PHA, religion leaders and community leaders in policy making, and in the development and implementation of programs.</p>	-reducing self-stigma -empowering PHA -increasing HIV testing and disclosure of HIV status
<p style="text-align: center;"><b>Improving health service system and promoting access to treatment</b></p> <p>-Free and effective treatment  -Integrating HIV/AIDS care with other chronic diseases clinics  -PHA-Friendly hospital</p>	-increase access to HIV care -increase HIV testing -reduce discrimination feeling
<p style="text-align: center;"><b>Law and regulation intervention</b></p> <p>- Law or regulation against stigma in general  - Law or regulation for the work places  - Code of professional ethics/code of practice  - Standard or universal guidelines</p>	- protection of patients' right - patients are eligible for petition the court and receive support for complaint due to stigma.

**Table 4 Scope of adherence to medication in TB/HIV care [41]**

Scope of adherence to medication in TB/HIV care	Targeted HIV-positive person	Expected health outcome of good adherence	Potential negative impact of non-adherence
Adherence to TB preventive Therapy	HIV-infected persons with latent TB infection (no clinical TB symptoms)	- Reducing risk to become sick with TB	- drug resistance
Adherence to TB treatment	HIV- positive TB patients (having TB symptoms)	-cure from TB and do not transmit TB to others	-death -treatment failure -drug resistant -continue transmitting TB to others
Adherence to antiretroviral therapy (ARV)	AIDS patients (usually CD4 < 200cells/mm <sup>3</sup> )	-prolong life, better quality of life -avoid opportunistic infection -reduce risk of HIV transmission	-drug resistant -treatment failure -death

**Table 5 Interventions for improving adherence to medication** [13, 20, 42-44].

Interventions for enhancing adherence to medication
<u>Improving health service systems</u> -Eliminating or lowering user fees -Providing directly observed therapy (DOT) -Organizing service hours convenient for patients and minimizing waiting time -Active follow-up system for non-adherent patients -Offering health education and counseling service by using linguistically and culturally appropriate messages. -Hospitalization may prevent non-adherence among patients exhibiting the profile of defaulter (e.g. homeless, alcoholic patients) -Involving people with HIV/AIDS network and community leaders in delivery services (e.g. providing medication education, follow up non-adherent cases, home visit)
<u>Improving attitude and performance of health care providers</u> -Good relationship between health providers and patients significantly improves patient adherence. -The providers should render service with courtesy and respect for patients. -The providers should understand patients' needs and constraints, understand patients' cultural differences in attitudes to disease. -The providers should spend more time listening to patients. -Giving rewards to health provider who achieve high adherence rate
<u>Facilitating patient medication</u> -Providing special packages of medicine such as a daypack for easier medication. -Prescribing medication once a day and fixing a time such as before breakfast or before bed. -Providing several medicine reminding system (alarm clock, calendar, reminding through pager or cell phone, linking medication time to daily life activity)
<u>Providing incentives to patient and community</u> -Providing transportation support to attend clinics, shelter support for homeless people, offering meals and assistance with job skills for poor patients -Giving rewards to patients who adhere well to the treatment. -Paying a deposit at the start of their treatment, which entitles the patient to cheaper drugs and is refundable on good adherence to pre-scribed course.

**Table 6 Literature on social science research in TB in comparison with AIDS cited by the National Library of Medicine (NLB) website** [26].

Searching keywords ..... AND TB ..... AND AIDS	TB (no. of papers)	AIDS (no. of papers)
Social sciences AND	1837	25,028
Behavioral research AND	4	515
Qualitative research AND	13	141
KAP AND (Knowledge, Attitude, Practice)	4	132
Poverty AND	137	1007
Stigma AND	31	433

**Table 7 Study topics and geographic location of tuberculosis behavioral and social science research (n=175)** [45]

<b>Research settings</b>	
-USA-based	47%
-International-based	36%
-Non-location specific (e.g. concept, position papers)	17%
<b>Study topics</b>	
-Patient adherence	47%
-Social, cultural factors (including Knowledge-Attitude-Belief)	45%
-Structural influences	33%
-Health seeking behavior	19%
-Provider adherence	14%
-Others	12%

stances require social science research to identify socially and culturally sensitive behavioral interventions.

UNAIDS and WHO identify stigma and adherence to medication as the major challenges in controlling the HIV/AIDS epidemic [1, 23]. In this article, we discuss two major social and behavioral interventions, namely interventions to reduce stigma (table 3) and interventions to promote adherence to TB/HIV medications (table 4, 5). These two social interventions are important prerequisites for implementing the medical interventions recommended by WHO (table 1). For example, interventions for reducing AIDS stigma can facilitate HIV testing for TB patients, and interventions for enhancing adherence are important to ensure treatment efficacy and to prevent drug resistance when patients receive ARV, CPT and INH.

#### **Status of social science research in TB and TB/HIV**

In 1975, the Special Program for Research and Training in Tropical Diseases (TDR), a globally coordinated effort of the United Nations Children's Fund (UNICEF), United Nations Development Program (UNDP), World Bank and World Health Organization (WHO), was established to combat neglected tropical diseases and diseases of the poor and disadvantaged [24]. In view of the importance of research in social sciences to control communicable diseases, TDR started supporting social science research in 1979. However, social science research for tuberculosis is still quite new to TDR, as shown by the fact that TDR added tuberculosis to the tropical disease portfolio only in 1999 [25]. Table 6 clearly shows that TB has received much less attention from social science researchers in comparison to HIV/AIDS. According to the United States National Library of Medicine (the world's largest literature database for medical and public health research), the number of TB social science research articles in scientific journals is 7 to 128 times less than HIV/AIDS articles [26]. Obviously, social science research in HIV/AIDS has received ample recognition because results of this research help to identify interventions to reduce the HIV/AIDS burden [27]. However, the role of social science research in improving TB care, especially in developing countries, is oddly limited for such an old disease as TB. A recent review of the 175 social science articles on TB (table 7) shows that half of the studies were conducted in the United State (Rawls and Booker, 2005), although 95 percent of global TB cases and 99 percent of TB deaths occur in the developing world [2]. Clearly, therefore, it is imperative that more social science research be conducted in high burden and resource-limited countries.

The difficulty of achieving the global target for TB control is mainly due to the lack of human resources and qualified staff [28]. At the global level, the published infor-

mation on human resources and TB control are limited and almost none relate to HIV-TB control [29]. Training is essential to the development of a health workforce geared to TB control, but regular international TB training courses are organized by a limited number of organizations [30, 31]. Most international training courses focus on clinical or laboratory training and the management of tuberculosis programs. To our knowledge, none of these courses include social science subjects in the training curriculum, except the international courses organized continuously by the Research Institute of Tuberculosis (RIT) Japan Anti-TB Association (JATA) since 1963. The RIT has incorporated social science subjects into the training curriculum for TB program managers from the start of training on the basis of the view that clinicians and TB program managers should apply a broader and more holistic perspective to TB services and TB programs. Currently, social science topics include concepts and practical examples about community beliefs and perceptions, social stigma, health systems and health-seeking behavior, gender, adherence to treatment, community participation and interpersonal communication skills. These topics are relevant to WHO's newly recommended Stop TB Strategy for achieving the MDGs [2].

#### **CONCLUSION:**

HIV/AIDS biologically and socially interacts with TB. Reducing TB associated HIV burden requires both biomedical and social interventions. The current involvement of social scientists in research and training for TB control in high HIV prevalence settings is limited. To facilitate the Millennium Development Goal for TB, social science research and training should be implemented in countries which are affected by these dual epidemics. Social science research can promote understanding regarding the complex psychosocial interplay of TB and HIV/AIDS. In addition to addressing these problems, social science research can help to identify the interventions which are effective in urging vulnerable patients, including women and the poor to take advantage of TB/HIV prevention and care services. Social science research should show how to implement these interventions on a large scale and how to influence national policy and care strategy [2,27,32]. The training courses designed for TB and HIV/AIDS program managers and service providers should include social science subjects to ensure that the program and services are responsive to the complicated biological and the psycho-social interactions of TB and HIV/AIDS.

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