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**Poverty and illness: Socio-economic factors influencing the  
health-seeking behaviour of TB patients in West Africa (the Gambia)**

**By  
Heather Ann McPeake**

**A Practicum Report submitted to Saint Mary's University, Halifax,  
Nova Scotia, in partial fulfillment of the requirements for the Degree  
of Master's in International Development Studies**

**August 2005, Halifax, Nova Scotia**

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## **Abstract**

**Poverty and illness: Socio-economic factors influencing the health-seeking behaviour of TB patients in West Africa (the Gambia)**

**By  
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**Abstract:** This study addresses the social, cultural, and economic components of TB control by tendering a broadened perspective of disease management that complements and enhances current biomedical protocols. Through semi-structured interviews it was possible to examine the socio-economic influences that direct the health-seeking behaviour of TB patients and explore the economic consequences of ill-health for patients and their families. By adopting a social role as a volunteer instructor with a local peer health education programme, an additional objective encompassed the promotion of TB prevention and education in rural and urban communities in the Gambia. This rapid assessment could be used with other social science research as a foundation for modifying current TB protocols to better suit the needs of the patients and their families. The findings presented here underscore the need for wider multidisciplinary perspectives that include the holistic experience of illness for vulnerable populations.

**August 15<sup>th</sup>, 2005**

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**ACRONYMS AND ABBREVIATIONS:**

<b>BCG</b>	Bacilli de Calmette-Guerin (anti-TB) vaccine
<b>CDR</b>	case detection rate
<b>CHN</b>	community health nurse
<b>DFID</b>	Department for International Development
<b>DOSH</b>	Department of State for Health (the Gambia)
<b>DOTS</b>	Directly Observed Therapy Short Course
<b>HIPC</b>	heavily indebted poor country
<b>KNCV</b>	Royal Netherlands Tuberculosis Association
<b>LDC</b>	lesser/least developed country
<b>LTi</b>	Leprosy/TB Inspector
<b>MDR-TB</b>	multi-drug resistance TB
<b>MRC</b>	Medical Research Council
<b>NLTP</b>	National Leprosy/TB Programme
<b>NSGA</b>	Nova Scotia Gambia Association
<b>PHC</b>	primary health care
<b>PHEP</b>	Peer Health Education Programme
<b>TB</b>	tuberculosis
<b>VHW</b>	village health worker
<b>WATI</b>	West African TB Initiative
<b>WHO</b>	World Health Organization

## SUMMARY:

**P**ulmonary tuberculosis (TB) is considered a central health concern in the Gambia, West Africa despite local improvements in case detection, countrywide availability of free government-sponsored antibiotics, and the implementation of the World Health Organization's directly observed treatment programme. Improved understanding of TB persistence may be achieved by addressing the social, cultural, and economic components of TB control by tendering a broadened perspective of disease management that complements and enhances current biomedical protocols. The effective representation of the previously *under-exploited* needs of TB patients and their families could serve to support the groundwork for more equity-based prevention strategies and integrated management plan.

The objectives of this project were developed to describe the holistic experiences of ill-health for poverty-stricken populations. Through semi-structured interviews it was possible to examine the **socio-economic influences that direct the health-seeking behaviour of TB patients** and explore the **economic consequences of ill-health** for patients and their families. Concurrently, by adopting a social role as a volunteer speaker/instructor with a local peer health education programme, a third and final objective encompassed the **promotion of TB prevention and education** in rural and urban communities throughout the country.

These goals were financially supported by a Canadian International Development Agency (CIDA) Innovative Research Award and regionally supported (by way of local project supervision, transportation and accommodation) in the Gambia by the British Medical Research Council (MRC) and the Nova Scotia Gambia Association (NSGA).

The research collected (between September 2001 and February 2002) suggests that the health seeking behaviour of TB patients in West Africa is directed by their experience with the Western health system, the influence of traditional healers, gender differentials, and local perceptions of the disease. It is also evident that, although medications and treatment are 'free of charge,' TB patients and their families face several impeding economic constraints before diagnosis and during treatment. These obstacles include the consultant fees charged by traditional healers, the price of travel to clinics, the need to borrow money, the cost of hiring replacement workers, and the time lost from work.

This rapid assessment could be used with other social science research as a foundation for modifying current TB protocols to better suit the needs of the patients and their families. The findings presented here underscore the need for wider multidisciplinary perspectives that include the holistic experience of illness for vulnerable populations. A biomedical orientation balanced with an adept social science appraisal could offer health care planners sustainable and culturally-relevant solutions and alternatives for the future.

## CHAPTER 1: INTRODUCTION

### 1.1 THE TB THREAT:

Pulmonary tuberculosis (TB) is an acute respiratory infection caused by the bacillus *Mycobacterium tuberculosis* (Loughlin, 1994). When compared to other health threats such as HIV/AIDS, TB is especially perilous because it is an airborne disease making it highly contagious through casual social contact. The inhalation of droplets containing sputum contaminated with the bacilli is the most common mode of TB transmission. As active bacilli can remain viable for hours after being sprayed into the air by a symptomatic patient, seemingly mundane actions such as coughing, sneezing and sharing utensils can become potentially life-threatening actions (Farmer, 1997).

Today's shockingly escalating incidence of TB is sustained by age-old factors fundamental to human dynamics such as the migration of populations, conditions of poverty such as over-crowding and under/malnutrition, cultural beliefs, and the marginalization of women. The world's historical struggle against the disease has been impeded because the contemporary threat of prevalence is further bolstered by rising cases of TB-HIV co-infection and the genesis of mycobacterium strains that are resistant to current chemotherapies.<sup>1</sup>

Studies have revealed that 95 per cent of new TB cases are detected in developing countries and 50 per cent of those cases are identified in the heavily-

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<sup>1</sup> Although the connection between TB-HIV co-infection and the occurrence of multi-drug resistant TB (MDR-TB) are respected research topics, they will not be represented in this study due to their low incidence in the Gambia (Harper, 2001).

indebted poor countries (HIPCs) of sub-Saharan Africa (Grange 1999; WHO 2000). Consequently, in regions where TB prevalence is presently high, the statistical reality of infection prophesies a dispiriting future. It is estimated that at the current rate of transmission 200 million people alive today will eventually contract the disease and (if left untreated) over 35 million people will die from active TB infection by 2020 (Grange, 1999; WHO, 2000).

Tuberculosis infection in the Gambia, West Africa has become a compelling health concern. The total number of TB cases including active (symptomatic, infectious) and non-active (non-symptomatic, non-infectious) cases in the country doubled from 882 in 1994 to 1631 1998 (KNCV, 1999). The reported case detection rate (CDR) for active TB was 61 per 100 000 in 1994 and increased to 73 per 100 000 in 1998 (KNCV, 1999). Concurrently, the increase of non-active TB cases amplified from 18% (1994) to 37% in 1998 (KNCV, 1999). These rates subsist despite recent local progress in case detection, the countrywide availability of free government-sponsored antibiotics, and the implementation of the World Health Organization (WHO)'s directly observed therapy programme (Liendhardt, 2001; Harper, 2001). As a result, the Gambian government, regional health care clinics, and hospitals have been forced to re-examine and evaluate existing approaches to TB prevention and control.

## 1.2 BACKGROUND INFORMATION ON THE GAMBIA:

The Republic of the Gambia is a small country in West Africa bounded by neighbouring Senegal and the North Atlantic Ocean (see Figure A). It is a long and narrow country, extending eastwards from the Atlantic coast for over 400 km (Harper, 2001). It has an average width of 35 km and the river Gambia strays across the length of the country (CIA, 2005).

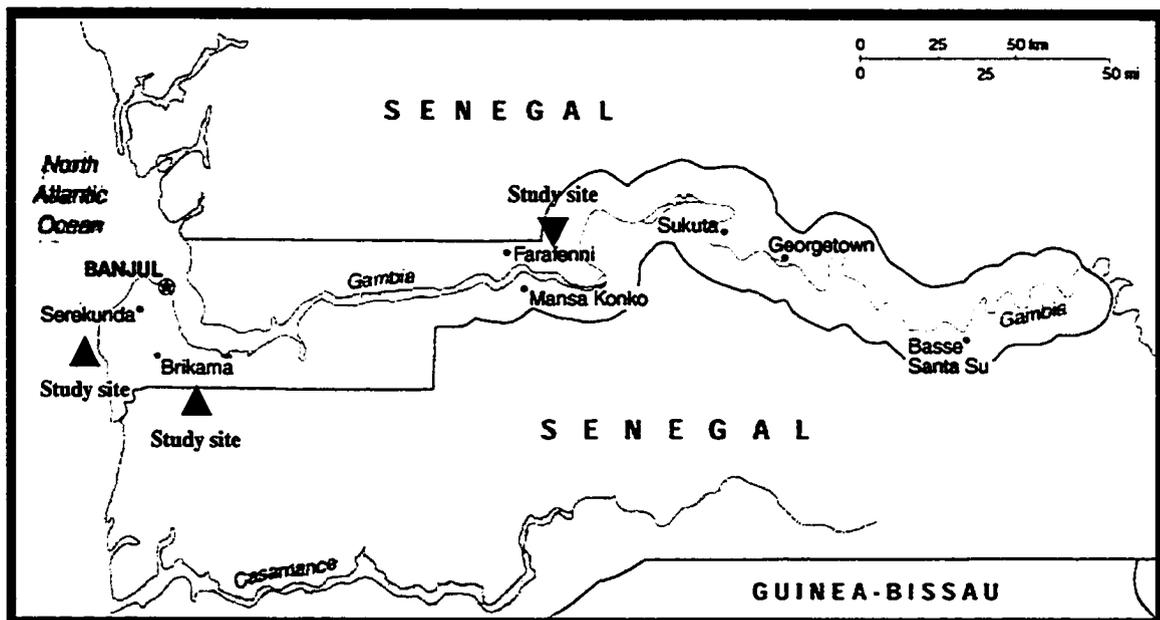


Figure A: Map of the Gambia<sup>2</sup>

The *1993 Population and Housing Census* indicated the country's population had surpassed the 1.3 million mark and maintained a polarized cultural makeup with 99% residents declaring African descent (with Mandinka, Fula, Wolof, and Jola representing the most prominent ethnic groups) and the remaining 1% assert non-African backgrounds (Republic of the Gambia, 1995). While English is the nation's official language, Mandinka, Wolof and Fula are of the most common indigenous vernaculars (van Bowel, 1999). Muslims amass the Gambia's largest

<sup>2</sup> Map adapted from the Nova Scotia Gambia Association website.

religious group (90% of the population), while Christianity (9%) and indigenous beliefs (1%) denote the minority (CIA 2005; Harper 2001).

Most (approximately 75%) of the country relies on crops (groundnuts) and livestock farming for its livelihood and small scale manufacturing pursuits include peanut, fish and animal hide processing (CIA, 2005; KNCV, 1999). Tourism is also a growing foreign exchange earner (KNCV, 2000). Un/underemployment levels are high and most trade/industry dealings depend heavily on bilateral and multilateral aid (van Bowel, 1999). With a GNP per capita income of \$320 USD, the Gambia is ranked one of the world's least-developed countries (LDCs) (KNCV, 2000).

Although schooling is highly valued in the Gambia, literacy levels are down. UNICEF reports that adult literacy rates are low for both males and females measuring 44 % and 30% respectively (2003). The agency also notes that although a reasonable number of children aged 7-12 enrol in primary schools (66% of girls and 71% boys), these attendance rates drop significantly when examining secondary-school rosters (reduces to 23% of girls and 34 % boys)(UNICEF, 2003).

In the secondary school setting, Gambian students have the option of participating in an extra-curricular peer health education programme jointly supported by the Nova Scotia Gambia Association (NSGA) (a Canadian non-

governmental organization based in the Gambia) and Dalhousie University's School of Medicine (Perrott, 2002). The programme offers student leaders the opportunity to act as peer health educators who offer relevant and culturally-appropriate health training at the local level (Wong, 1997). The programme is offered to both young men and women in both rural and urban schools countrywide and includes training segments that influence healthy living (such as HIV/AIDS prevention, substance abuse education, and anti-smoking strategies)(Perrott, 2002). The agency has reported that by July 2004, over 80 000 students had been presented the fundamentals of the peer health education programme (PHEP) and over 4000 young people had been trained to serve as peer health educators (PHEs) in their schools and communities (Devanney, 2005).

In 1978, the Gambia adopted the Primary Health Care (PHC) model as its national health policy (Hill AG, 2000). The PHC programme was designed with comprehensive features that encompass health education, water sanitation initiatives, maternal and child health care programmes, countrywide immunization strategies, disease control, and the provision of essential medicines (Hill, 2000; Harper, 2001).

The Gambia's health districts are sub-divided into PHC villages and the national health system is organized under the Department of State for Health (DOSH) headed by the Secretary of State for Health and Social Welfare (KNCV, 2000;

Harper 2001). Inspired by the Primary Health approach, an innovative health policy called “Changing for Good” has been created to ameliorate the transition to decentralized services and under this design Divisional Health Teams have been conceived to manage these new sectors (KNCV, 2000).

Patient access to primary health care services is considered to be “of good quality” in the Gambia where over 85% of the population live within a 3km distance to a health centre or appropriate health site (Liendhardt et al., 2001). Health care is accessed via 2 major hospitals, 7 major health centres, 11 minor health centres, 17 dispensaries, 145 outreach stations and 81 health posts (KNCV, 1999). There are also 6 non-government organization (NGO) hospitals, 12 private clinics and 1 TB sanatorium (van Bowel, 1999).

Whilst these provisions represent the Gambia’s *official* health network, they are supplemented by an important (if not controversial) contribution from local traditional healers. Much like their counterparts in the formal health care system, these alternative therapists have also been subject to categorization: those who practise in the villages and are known members of their local community, and those who diversify and service broader public venues such as food markets (Harper 2001).

### 1.3 NATIONAL HEALTH SERVICES WITH RESPECT TO TB:

The design of competent and practical management approaches to TB control and eradication is an important feature of many general health care programmes. Like most countries, the Gambia has adopted the *'triple therapy'* strategy for the prevention and control of TB infection (Lienhardt, 2001). First, protect the population with the anti-TB vaccine; second, treat all detected cases with standardized chemo-prophylaxis (drug therapy), and third, reduce the source of contagion through the complete and proper treatment of current TB cases (KNCV, 1999; WHO, 2000).

In the Gambia, all children born in hospital are required to be immunized against TB with the bacilli de Calmette-Guerin (BCG) vaccine as part of the national Expanded Programme on Immunization (Lienhardt et al., 2003; KNCV, 1999). Childhood vaccines have been provided since 1984 and, as of 2002, vaccination coverage was estimated to be operating at 96% (Lienhardt et al., 2003). However, international health reports have revealed that the BCG vaccine (which only offers *partial* protection against infection and illness) may not independently offer a sufficient immunological defence to vulnerable populations.

Consequently, the government agency known as the National Leprosy and TB Control Programme (NLTP) has enhanced its vaccine programme with *directly observed therapy short-course (DOTS)* (as promoted by the WHO) for TB patients in order to cure existing cases and to prevent new and recurrent

infection (Harper, 2001). The programme aims for disease control and prevention by encouraging:

- Government commitment to ensuring sustained, comprehensive TB control activities;
- case detection by sputum smear microscopy among symptomatic patients self-reporting to health services;
- standardized short-course chemotherapy using regimens of 6-8 months for at least all confirmed sputum smear positive patients;
- a regular uninterrupted supply of all essential TB drugs, and
- a standardized recording/reporting system that allows the assessment of case finding and treatment results for each patient and of the TB Control Programme performance overall (WHO, 2002).

Also known as 'supervised swallowing,' this chemotherapy scheme demands that patients recurrently cooperate with health care representatives and have their compliance (the intake of numerous anti-TB tablets) monitored on a daily and/or weekly basis.

Tuberculosis control in the Gambia relies on passive case detection (whereupon suspect TB cases voluntarily present themselves to health services). Nine chest clinics operate out of optimal sites across the country and all patients identified as being sputum smear positive (active TB cases) are recommended into the DOTS programme (KNCV, 1999). The antibiotics are supplied to the clinics through a joint commitment between the NLTP and the Royal Netherlands Tuberculosis Association (KNCV) and are free of charge for Gambian citizens (KNCV, 2000). Given that the antibiotic tablets are not distributed through the local pharmacies, protocol necessitates that all TB cases be referred to the National Programme (Liendhardt et al., 2001).

Conforming to DOTS, all TB patients are required to visit their local chest clinic (or NLTP- authorized village health worker (VHW)) to receive their antibiotic tablets 3 times a week for a period of 6 consecutive months (Harper, 2001). In an effort to ensure high cure rates and to improve patient compliance, the patient observance of the treatment regimen is monitored and enforced by health care workers known locally as Leprosy and TB Inspectors (LTIs). The LTIs are responsible for case identification, overall supervision of DOTS, and follow-up activities including locating patients who fail to complete their prescribed treatment schedule (Harper, 2001). Although patients are required to pay a small service fee of 5 Dalasies (approximately .50 CDN) at time of initial consultation, diagnostic testing (sputum smear microscopy, chest X-ray, blood tests, etc.) and chemotherapy tablets are provided free of charge (van Bowel, 1999; Harper, 2001). This functional strategy is to better diagnosis rates, improve patient compliance, decrease cases of new infection, and minimize the opportunity for multi-drug resistance TB (MDR-TB) (Donald, 1999).

In the rural areas, it is the LTI's prerogative to assign certain responsibilities to the Community Health Nurse (CHN) who is then accountable for the management of the VHWs who are then accountable for individual villages (Harper, 2001). With such widespread and comprehensive order, TB officials do not expect many patients to receive TB treatment without proper contact with government subsidized health services.

In addition to the above outlined agencies and representatives, the Gambia has also enjoyed health care research and participation from the British Medical Research Council (MRC) and the West African TB Initiative (WATI). Expatriate and Gambian staff at the MRC hospitals and research laboratories in Fajara and Farefenni are involved in several different programmes aimed to achieve improved health for developing countries. These projects include studies on malaria, TB, HIV/AIDS, reproductive health, nutrition and communicable diseases (MRC, 2005). The WATI project was an operational multidisciplinary research survey across five West African countries (including the Gambia) between 1999 and 2001 that served to identify the assets and restrictions experienced by TB patients and the local health system (LSHTM, 2005).

### **1.3 TRANSITIONS IN RESEARCH AND PLANNING**

Although the menace of TB infection is *universal* in that the offending bacterium is indiscriminate, the contention has been advanced that certain groups of people are *pre-disposed* to ill-health due to the social, cultural and economic forces that influence and direct their everyday realities. It has been asserted that, "The poor have no option but to be at risk for TB, and are thus from the outset victims of 'structural violence (Farmer, 1997).'" This recognition of the need for change is echoed by Zumla and Grange who suggest that, although the administrative and biomedical structures are in place to inhibit infection rates, TB patients are often vulnerable to health seeking obstacles:

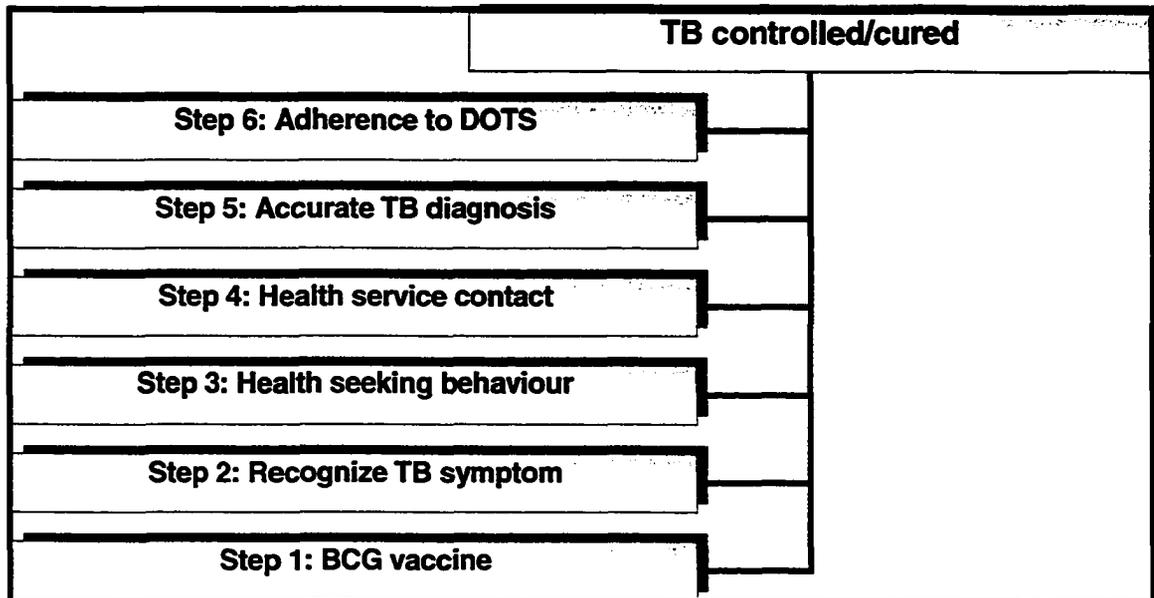
Since the problem lies with patients' inability to access effective therapy, emphasis must shift away from [medical explanations] and shift toward societal and political factors that generate poverty, inequity and injustice (1998).

They are difficult to quantify, but these socio-economic justifications are advantageous in research and programme development because they transcend the conditional biomedical capacities traditionally used to rationalize the persistence of TB infection. This theoretical modification of focus represents a fundamental shift in the classification of the disease and demands a re-evaluation of current protocols.

This progressive shift in thinking is timely given that a single actively infected individual has the potential to infect 10 to 15 other people per year, so even relatively low TB incidence could denote rapidly expanding rates of infection and prevalence for the future (WHO, 2000; Lawn, 1996). In this context, DOTS initiatives and passive case finding strategies fail to reflect the holistic burden facing vulnerable populations and should be regarded as guidelines in TB control, not solutions.

Currently, the keys to successful TB eradication programme (as outlined in Figure B) include quick and accurate diagnosis complemented with treatment compliance by the patient. However, when the *socio-economic* aspects of TB management are considered, the path to disease control transfers the responsibility of health care from the health care *workers* to the health *receivers* (Hurtig, 1999). As Paul Farmer contends, "Throughout the world, those least

likely to comply are those least able to comply . . . these settings are crying out for measures to improve the quality of care, not the quality of patients (1997).”



**Figure B. Avenue to successful disease management.<sup>3</sup>**

Several explanations of the social, cultural, and economic obstacles that serve to obstruct health seeking behaviour defer disease management have been explored and presented below as a literature review. Reasons for persistence of the disease and patient non-compliance to TB treatment include (but are not exclusive to) the following observations and experiences collected by social science researchers and health care workers in the Gambia and across the globe:

## **1.4 SOCIAL AND CULTURAL FACTORS INFLUENCING HEALTH SEEKING BEHAVIOUR**

### **1.4a Gender differentials in TB diagnosis and management**

Tuberculosis infection can sometimes manifest in diverse ways. Population studies and epidemiological reviews estimate that on a global level approximately

<sup>3</sup> Figure concept adapted from WHO (2005) and Thorson (2003).

two thirds of reported new cases are men and one third are women (WHO, 2000). However, given that the disease does not biologically discriminate, the statistics demand further scrutiny: Does this polarization reflect a true disparity in levels of infection, or are female cases simply under-reported?

Thorson recounts a study in Nepal that contrasted active (patients assertively sought out by health care workers) and passive case finding. When relying on voluntary self-reporting, women represented a mere 28% of TB occurrence (2003). However, active case finding offered more equalized results revealing that closer to 50% of women were actually sputum smear positive (Thorson, 2003). Examples such as this case of under-notification demand a review of gender differentials with respect to illness and health seeking behaviour as it is prudent to balance quantitative tangibles with qualitative rationalizations.

References to 'gender' help compartmentalize the biological characteristics of men and women from the roles and features that develop out of religious, economic, social, cultural and historical influences (Doyal, 1995). From a scientific viewpoint, it would appear that TB infection occurs in men more frequently. However, a gendered perspective explores the collective differentials that affect exposure to the bacterium, risks of infection, and health seeking behaviour (Uplekar, 2001; Thorson, 2003).

General TB risk factors that concern both men and women include poor lighting, inadequate ventilation, and conditions of overcrowding. However, the more

specialized *social* capacities assumed by men and women may ultimately increase susceptibility to ill health. Typically, men in HIPC countries have a wider social network through work, leisure activities and, as in the Gambia, visits to communal worship sites such as mosques (Hudelson, 1996; Thorson, 2003). Likewise, it could be argued that women's roles as domestic workers and caregivers may put them in prolonged contact with friends and family (some of whom may already be TB carriers) thereby leading to increased risk for infection (Thorson, 2003).

Concurrently, poor dietary status is associated with lowered immunity and the inherent power structures within society often translate into inequitable distribution of food (Thorson, 2003). Because under/malnutrition is associated with compromised immunity against TB and can negatively influence disease prognosis, women who do not have reasonable access to nutrient-rich foods may experience amplified risk of illness and possibly TB mortality (Hudelson, 1996).

Health-seeking behaviour may also contribute to skewed statistical rates. It is constructive to consider how the social and economical constraints experienced by men and women affect their opportunities for health care. TB control programmes such as DOTS require patients to actively seek health care attention and supervision and these demands can be restricting in different ways for both genders. Nonetheless, women are typically at more of a structural disadvantage as they lack the resources of time, money, and social power which

may result in lower rates of female diagnosis and compliance (Thorson, 2003). These outcomes are illustrated in Lawn's investigation in Ghana where men outnumbered women who self presented at TB clinics by almost 2:1 (1998) and in Pronyk's research that showed women in South Africa, Ghana, Nepal and Vietnam tend to be diagnosed more slowly than men (2001).

*In some cases though, being a woman has proven beneficial in health seeking.* Lienhardt's study in the Gambia noted that although men presented more often with TB infection, women turned up at general health clinics more often than men (2001). In this case, researchers deduced that because women attend health care clinics more frequently as part of the country's antenatal programme, they may feel more comfortable in their trust and familiarity with the formal system (Lienhardt, 2001). Hudelson also observed that women seem to be more comfortable reporting to clinics and suggests that pregnant women and mothers with small children often take advantage of their child's visit for consultation to have their own health status assessed (1996).

The impact of TB on male and female patients differs considerably. While men characteristically define their main concern of illness as having economic consequences (i.e.: not being able to derive an income, potential job loss) (Hudelson, 1996), the impact of a woman's illness can be viewed as somewhat more multifaceted:

***The impact of women's illness on their own lives:***

- Women often have to obtain husband's approval to seek health care and may experience undue suffering (Harper, 2001).
- Stigma and social isolation (see section 1.4b) appears to be more exceptional for women. TB diagnosis often incurs feelings of fear of spousal rejection, dismal from work and harassment (Hudelson, 1996). Women have also reported that they feared being categorized as 'lazy.'
- Women who are family heads cannot provide financial support and do not have husbands to rely on.

***The impact of women's illness on others:***

- The health and welfare of children is closely related to the health of their mothers and TB in women potentially imposes serious repercussions for families and households (Hudelson, 1996).
- Women who are ill often postpone their own care and disregard symptoms until the sickness begins to interfere with their productivity (Hudelson, 1996). This leads to increased contagion levels for families and friends.
- As previously indicated, illness often leads to poor nutrition and women's dietary deficiencies are frequently mirrored in the diets of their children (Ahlburg, 2000).
- When a woman suffers (or dies) from TB her household suffers not only emotionally but from the loss of her earnings and from the loss of a productive domestic labourer (Ahlburg, 2000).

Correspondingly, ***the impact of other TB patients on women*** should not be discounted. Cohabiting with a friend or family member with TB is an increased liability on women due to their inherent role as caregiver (Thorson, 2003). Not only do they incur increased domestic responsibilities and time constraints, but they also accept a greater hazard of infection.

With female morbidity rates showing that one million women die of TB per annum (Lawn 1998) and more than one billion women and girls are currently actively infected (Thorson, 2003) it seems that the time has come to adopt a gendered approach to health and reconstruct current formulas for prevention and control to include the socio-economic and cultural frameworks of the targeted beneficiaries. Gender as a determinant of health needs to be taken into account so to benefit

both men and women living with TB and secure sustainability in the development of patient-centred health systems.

#### **1.4b Geography and access to health care**

Urban dilemmas for case finding and treatment have been related to large volumes of patients seeking care while rural predicaments stem from the scattered geographical distribution of the patients (Harper, 2001). Rural residency has been identified as a key risk factor for late diagnosis, a phenomenon that can be explained by poor access to health care, lack of training of VHWs, lack of supervision of health staff, lower education/literacy levels in rural regions (Lienhardt et al. 2001). Additionally, there is a larger propensity for rural patients in the Gambia to seek out traditional healers before consulting health personnel (Lienhardt et al, 2001).

Also, despite the fact that TB clinics in the Gambia are distributed fairly evenly throughout the country with over 85% of the population living within 3km of an outpost (Lienhardt, 2001), the pro-patient perspective demands the appreciation of costs of travel fares, time off work needed to attend clinics and the fact that even 3 km walk (6km return) can be burdensome for someone who is ill.

#### **1.4c Perception of the disease, stigma and delay in diagnosis**

Inaccurate and/or deficient local perceptions of TB combined with the influence of social stigma and the correlated risk of social marginalization are significant obstacles in the task of reducing diagnostic delay. A patient's suspicion of TB can be an emotive experience laden with extreme feelings of sadness, fear of dying,

guilt, and loss of self-esteem (Auer, 2000; Wandwalo, 2000). Concurrently, the social response to an encounter with a TB patient can be similarly negative resulting in discrimination and isolation (Ahlburg, 2000). Whether the stigma is a perceived intimidation or an experienced misery, the threat of humiliation or isolation can be debilitating and can inhibit health seeking behaviour leading to higher infection risks to the community and impairing the prognosis for the patient.

TB symptoms typically present in a subdued, gradual manner and often resemble those of other common afflictions such as the common cold or malaria (cough, fever, body aches) (WHO, 2000). Thus, infected individuals frequently choose to disregard the signs of their deteriorating health in favour of other pursuits and/or erroneously waste time and money seeking out treatments for the wrong illness (WHO, 2005). Additionally, the insufficient provision of health information may lead to the reinforcement of misleading details that can induce fear and perpetuate stigma. Reports have verified that TB is often equated with conditions of poverty, genetic predisposition, poor personal hygiene, and even mysticism (Wandwalo, 2000; WHO, 2005). Since those who sense the threat of being shunned often have a longer delay in diagnosis (Auer, 2000), whereas patients with social support networks not only report to clinics sooner but also have higher rates of treatment adherence (Sumartojo, 1993), it is important to expand the realm of information dissemination.

Misinformation is typically embedded in the social framework of the rural poor due to their reduced access to health care and health information, and lower rates of education (Lienhardt et al. 2001). Sadly, these groups may subscribe to the flawed information and remain oblivious to the fact that TB is not only treatable but curable and that treatment is free of medical fees. Stigma and lack of knowledge about TB were widely reported and were worse in women. This functions as an amplified threat because women are more vulnerable to the stigma of ill-health because of their less significant position within society and traditional family structure, plus their dependence on marriage (Eastwood, 2004; Thorson, 2003). As reflected in studies such as Hurtig's and Harper's, that there may be increased incentive for women to hide their illness so to enhance their options for marriage and to lessen their chances of divorce (Hurtig, 1999; Harper, 2001; Ahlburg, 2000).

Accordingly, it is very important to remember that prospective TB patients are influenced by a myriad of misleading information and cultural constructs and they may reach diagnosis through variety of different routes. It is therefore the concern of the health system to offer more comprehensive learning avenues to provide culturally relevant information to everyone and reduce the reliance on the patient to discover the most direct way on their own.

#### **1.4d The role of traditional healers in TB management**

In sub-Saharan Africa the traditional healer is an important and powerful member of local society and most villages have at least one in their midst (Brouwer, 1998). Often these healers are the first consult for people who have become ill as

shown in Pronyk's study in Tanzania where over 40% of patients in a TB health study chose to visit traditional healers over a Western health care facility (2001).

Although cultural frameworks and social structures that include indigenous therapies should be valued and appreciated, it is important to note that inaccurate TB diagnosis and treatment by a traditional healer inevitably lead to horrific consequences for the individual and the community. Bio-medically unorthodox 'traditional' treatments for pulmonary TB may be customary within the local communities but they have been ineffective in managing long-term symptoms, they do not decrease contagion, and they have been futile in their attempts to reduce mortality rates (Farmer, 1997).

Curative measures prescribed against TB often include milk-based concoctions to reduce cough, herbal mixtures to control fever, prayers, and specially-packaged verses of the Koran (Harper, 2001; Salanopini, 2000). These remedies may be recommended to reduce symptom presentation but ironically only serve to increase patient delay to TB diagnosis and prolong feelings of ill-health. In Malawi, TB patients who first visited traditional healers spent a median of four weeks taking traditional medications during which time almost  $\frac{3}{4}$  of these patients did not experience improvement and/or saw deterioration in their health (Brouwer, 1998).

Additionally, traditional remedies and consultation are not inexpensive. Initial consults (and presumably repeated visits to a traditional healer when symptoms persist) can be very costly when compared to the nominal fee charged at the chest clinic at the time of initial consultation.<sup>4</sup> These expenses do not include extended time lost at work or loss of productivity at home during prolonged illness.

Eastwood and Hill's study in the Gambia revealed that the women in their study reported to traditional healers more often than men, probably due to stronger traditional beliefs and the perception of increased confidentiality (2004). This is of great concern from a gender perspective because, as discussed in the previous section, women are already at higher risk for ill-health due to poor nutrition, reduced access to health care, and their marginalized positions in their family society. Thus, the dilemma for women's reliance on traditional healers is multifaceted: they exhaust their time and economic resources unsuspectingly searching for traditional cures and treatment that are scientifically futile and subsequently hazard worsening their prognosis and infecting other people.

Substantial success has been recently reported working with traditional healers to provide STD treatment and HIV prevention and the potential for collaboration on TB initiatives is high (Wilkinson, 1999). Wilkinson reported that patients in South Africa indicated a preference for a choice in healer and obliging patients in this way may perhaps increase compliance to DOTS (1999). In his work with the

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<sup>4</sup> Fees for traditional healers in the Gambia are reported in the 'Research Findings' section.

West African TB Initiative (WATI), Michael Harper evaluated the knowledge of traditional healers with respect to TB and found that most appreciated TB to be 'a coughing disease' and appreciated the Western medical treatments and expressed readiness to be instructed on how to refer to the NLTP (2001). Also in the Gambia, 28 traditional healers were educated in the recognition of signs and symptoms of TB and indications for referral. When possible, they helped provide DOTS to confirmed cases and they referred 66 suspect cases to the NLTP (of which 8 diagnoses were made) (Harper, 2004). As a result, the potential for traditional healers to play a beneficial role in the health system is apparent and should be capitalized on in an effort to achieve patient-friendly, integrated health services.

#### **1.4e Health care worker rapport and patient adherence to treatment**

A good deal of research indicates that once patients finally reach the doors of the health clinics they face the extra challenge of communication with (frequently overburdened) health care workers. In addition to their clinical work, DOTS staffers also have the responsibility of contacting and convincing any patients who miss appointments to resume their treatment and often have little time for interpersonal relations and even less time to provide health education to each individual patient (Kochi, 1997; Hurtig, 1999; Auer, 2000).

These obstacles can be damaging for the patient and, in effect, their families and communities should treatment be abandoned. If the diagnostic delay and/or treatment default is the result of a health care worker (i.e.: due to an incorrect

diagnosis or poor rapport) then patients may not return to Western health care facilities for further advice (Harper, 2001). Also, as in a survey in Tanzania, treatment disruption often occurs because patients fail to fully understand the details of the extent of chemotherapy (six months of supervised intake of antibiotic tablets) and the lifestyle changes (TB patients must eat and sleep alone and refrain from sharing cups and utensils) necessary to restore good health (Wandwalo,2000).

Thus, the lines of communication must be enhanced in an effort to achieve a culturally-sensitive and respectful style that facilitates open and honest discussions between patient and caregiver. This stimulates what Auer labels a *'therapeutic alliance'* which can prove invaluable during a six-month regimen of therapy (2000).

#### **1.4e The function of family/community in TB case finding and disease control**

The community's knowledge, attitude and perception of TB are important influences in seeking health care. The perpetuation of inaccurate information, discrimination, and stigma has all been shown to negatively impact diagnosis times and adherence to treatment. This reciprocally has a negative affect on the community through increasing rates of transmission mortality and the loss of productivity of TB-affected individuals.

However, as recent investigations have shown, it is possible to view the community as a valuable *resource* in health education. Theoretically, as the community becomes involved in TB awareness, confidence will grow in the

health care system and negative perceptions that propagate stigma will diminish thereby leading to a decrease in diagnostic delay and better adherence to the DOTS programme (Lawn, 1998).

A variety of community inclusion strategies have been identified and recommended as useful tools in effective planning for the future. Hurtig has identified that when a TB patient's family and/or peers are involved in education and case holding, adherence to treatment improves (1999). Auer suggests that ensuring patients always be accompanied by a family member when seeking care is a good way for health care staff to educate families and increase social support (2000). One study showed that including the family was additionally beneficial because, after gaining awareness about the disease, 28% of family members reported others in their homes who were symptomatic (Auer, 2000).

Other research has championed the roles of traditional healers as community motivators (Harper, 2001; Liendhardt et al. 2001), and the potential for former TB patients to function as community educators proved to be just as important as health care workers (Wandwalo,2000).

Awareness programmes make the most sense when they correspond with existing local services and encompass the realities and priorities of people's everyday lives (Hurtig, 1999). In the Philippines health care staff utilized culturally-sensitive materials for patients and their families (Auer, 2000). In one

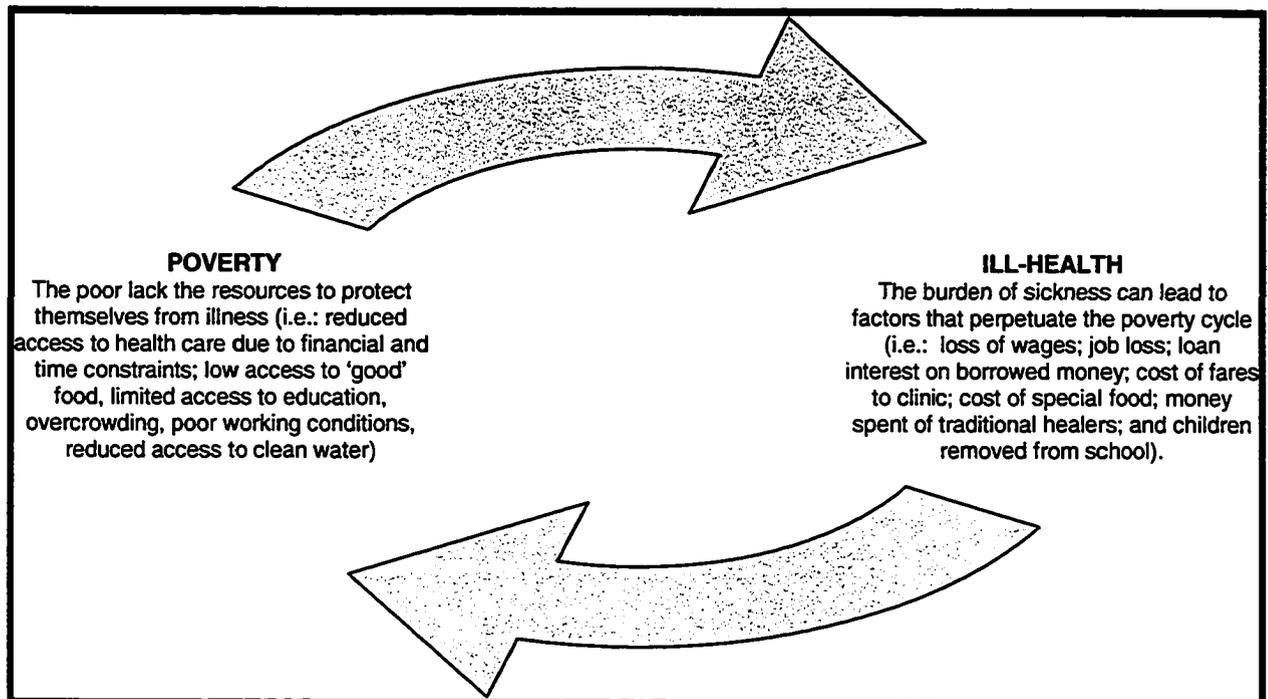
case 'cue cards' demonstrating ten essential TB messages were developed to help portray accurate information in an alternative form (Auer, 2000). In the Gambia, the NSGA's peer health educators inform their fellow students, families, out-of-school youth, and the general public about healthy lifestyle strategies and this outreach work has been achieved through creative vehicles such as community-based drama troupes, weekly radio programmes, and large-screen outdoor video presentations (Devanney, 2005).

Culturally-sensitive targeted information is needed to transform community *deficits* (i.e.: lack of education, low literacy rates, and inaccurate perceptions about health and wellness) into community *assets*. Integrated and comprehensive participatory projects have been shown to minimize diagnostic delay and boost social support and should therefore be exploited as a sustainable, resource-efficient way to bolster an educated, supportive community.

## **1.5 THE CONNECTION BETWEEN ECONOMIC POVERTY AND ILL-HEALTH**

It could be argued that the poor are predisposed to infirmity because ill-health is often instigated from the conditions associated with poverty and, in turn, ill health inhibits the generation of financial resources (Figure C). In the case of TB, poverty influences the potential infection of vulnerable groups due to conditions of overcrowding, substandard living and working conditions, under/malnutrition,

and the increased prevalence of other infectious and/or communicable diseases (such as HIV/AIDS or malaria).



**Figure C. The cyclical connection between poverty and ill-health.<sup>5</sup>**

Reinforcing the dilemma for economically disadvantaged groups has been the academic and political impassiveness for this never-ending cycle of misfortune. Previous studies have too often focused on the economic aspects of TB management and have converged upon the cost-effectiveness of DOTS strategies and/or on the fiscal analyses of intervention strategies (for example Barnum, 1986; Chunhaswasdikul, 1992). However, it is the aim of this project to encourage the modification of archetypal financial evaluations to incorporate the

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<sup>5</sup> Diagram concept adapted from World Health Organization (WHO) "Addressing poverty in Tuberculosis Control: Options for National TB Programmes" Geneva, 2005.

economic ramifications of illness as experienced by the patient and not from the perspective of the health care system.

These personalized economic features of TB are perhaps the most difficult for planners to recognize because TB treatment programmes are typically provided 'free' via subsidized government programmes and therefore seem innately *patient friendly*. However, financially 'affordable' health programmes are not wholly patient-oriented and do not guarantee accessibility. In reality, the social scientists claim, an effective health care programme must be designed to appreciate patient costs (and *household* costs) in their entirety not solely at the point of consult.

For instance, the costs of delay in diagnosis and prolonged case finding can be a tremendous financial burden for TB patients. One study in rural Africa showed that almost 50% of patient costs and income lost due to time missed from work occurred *prior to* diagnosis (Auer, 2000). Additional pre-diagnosis costs to the patient, as discussed in the section above, are the fees paid to traditional healers for advice and therapeutic treatment.

Post-diagnosis there are time and energy costs to consider: Waiting for public transport, transport time, and duration of time at clinic multiplied by six months of DOTS treatment is an expensive burden for otherwise productive individuals. Concurrently, income, cash availability and food supply have a tendency to vary

seasonally in resource poor countries. As in the Gambia, although there is more money available at harvest time, there is also less time available to spend traveling to health posts for treatment (Hudelson).

Furthermore, it is often overlooked how a family member diagnosed with TB reduces the welfare of the family. Household coping strategies that are rarely taken into account in economic assessments include:

- The diversion of resources from other forms of health care (thereby increasing vulnerability of the patient and family members to other illnesses).
- The reduction of nutrient rich food consumption (which can inhibit the prognosis of the TB patient and lead to reduced immunity for others in the household).
- The need to take in extra family members into the household or move to a relative's house (thus increasing overcrowding and increasing rates of transmission).
- The withdrawal of children from school to save fees and/or generate extra income (thereby decreasing the child's potential for a prosperous future).
- The need for family members to increase hours of labour at home or at their workplace
- The need to sell productive assets to have enough money for TB related costs and make up for lost income.
- The need to plant alternative crops that reduce amount of labour for the household.
- Expelling the infected individual from the household.
- The sharing of work and resources with others.
- Taking out consumption loans that often carry high interest rates and demanding payback schedules (as described by the WHO, 2005; Ahlburg, 2000 and Auer, 2000).

Patients may find that these types of costs exceed their capacities and may opt to avoid the six-month treatment regimen further advancing health-related costs for their households by damaging their own prognosis (and possibly risking mortality) and increasing the potential of infection for others (WHO, 2005; Ahlburg, 2000).

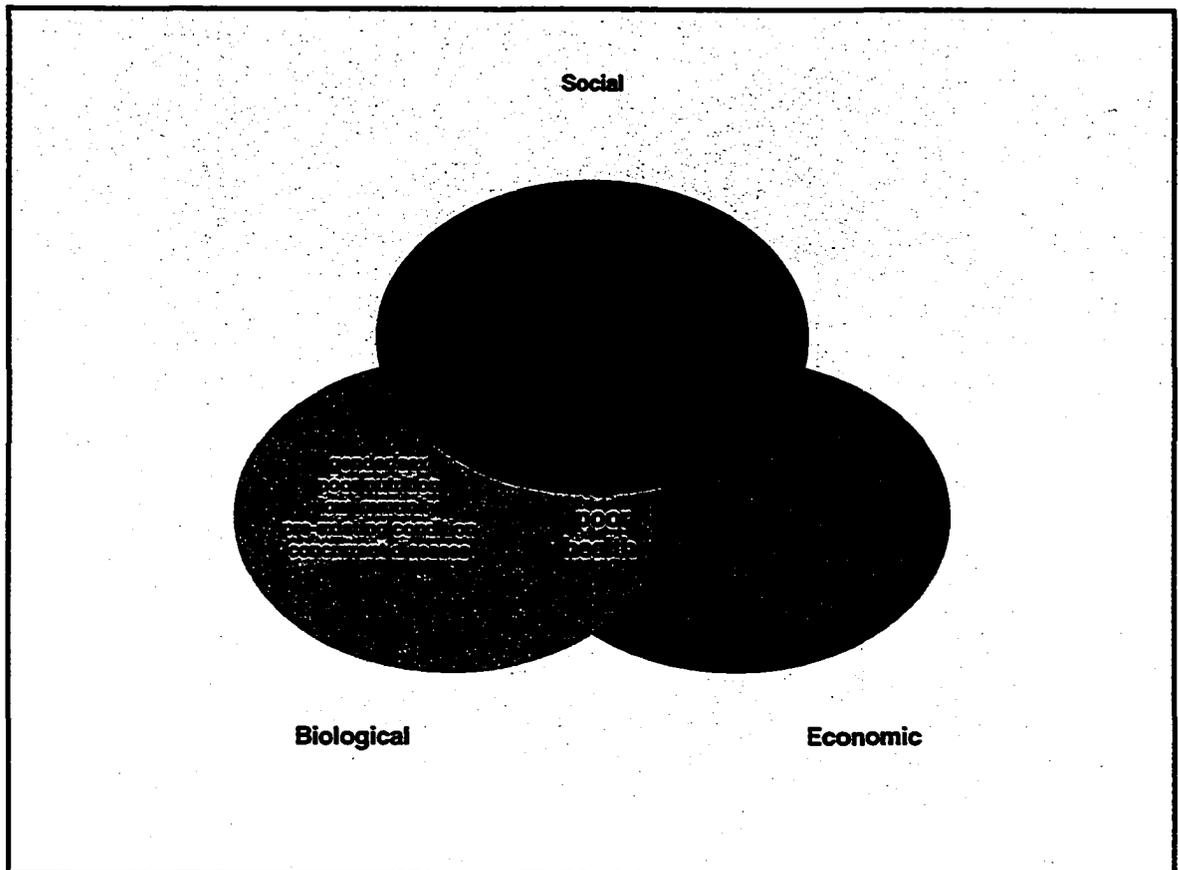
Furthermore, as indicated above, the financial burdens of illness are often taken on by caregivers who have been shown to experience severe financial infringements and are subject to many of these lifestyle changes and personal sacrifices. For example, in 30% of cases of Needham's study in Zambia, caregivers took time off work to support a household member who was diagnosed (1998).

New ways to reduce costs are needed and many suggestions are identified in the literature. In addition to the introduction of social security pay, Kamolratanakul recommends further decentralization of health care so to reduce travel costs and work absences (1999), while Hudelson sees potential in mobile clinics like those favourably reviewed in Nepal (1996). Alternatives such as these are essential not only to diminish the financial burden of TB for households but to increase the related rewards of reduced rates of transmission, lower rates of mortality and reduced loss of productivity. A further (and often overlooked) benefit of reducing the costs of case finding time is the possibility of facilitating a healthy attitude toward Western health care services which could also serve to cut back on pre-diagnostic expenditures for health-care seekers (Auer, 2000).

International research has revealed that most patient households are willing to face financial devastation to overcome TB (Kamolratanakul, 1999). It is ironic that, while this strategy may lead to alleviate the burden of TB, actions such as the sale of assets or the removal of children from school can seriously undermine

future economic prospects for the family and further contribute to the poverty and ill-health cycle illustrated in Figure C (Ahlburg, 2000). Thus, as when describing the socio-cultural aspects of diagnostic delay, current TB programmes indirectly place the onus on *the patient* to forfeit financial stability and the welfare of their households in an effort to achieve good health. This is implausible for social scientists who charge that by offering ‘free’ treatment, health care planners are simply “ . . .masking the responsibility of health care professionals and health care structures to provide the conditions in which people can be healthy (Hurtig, 1999).”





**Figure D: Social, biological and economic determinants of ill-health.**

As seen in the previous pages, ‘poverty’ in the context of international and human development needs to be expanded to include the economic, social and psychological costs incurred in the pursuit of well-being. At the same time, the concept of ‘accessible health care’ needs to be redefined to include all of the factors that contribute to ill-health such as the social, economical and biological determinants illustrated in Figure D. While the interest of current TB protocols is “. . . ultimately for the good of a population, it focuses on the individual patient who is treated without reference to the social conditions that frame his/her life (Hurtig, 1999).” Thus proposals that require TB controls to adopt a wider

interdisciplinary, multi-sector standpoint and complement current biomedical orientations are supported by social scientific research projects (such as this one) and stand to accurately serve the best interest of vulnerable populations.

## **1.6 WHAT THIS STUDY OFFERS CURRENT TB PROTOCOLS:**

*Tuberculosis is a social disease, and presents problems that transcend the conventional medical approach. . . its understanding demands the impact of social and economic factors on the individual be considered as much as the mechanisms by which tubercle bacilli cause damage to the human body.<sup>6</sup>*

Within the framework of human development, TB research demands the comprehensive inclusion of scientific goals intertwined with culturally sensitive evaluation and assessment. Reductionist decisions and observations based strictly on quantitative gains and appraisals should be consistently and systematically enhanced with cautious efforts to appreciate the burdens of the target population. This study endeavours to distinguish the social, cultural and economic obstacles that influence health seeking behaviour and patient compliance to current TB curative and prevention protocols in the Gambia. By doing so it is anticipated that both the rewards and weaknesses of existing practices will be identified from the previously *under-exploited* perspective of TB patients and their families. In effect, by considering the viewpoint of the patient, it may be possible to gain insights on how to improve the quality of life for TB-vulnerable populations while guaranteeing higher cure rates and improved levels of adherence to treatment techniques. Additionally it is proposed that this study will enhance the findings of prior reports recently (1999-2005) presented by local

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<sup>6</sup> Dubos, R and Dubos J. (in Farmer, 1997).

health teams such as the British Medical Research Council (MRC), Gambia's National Leprosy/TB Programme (NLTP), and the West African TB Initiative (WATI).

A supplementary component of this project has involved the formulation of a TB education programme for local school peer health counsellors through the Nova Scotia Gambia Association (NSGA). The Peer Health Education Programme curriculum symbolizes a progressing effort to bolster good health practices among the country's youth and provide an avenue for sustainable participatory community development in the fight against preventable diseases. The TB module that was created as part of this research study was integrated into the regular programme in February 2002 and is currently taught in the Gambia and Sierra Leone.

## CHAPTER 2: OBJECTIVES

### 2.0 KEY OBJECTIVES

When discussing TB prevention and control strategies in developing countries, it is essential to acknowledge that the mere availability of antibiotics and health care services may not guarantee their use. In addition to increasing the physical access to chemo prophylaxes and treatment centres, it is imperative that TB treatment protocols are socially and culturally acceptable, and it is equally important that these services be economically accessible by the target community. Although the precedence represented here is TB, it is conceivable that the constructs and arguments presented in this paper could be transferred to other health issues in resource poor countries.

This project encompasses three key objectives:

1. To examine the socio-economic influences that direct health-seeking behaviour for TB patients in the Gambia.
2. To investigate the economic consequences of TB infection for individuals and their families.
3. To promote TB prevention and education in the Gambia.

These goals were supported by a CIDA Innovative Research Award and were designed with Canada's Official Development Assistance (ODA) priorities in mind. First this project addresses the provision of **basic health needs** through the identification of the health requirements of TB patients and their families in the Gambia. Second, through the recognition of **gender inequality** in health care planning this project may be used as a vehicle to identify specific health challenges for Gambian women and promote equitable and appropriate solutions for change. Third, the scrutiny of TB control programmes from a **public**

**health/human rights** viewpoint analyzes the imperative dimensions of social, economic and physical access to TB services that need to be carefully gauged and accounted for in programme design. By demonstrating that financial destitution and lack of access to resources are directly correlated with serious illness, the intentions outlined here stand to support a more holistic interpretation of local health care objectives and the inherent effects on those at risk of TB infection.

Finally, the interactive peer health education component of this project embodies the philosophy behind **participatory development** models. By providing secondary school students with the TB-related information to enable them to counsel their peers, the PHEP promotes sustainability through capacity building and increases community consciousness. By including young Gambians in the process of their own development, participation becomes the impetus of community empowerment.

## CHAPTER 3: METHODOLOGY

*This research was ethically reviewed and approved by St. Mary's University (Halifax, Nova Scotia), the Scientific Coordinating Committee of the British Medical Research Council (Fajara, the Gambia), and the Ethics Review Committee of the British Medical Research Council (Fajara, the Gambia)(see Appendix A).*

### **Step one:**

*(September 2001 – October 2001)*

- Literature review and collection of local relevant statistics.

### **Step two:**

*October 2001 – February 2002*

- Semi-structured interviews were performed with TB patients and family representatives as part of a rapid assessment.

Three sites were chosen to necessitate patient representation from rural, urban and semi-rural locales. Serekunda (urban) and Brikama (semi-rural) are located close to the west coast while Farefenni (rural) is positioned near the country's center (see Figure A: Map of the Gambia).

Between October 2001 and February 2002, LTIs in each of the three selected locations identified potential interview subjects from their central TB registers. Patients over the age of 18 were selected based on their level of economic disadvantage (those living below the poverty line), diagnosis with sputum smear positive TB according to NTLP guidelines and last contact with local TB service not more than one calendar year preceding interview. Patients diagnosed with additional incapacitating illnesses were excluded from the study.

Twenty four TB patients plus two members of each patient's peer group and/or family were interviewed. Although there were no refusals, three patients could only identify one acceptable peer or family member, and one patient in Farefenni

had no eligible peers available for interview thereby limiting or study sample to 68 subjects.

Semi-structured questionnaires were designed and piloted with the assistance of local fieldworkers and LTIs prior to its distribution amongst interview subjects. One questionnaire was aimed at the TB patient; the other was designed to survey the patient's family members (see Appendices B and C). Modifications were incorporated in the final draft.

The questionnaires were administered at each patient's place of residence with the assistance of an experienced fieldworker and consent was obtained from all patients and family members prior to initiating the interview. All interviews were conducted in the native language preferred by each subject (local languages expressed in the study were Wolof, Mandinka, Fula and Jola). The interview process took approximately 1.5 hours per household and respondents were given the opportunity to explore answers in an open-ended fashion. All interviews were tape-recorded, translated into English and recorded into a computer format.

The interview included questions regarding the patient/peer (e.g. marital status, education, socio-economic status); the emotional impact of having TB; the perceived quality of health care received in health care centres and outposts; and details about the patient's initial consultation (e.g.: visits to a spiritual or

traditional healer prior to visit to health centre). Questions regarding the economic impact/consequences of TB diagnosis were introduced in an effort to quantify specific costs incurred due to illness (e.g.: costs of traditional healer, traditional medicines, fares to clinics, and the loss of income due to time missed from work).

A thematic analysis was performed on the qualitative data collected and comments were amalgamated under headings representing topic areas.

**Limitations of the study:**

- a) *Not all consecutive patients were interviewed according to study protocol as not every patient could present two peers for interview at the time of our meeting.*
- b) *Patients who were unable to seek care at the chest clinic were excluded. Additionally (possibly due to economic barriers delaying their diagnosis) patients may have died of tuberculosis at home or in hospital before registration at the Chest Clinic. This may serve to underestimate the economic burden on patients.*
- c) *Deviations from the original study design exist due to the small sample size, the lack of two corresponding surveys for each patient, and inconsistencies in the depth of patient responses (e.g.: “How much money did you borrow?” “I cannot say for sure.”). In lieu of a statistical analysis based on quantifiable data, the MRC supervising board recommended that the study be modified and restructured as a rapid appraisal.*

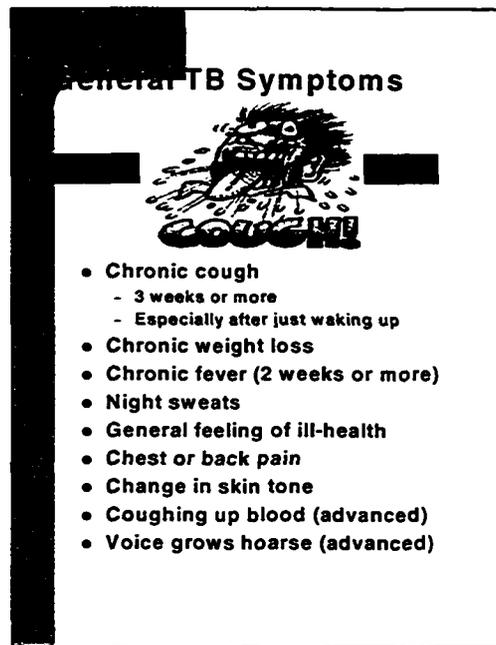
**Step three: Peer health education**

*December 2001 – February 2002*

*This component was not ethically reviewed by the MRC or Saint Mary’s University and therefore will be described in this report only to expand on my volunteer participation. The outcomes from question periods with students will not be included in the rapid appraisal. A performance evaluation of my experience has been graciously provided by Burris Devanney (Executive Director of the NSGA) and has been included as an addendum to this study (Appendix D).*

The opportunity to become a guest lecturer with the NSGA's Peer Health Education Programme in Fajara offered the chance to adopt a participatory social role in the local community. The addition of a TB education component to the NSGA's health-based curriculum helped raise awareness via the education of peer health counsellors. These counsellors use this newly-acquired information as part of their outreach programmes for students, out of school youth, and the general public.

The educational guide **"TB or not TB?: Tuberculosis in the Gambia"** was researched using the objectives founded by the WHO, CIDA and the NTLP and featured information regarding TB diagnosis, the DOTS programme, and suggestions on how to reduce stigma (see Appendix E). The package included an interactive educational booklet that mirrored classroom discussion/learning topics, full colour flip charts and posters for classroom use, a Microsoft PowerPoint presentation (when electricity was available), and in-class quizzes and handouts.



**Figure E : A page from the education guide “TB or not TB? Tuberculosis in the Gambia.”**

In addition to the development of the training handbook, supplementary tasks were outlined by the NSGA in Fajara:

- Work with full time staff to deliver the TB programme to teams of peer health educators from junior and secondary school schools on trial basis
- Assess the learning experience of the peer educators
- Revise and manual based on student and peer health educator evaluations and reviews.

Between December 2001 and February 2002 the programme was presented to students in several schools across the country including Serekunda, Farefenni and Basse and is currently part of the regular training programme for over 1000 peer health educators.

## CHAPTER 4: RESEARCH FINDINGS

Over the five-month study period, interviews with 24 TB patients and their close contacts were completed in Brikama, Farefenni, and Serekunda. The response to requests for interviews was positive with no refusals. All respondents impressed with their willingness to provide open answers, however, only a handful offered lengthy, detailed descriptions about their experiences. The local health care staff and fieldworkers attributed this inhibition to the private issues discussed (such as money borrowing), and the inherent cultural power structures that prevented women from speaking freely about private issues. An additional encumbrance developed because our total survey population was Muslim and 75% of the interviews were performed during the Ramadan fast. As a result, many interview subjects were lethargic with hunger and/or exhausted from the physical and spiritual demands of daily prayers combined with regular work responsibilities.

A summary of the gender and geographic breakdown of the study subjects is detailed in below in Table 1, followed by a description of occupational levels (Table 2), educational backgrounds (Table 3) and patient households (Table 4). This information has been provided to better describe the target demographic and offer an insightful overview of the living conditions experienced by the subjects. As may be expected a divergence in lifestyles is represented across the geographic spectrum and conditions of overcrowded living quarters are visible across the board.

**Table 1: Total number of TB patients according to gender and location**

	Brikama		Farefenni		Total
Male	5	4	4		13
Female	3	4	4		11

**Table 2: Occupational levels of TB patients by gender and region**

	Brikama		Farefenni		Male (4)	Female (4)
	Male (5)	Female (3)	Male (4)	Female (4)		
farming	5	3	2	2		
crafts				1		
driver			1			
housewife				1		
carpenter			1			
insurance agent					1	
masoner					1	
factory worker					1	
student						1
trader						3
pumps gas					1	

**Table 3: Educational breakdown of TB patients according to gender and location**

Schooling type	Brikama		Farefenni		Male (4)	Female (4)
	Male (5)	Female (3)	Male (4)	Female (4)		
Formal						
Primary	1		1	1	1	1
Secondary			1		2	2
University						
Koranic	3	1	2	2	1	1
None	1	2		1		

**Table 4: Demonstration of living conditions by region**

<b>Interview #:</b>	<b>Region</b>	<b># people on compound</b>	<b># bedrooms</b>	<b># windows</b>
<b>1</b>	<b>Brikama</b>	<b>16</b>	<b>6 (two houses)</b>	<b>3 (per house)</b>
<b>2</b>	<b>Brikama</b>	<b>8</b>	<b>4</b>	<b>2</b>
<b>3</b>	<b>Brikama</b>	<b>12</b>	<b>2</b>	<b>2</b>
<b>4</b>	<b>Brikama</b>	<b>40</b>	<b>3 (4 houses)</b>	<b>2 (per house)</b>
<b>5</b>	<b>Brikama</b>	<b>15</b>	<b>7</b>	<b>7</b>
<b>6</b>	<b>Brikama</b>	<b>9</b>	<b>3</b>	<b>3</b>
<b>7</b>	<b>Brikama</b>	<b>10</b>	<b>4</b>	<b>4</b>
<b>8</b>	<b>Brikama</b>	<b>10+</b>	<b>6</b>	<b>2</b>
<b>17</b>	<b>Serekunda</b>	<b>6+</b>	<b>4</b>	<b>8</b>
<b>18</b>	<b>Serekunda</b>	<b>1</b>	<b>1</b>	<b>2</b>
<b>19</b>	<b>Serekunda</b>	<b>9</b>	<b>4</b>	<b>2</b>
<b>20</b>	<b>Serekunda</b>	<b>2</b>	<b>1</b>	<b>1</b>
<b>21</b>	<b>Serekunda</b>	<b>8</b>	<b>5</b>	<b>1 per room</b>
<b>22</b>	<b>Serekunda</b>	<b>11</b>	<b>2</b>	<b>1 per room</b>
<b>23</b>	<b>Serekunda</b>	<b>8</b>	<b>2</b>	<b>2 per room</b>
<b>24</b>	<b>Serekunda</b>	<b>30+</b>	<b>5</b>	<b>"plenty"</b>

The small sample size limited potential hypotheses that might link geographic location, educational levels and gender (e.g.: it was not possible to accurately juxtapose rural living with an increased dependence on traditional healers). It was however feasible to identify useful categories of recurring topics based on the demographic information and the descriptive responses provided by the interview subjects. Not every issue can be discussed in detail here but central themes were established regarding the health seeking behaviour of TB patients and the social, psychological and economic costs of illness incurred by sick individuals and their close contacts.

**Theme 1:****Family and community perceptions influence the way people deal with illness****a) Few patients had previous TB knowledge before diagnosis**

Only two patients in the study had previous knowledge of the disease before their diagnosis (see Table 5). Those who did have prior experience with the disease knew friends or family who had suffered from it, had heard about it via local awareness programmes and/or were influenced by a friend or relative to seek care.

**Table 5: Patients with previous knowledge of TB**

Brikama		Farefenni		Serekunda	
Male (5)	Female (3)	Male (4)	Female (4)	Male (4)	Female (4)
0	1	0	0	0	1

*"I did not have a reaction to [the news of my diagnosis] because this is the first time I have heard of it." Male patient, Serekunda*

*"I was not frightened because I knew she was having TB because I told her she was having TB and she asked me why and I told her that this type of cough is TB." Male relative of patient, Serekunda*

*"I heard it from the health programming on the radio that [TB] is transmittable." Female patient, Serekunda*

*"I was frightened because my husband thought I had AIDS." Female patient, Farefenni*

Patients often indicated that their delay in seeking help was at least partly due to the symptoms they experienced which were congruent with indicators of other illnesses.

*"I was innocent of TB before this. I thought that it [cough] was from malaria or smoking. I used to drink milk to subdue the cough because I thought it was pneumonia." Male patient, Serekunda*

**b) Community perceptions about TB transmission and diagnosis were mixed**

Following their diagnosis with TB and after acquiring an understanding that they had become afflicted with a dangerous and contagious medical condition, TB patients reported some apprehension and uncertainty.

*“I was afraid because I thought I was not going to be well. Because I do hear people saying that if you have TB you are never better.” Male patient, Serekunda*

*“They [family] said it was from smoking. They pray for me to get better.” Male patient, Serekunda*

Negative emotional reactions from friends and families and the threat of social exclusion were underscored as major psychological costs.

*“I was afraid of eviction because we are not on our own compound.” Female patient, Serekunda*

*“They should improve the sensitization process. This is because people still think if you have TB it is not curable and you are always expected to die. So people need to know there is life after a diagnosis of TB. Let them not see you as a dying person.” Male patient, Serekunda*

*“If people know you have TB they will run away from you.” Female patient, Brikama*

*“If one is TB positive then people will look for the person who transmitted the disease.” Sister of patient, Serekunda*

Conversely, many patients and their close contacts seemed surprised at the notion of alienating a sick individual. Anecdotes of “selling” and “buying” one’s sickness were popular:

*“People should sell their illness.” Male patient, Brikama*

*“We told friends. They accepted it and visit frequently.” Wives of patient, Brikama*

*“If you hide your illness you make things worse.” Female relative, Brikama*

*“Some people may hide their illness, but it is best to ‘sell’ your illness so someone will ‘buy’ it.” Female patient, Farefenni*

*“People should not hide their illnesses. They should sell their illness for other people to buy it. If your family buys your illness then they can help you get better.” Female patient, Farefenni*

*“I do not hide my illness, it is better to get group help.” Male patient, Brikama*

The opinion that those who hide their illness from others often brought about feelings of confusion and disdain:

*“I think those who hide it want to die.” Male patient, Serekunda*

*“Some people hide illness [like TB] because they do not have good sense. It is better to tell them or else you might infect them and not get support.” Male patient, Farefenni*

*“Some hide it because they lack the mentality to do what is best.” Female patient, Farefenni*

*“Some hide it because they don’t value life.” Male patient, Serekunda*

Friends and family were shown to play important roles in adherence to care and health seeking:

*“I told him and reminded him to go to the clinic.” Wife of patient, Brikama*

*“It was my husband who said to me that I should go to the health centre immediately when it started.” Female patient, Serekunda*

*“I was not frightened because I knew she was having TB because I told her she was having TB and she asked my why and I told her this type cough is from TB.” Male patient, Serekunda*

*“Friends advised me to take drugs as instructed. They are worried about it being contagious.” Male patient, Brikama*

Additionally, the concept that only 'poor people' contract TB was dismissed by most interviewees:

*"There is no difference – everyone is likely to pick it up." Female patient, Brikama*

*"Disease has no barrier." Son of TB patient, Brikama*

*"All souls are one. Pain has no barrier." Wife of patient, Farefenni*

### c) The "Allah" factor: fatalism did not predict patient compliance

In close relation to the above opinion that rich and poor are equally susceptible to illness, is the notion TB is a disease fated by Allah. Fourteen of our respondents credited Allah with TB infection (Table 6).

**Table 6: TB patients attributing disease to "Allah"**

Brikama		Farefenni		Serehunda	
Male (5)	Female (3)	Male (4)	Female (4)	Male (4)	Female (4)
4	0	2	2	3	3

*"The disease is from Allah. The disease does not know from rich or poor. If Allah says that you must have it, you must. There is no way about that." Male relative, Serekunda*

*"I have no idea [if poor people get TB more often than rich people], Allah determines fate." Female patient, Brikama*

*"Pain is not related to anything, the disease is from Allah." Female patient, Farefenni*

## Theme 2:

### Gender differentials influence perceptions of illness & health seeking behaviour

#### a) Women are susceptible to inherent cultural and economic power structures

One woman claimed that she had been divorced and consequently expelled from her compound due to her diagnosis, and several women reported having to gain permission from their husbands to seek treatment (Table 7).

Table 7: Wives who required spousal approval before treatment

Brikama		Farefenni		Serekunda	
Male (5)	Female (3)	Male (4)	Female (4)	Male (4)	Female (4)
N/A	1	N/A	2	N/A	2

*"I obtained permission from my husband to go for diagnosis and he accepted to give me a chance." Female patient, Brikama*

**c) Concurrent disease or pre-existing health condition help identify female cases**

Two women reported being diagnosed with TB after visiting the health clinic for other illnesses or pregnancy.

*"I decided to go to the clinic for an eye problem." Female patient, Farefenni*

*"Nine months passed [between the time I realized I was ill and the time I was diagnosed]. This was during my pregnancy. I was told about it [TB] when I gave birth. I always go to the centre for antenatal care." Female patient, Serekunda*

**c) Gendered perceptions exist regarding post-diagnosis lifestyle changes**

Women and men expressed similar concerns over their loss of productivity.

*"I couldn't do my cooking by myself at first. I have to give this to my relatives and they have to do it for me without pay or anything." Female patient, Brikama*

*"I could not fetch water. I could not pound." Female patient, Farefenni*

*"I think if you are a family man and you are not working then it is always a problem. People cannot support you. You have your diagnosis and at the same time [have to] support your family and feed them which is very difficult." Male patient, Brikama*

*"My illness has really disturbed the farming because I cannot finish the harvest." Male patient, Farefenni*

Many men also connected their TB diagnosis as an imposition on their spirituality:

*"I miss going to mosque. I have missed the call to prayers for almost three months now." Male patient, Serekunda*

*“I stopped my [drugs] during Ramadan because I am an adult and I cannot stop fasting because of my prescription. How about if I stop fasting and I continue my prescription and I die? What will I tell Allah about this?” Male patient, Brikama*

Very large disparities (and enthusiastic responses) existed between the opinion of men and women with regard to the question: “Some people think that having TB is more difficult for women (men) than men (women) - Do you agree?” Men equated their infection with a loss of economic power while women associated illness with an increased burden on their domestic duties and their emotional capacities.

*“You do have family problems and financial issues because you are not working. For me I have a lot of that because some of my children are in school and I was unable to pay for their school. As you know, a family man, you face a lot of challenges on the side of the family when you are well, then how about if you are sick (especially with TB) for six months.” Male patient, Serekunda*

*“Women suffer more [than men] because they are powerless. They do not have their own money and they do not have time. A woman cannot get anything on her own” Female patient, Farefenni*

*“We think it is more difficult for men, men have to provide money, food and other things for the family. But men have TWO wives to help out!” comments from a pair of wives in Brikama.*

*“A wife’s duties are doubled and tripled! Have to do husband’s work, care for husband, care for the family.” Wife of patient, Brikama*

*“Women are more affected than men because women are powerless.” Female spouse, Brikama*

*“I was worried [after spouse’s TB diagnosis] because I am the only one working in the family and I have to get everything for them. I think [having TB] is harder for men because for everything, the family goes to him. But to really care for the family, that is the women.” Wife of patient, Brikama*

**Theme 3:****The influence of traditional healers is important in Gambian society**

Thirteen of 24 patients interviewed identified traditional healers as their initial consult while 11 patients visited a Western clinic at the outset of illness (Table 8).

**Table 8: Initial consult**

Care source:	Brikama		Serekunda		RVH	
	Male (5)	Female (3)	Male (4)	Female (4)	Male (4)	Female (4)
Traditional healer	3	1	3	2	3	1
Western clinic	2	2	1	2	1	3

**a) Reasons for choosing traditional therapies over Western clinics varied**

As previously stated, it was not possible to formally connect the use of traditional healers with geographic location or gender but this small survey revealed that traditional healers are popular by both men and women in each of our study sites. Reasons for consulting traditional healers instead of Western health clinics varied:

*"[I chose to go to a traditional healer because] I am used to it and it is what I believe in." Male patient, Brikama*

*"[I stopped my DOT treatment] because when I started using the drugs I noticed some skin reactions. That made me stop. People asked me to visit a traditional healer for the cause. That is why I stopped it. But later my friend came to visit me and told me that he was going to take me to visit Dr.Sillah at MRC. After when he left, Abdullie and Jabou also came and told me to please come back for my prescription, which I did." Male patient, Serekunda.*

*"[I chose to go to a traditional healer because] I was worried and did not know what to do. I used the Western Medicine but still, I was not better." Male patient, Brikama*

*"I thought I should apply the local herbs because I was totally desperate about my sickness because it had been a long time. I went to RVH [Royal Victoria Hospital in*

*Banjul] but I could not see the doctor because I was told he was in a meeting.” Male patient, Serekunda*

*“I told you that I always go to the health centre but they always give me paracetamol tablets and they never work.” Female patient, Serekunda*

### **b) Traditional healers are more expensive than health clinics**

One female patient in Brikama traded a bull for her consult with her local healer, when at the market she could have collected 3000 Dalasies for the animal. A woman in Farefenni thought she had influenza and was charged 1000 Dalasies for traditional remedies that only temporarily eased her symptoms.

*“I spent 500 Dalasies [excluding fares] on traditional healers.” Male patient, Serekunda*

*“I spent about 620 Dalasies on traditional healers using my own savings and loans from relatives.” Male patient, Serekunda*

*“I paid the healer in a litre of palm oil.” Female patient, Serekunda*

*“I cannot remember exactly but I remember paying at least 600 Dalasies not including my fares.” Female patient, Brikama*

### **Theme 4:**

**Patient rapport with health care workers has a positive impact on care seeking**

#### **a) Satisfaction with treatment had a positive impact on TB patients**

Nearly all patients (23 of 24)<sup>7</sup> reported positive experiences with the staff and the Western health care system, including those who sought treatment from traditional healers prior to consulting the chest clinic (see Table 9). Generally, people found the drugs to be fast-working and reported feeling better very quickly.

<sup>7</sup> It should be noted here that the male patient in Brikama who maintained a negative view of Western care (because the drugs did not relieve him of his ailments) was elderly and was disappointed the antibiotics did not help his arthritis.

**Table 9: Patients with favourable views of Western clinics following treatment**

Brikama		Farefenni		Serekunda	
Male (5)	Female (3)	Male (4)	Female (4)	Male (4)	Female (4)
4	3	4	4	4	4

*"I am very pleased with the treatment and with the health care staff. They are always very friendly and helpful towards me." Female patient, Brikama*

*"I am very pleased because the treatment has brought relief and therefore my family is happy too that I am getting better." Female patient, Farefenni*

*"Now I am not coughing as much." Male patient, Serekunda*

*"[I am] very impressed. I feel good enough to garden." Female patient, Farefenni*

Many patients recounted that if their DOTS medication had not been delivered to their home then they would have probably defaulted from the programme.

*"I am very pleased with the treatment I have received from the health clinic workers. If it had not been for Abdullie and Jabou [two health care workers in Serekunda] I would not have been able to continue my treatment. They came to my house when I was sick. Too sick to visit the clinic. I would have stopped treatment if it were not for them." Male patient, Serekunda*

#### **b) Good rapport with patients offered opportunities for health education**

Furthermore, the positive relationship between health care staff and patients served as an excellent conduit for conversations about TB education. Every household surveyed reported that they had received specific information about TB transmission, the lifestyle changes necessary to inhibit infection, and the dietary and health needs of the patient.

*"It has been a change because she [the patient] eats alone and drinks with her own cup and sleeps alone." Male relative, Serekunda*

*"Yes, I learned that the person should not spit openly in the air and the person should have all his needs separate from the rest of the family." Female patient, Serekunda*

**Theme 5:****The economic costs of being ill are far-reaching****a) Money problems translate into financial and emotional costs**

When patients and close contacts were asked to identify the biggest obstacles of illness, their answers irrefutably pointed to financial difficulties.

*“If you are sick you cannot have money. You need money for family feeding and also to go to the clinics if you are sick or if another family member is sick. You have to be responsible for the clothing of children and for their education.” Male patient, Brikama*

*“You do have family problems as a financial issue because you are not working.” Male patient, Brikama*

*“Money. Because if you are sick you cannot get money.” Female patient, Serekunda*

*“If you are not working and don’t have a strong relative to help you, you must face financial problems because who is going to help you free of charge? So money is a big problem if you have TB.” Male patient, Serekunda*

*“If you are sick you cannot have money. You need money for family feeding and also to go to the clinics if you are sick or another family member is sick. You have to be responsible for the clothing of the children and their education.” Male patient, Brikama*

*“Shelter. Shelter is always a problem because if you go home you may have no money to live in your own compound it will not be easy.” Female patient, Serekunda*

**b) Pre-diagnosis expenses can be severe**

It has already been discussed that much of a TB patient’s pre-diagnosis expenditures can be attributed to the fees and related costs of consulting a traditional healer. It is also important that TB symptoms can be severe enough for an individual to miss work thereby increasing the costs of diagnostic delay further. This is not to discount the loss of productivity of unpaid workers such as housewives.

*“TB has affected my work because I was laid off from my work and somebody had to replace me. And my chances of picking my job up are very little. I was told that if there*

*was a vacancy, then I will be taken to do the work. If not, I will have to look for a job elsewhere.” Male patient, Serekunda*

*“I missed five months farming before I was diagnosed.” Male patient, Serekunda*

*“Since last year I did not do any work. [I have lost] plenty of money because I used to fetch for firewood and sell it. Also I do take milk from people and sell that and a lot more other jobs.” Male patient, Brikama*

*“For two weeks I did not go to work. . . I have lost more than 1000 Dalasies.” Female patient, Brikama*

**c) Transportation fees to and from clinics are accumulative and expensive**

Many patients indicated that transportation fares were a major financial concern. The fares are quite high (Table 10) and they are even more of a burden for patients registered in the DOTS treatment regimen as multiple trips are needed over six months.

**Table 10: Cost of return trip to health care clinic (Dalasies)**

Brikama		Farefont		Serekunda	
Male (5)	Female (3)	Male (4)	Female (4)	Male (4)	Female (4)
8	100	2	20	12	6
30	16	26	Unsure	12	12
112	Drugs delivered	40	Free	15	6
14		12	20	50	20
Drugs delivered					

*“Because you should go for your medication and you do not have money to pay for fares it is always a problem. I am pleased with DOTS but I am expecting fares to be a problem because the [treatment] days are so close together.” Female patient, Serekunda*

*“If you are not working and you have no means of generating extra funds. . . if you are sick it is always different because if you think of the [transportation] fares it is really a problem.” Female patient, Serekunda*

#### d) Transportation times to and from clinics can be extensive

As seen in Table 11, transportation times to and from health clinics can consume many productive hours in a patient's day. Travel times were especially lengthy for patients in the rural areas, and like fares, can be extremely burdensome after multiple trips.

**Table 11: Transportation time to and from health care clinic**

Time in mins./hrs	Brikama		Farefenni		S	
	Male (5)	Female (3)	Male (4)	Female (4)	Male (4)	Female (4)
Unsure	2	2	1	3	3	1
0-15	1					
15-30					1	1
30-45						
45-60	1					
> 1 hour			1	1		
>2 hours			2			2
Drugs delivered	1	1				

*"There are bad roads in Farefenni. Public transport can take two hours." Male patient, Farefenni*

Road conditions and transport times are even less appealing when it is considered that many of the rural patients travel on horse carts or on foot.

#### e) Alternate ways to generate funds are often necessary for economic survival

Often left without employment or subsistence-based income due to illness, it was reported that many households sought alternate means to generate extra funds. Table 12 illustrates how many patients borrowed money from friends and relatives to compensate for lost income and support their families following TB diagnosis.

**Table 12: Patients who admitted borrowing money for treatment:**

Brikama		Farefenni		Serekunda	
Male (5)	Female (3)	Male (4)	Female (4)	Male (4)	Female (4)
2	2	3	1	4	1

*"I have borrowed 300 Dalasies from relatives and taken 600 Dalasies from my own savings." Female patient, Serekunda*

In addition to borrowing money, many patients and close contacts opt to make lifestyle changes and take on extra work so to better cope with TB related expenses. Women often described selling produce and crafts at local markets to supplement income, and one family in Brikama had to sell part of their compound to have enough money for fares and food. Other examples are listed below:

*"Walking to the clinic is free but it takes over one hour each way." Female patient, Farefenni*

*"Farm is not operational. No family to help." Male patient, Brikama*

*"My spouse does extra washing for people." Male patient, Serekunda*

*"I begged from the people and got about 75 Dalasies." Wife of patient, Brikama*

*"We sold the compound and shared responsibilities at the new home." Female relative, Brikama*

Often households reported that the nutrient rich 'special' food that was recommended by the health care staff was a dangerous sacrifice made in an effort to reduce household costs. One wife of a TB patient indicated that firewood was once collected by the patient but, following his illness, the firewood had to be purchased. Consequently food that was once brought home from market was no longer available due to a shortage of funds.

*"The biggest problem? Mostly it is the diet that is a problem because you cannot [stick to] your diet if you do not have the money." Male patient, Serekunda*

**f) Children often miss school to help compensate for lost productivity**

No one surveyed admitted to removing children from school completely in an effort to save registration fees. However, many admitted to removing children from regular classes to gain extra help on the farm and/or compound.

*“Yes [the children miss school] because he [patient] has been someone whose position in the family is very big as he always does work on the farm and helps in domestic jobs at home and even cares for the children at home. I really felt his sickness and pray for his recovery.” Female patient, Serekunda*

*“Yes children have to miss school sometimes to help out.” Wife of patient, Brikama*

*“Some of the children missed 2 weeks of school to help out.” Mother of patient, Farefenni*

## CHAPTER 5: DISCUSSION

By connecting the information gathered in the literature review with the data collected from interview sessions with TB patients and their close contacts it is possible to gain an enhanced, patient-centred understanding about the relationship between socio-economic poverty and illness. All of the patients (males and females over the age of 18) included in the study were economically disadvantaged, most patients had limited schooling (Table 3) and almost all lived in large households on crowded compounds (Table 4). As a result, this study facilitates a colourful snapshot of the different aspects of vulnerability through the depiction of a variety of personal experiences influenced by gender, socio-cultural structure, and financial constraints.

### **Theme 1:**

**Family and community perceptions influence the way people deal with illness**

#### **a) Few patients had previous TB knowledge before diagnosis**

The perception of TB within the community is an important factor for disease control because inaccurate perceptions, the inability to assess symptoms and the threat of social isolation can all lead to diagnostic delay and the related risks of reduced prognosis and increased transmission. This study revealed that – despite the presence of the National TB Programme and the existence of nationwide chest clinics – only 2 patients out of 24 interviewed had any previous knowledge of the disease (Table 5). Those who did have prior experience with the disease knew friends or family who had suffered from it, had heard about it

via local awareness programmes and/or were influenced by a friend or relative to seek care. Oblivious to the specifics of the symptoms and frightened that they might be stricken with other fearsome afflictions such as HIV/AIDS, patients did report suffering through diagnostic setbacks.<sup>8</sup>

The literature parallels these findings and suggests that a lack of schooling and not knowing another TB-infected person increases the risk of diagnostic delay and therefore promotes the use of culturally-relevant posters and radio broadcasts to help increase community familiarity with the disease (Salanopini, 2000; KNCV, 2001). Some studies have shown that public health education contributes to the success of TB control programmes especially when peers and family members were also exposed to education (Liendhardt, 2001). Thus, the presence of a TB component within the NSGA's Peer Health Education Program may also serve as a useful vehicle to promote TB awareness and prevention while helping to diminish social stigma because, as Farmer has suggested, “. . . before obstacles to a treatment can be cleared away, patients have to develop health beliefs and social norms consistent with it (1997).”

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<sup>8</sup> The time duration between onset of illness and diagnosis, and the relationship between gender, geography and education could not be analyzed here due to small sample size.

**b) Community perceptions about TB transmission and diagnosis were mixed**

Psycho-social costs such as fear of social marginalization were evident in the responses but, because accounts of prior knowledge of the disease were minimal, it is conceivable that this trepidation was perceived and/or related to the information received at the clinics regarding the dangers of TB transmission. Similarly, although many patients and families expressed fear and anxiety regarding a serious illness, these emotions could not be completely related to the fear of TB. Although the news that TB diagnosis carries a risk of infection, the worries expressed in the interviews seemed to be a generalized reaction to the news of the poor health of a loved one.

Again, the issue of stigma that was widely reported in the literature was mitigated by the wash of anecdotes about the importance of “buying” and “selling” one’s illness to others. Not only did patients and close contacts alike insist that group support was a necessary and acceptable means for recovery, but there was a general consensus that those individuals who conceal their infirmity “do not value life” and/or do not possess the mental resourcefulness to do what is right for themselves and others.

Additionally, responses showed that friends and family played important roles in health seeking behaviour and adherence to TB treatment. Close contacts were

often identified as chief patient supporters who encouraged regular clinic visits and monitored compliance with TB regulations.

These responses are encouraging for the Gambia's health planners in that there appears to be a certain readiness for friends and family to accept and support TB patients. Research has shown that friends and family play an important role in adherence to care and health seeking. While not verified here, Pronyk's research offers further optimism citing that people from larger households (such as in our sample population, Table 4) had significantly shorter delays to diagnosis possibly to the credit of a family member who influenced health promotion (2001). This offers a constructive foundation for the expectations of peer health education and the potential for TB patients to act as peer mentors at the local level (Harper, 2003; Wandwalo, 2000).

**c) The "Allah" factor: fatalism did not predict patient compliance**

Although no questions were designed to invoke responses regarding religious beliefs, 13 of the surveyed patients indicated that they believed TB infection was fated by Allah (Table 6). Despite fatalistic outlooks, patients were willing to follow the DOTS regimen to 'improve' their destiny. Similar disjunctions were found in research where patients' etiologic values did not predict their adherence to treatment. For example, Rubel cites a study of Mexican farm workers in California who attributed their symptoms to "folk illnesses" and denied their TB diagnosis regardless of their active participation in a registered TB management

programme (1992). Thus, compliance may not be exclusively based on patients' cultural belief systems but should be considered by health planners as a potential deterrent for health seeking.

**Theme 2:****Gender differentials influence perceptions of illness & health seeking behaviour****a) Women are susceptible to inherent cultural and economic power structures**

Tuberculosis kills more women than any other infectious disease including malaria and AIDS (WHO, 2005; Thorson, 2003). Thus it is important to consider that gender and power relations exist where men and women are subject to a hierarchal order which leads to inequities in health and well-being. These relations are often of special significance to women because the subordination of women is present in most societies and leads to inequality and discrimination in health (Thorson, 2003). Women in the Gambia appear to be susceptible to these customary cultural and economic power systems that limit their opportunities for medical attention. As illustrated in Table 7, several women indicated that their access to health care depended largely on the permission of their husbands. While all the women in the survey eventually gained spousal consent, the study indirectly suggests that many women fail to present to clinics due to gender biases in the home.

Furthermore, one woman reported she experienced the social cost of divorce after being diagnosed with TB and then faced the economic cost of being expelled from her compound. This occurrence is consistent with Harper's report which proposes that gender inequities fuel the rationale to hide illness, as illness leads to social exclusion (2001). These are important factors to consider when evaluating current protocols as the health of women influences the health of those in their care. New ways of increasing accessibility are needed along with strategies that recognize and moderate the imbalance of power so that women are not neglected or structurally eliminated from TB eradication plans. Uplekar suggests that most TB programmes can be improved by (a) analyzing gender-based quantitative data that is systematically collected and, (b) familiarizing and educating health personnel to gender issues and bias (2001). Peer health education and TB awareness programmes may also help in reducing the social and health costs faced by women and, in effect, their families.

**b) Concurrent diseases or pre-existing conditions help identify female cases**

Two women in the survey were diagnosed with TB by a health care professional who noted their symptoms during an unrelated consultation. One patient was diagnosed after she self-presented for an eye problem, and the other patient was identified after she gave birth. Research has shown in the Gambia and elsewhere that women may have a unique comparative advantage in health seeking due to their familiarity with the health system and increased opportunity for consults thanks to maternal and paediatric clinics (Lienhardt, 2001; Hudelson,

1996). Conceivably, this type of indirect TB detection may help counter the disadvantages of passive case finding and offset the health inequities faced by women as spousal consent may not be needed to attend free clinics aimed at children. Also, if women can take advantage of 'one-stop-shopping' at health clinics and have a personal check-up added to a child's visit, ideally her time limitations will be lessened.

**c) Gendered perceptions exist regarding post-diagnosis lifestyle changes**

The disparities between the opinions of men and women offer additional insight into the gendered experiences of illness. Men and women expressed similar concerns regarding their loss of productivity yet men's productivity was more closely related to income and subsistence. Concurrently, while men equated TB infection with a loss of economic power and status, women indicated their own illness limited their unpaid domestic duties and the illness of others represented both a strain on their time and their emotional capacities.

There appeared to be a stronger concern among men that the social aspects of their spiritual commitments were compromised due to illness. For at least one male patient this apprehension led to an interruption of his DOTS treatment. In a predominantly Muslim country where the rules of observance are strict and well-heeded, the risk of forgoing treatment in favour of events such as the Ramadan fast needs to be examined and perhaps mediated by local spiritual leaders.

**Theme 3:****The influence of traditional healers is important in Gambian society****a) Reasons for choosing traditional therapies over Western clinics varied**

Just over half (13 of 24, see Table 8) of TB patients surveyed indicated that traditional healers were their initial consult (others indicated they returned to traditional healers following visits to Western clinics). Responses varied when asked for the rationale behind patient preference. Some cited that indigenous medicine was structurally embedded in their culture while others indicated that they consulted traditional healers following a negative experience with Western clinics (e.g.: one patient was turned away when a doctor was in a meeting) and/or there were unexplained complications and side-effects with the DOTS therapy.

Although the importance of traditional medicine needs to be respected, research has discounted the benefit of alternative therapies in reducing the symptoms and improving infection rates of TB bacteria. Proposals to include traditional healers in education and planning with primary health stakeholders are well supported and mutually respectful collaborations could increase the chance for beneficial partnerships (Salanopini, 2000; Pronyk, 2001; Wilkinson, 1999; Harper, 2004). However, it is important that traditional healers be taught to recognize TB patients who they should not treat but instead refer to the chest clinics for prompt (Brouwer, 1998).

**b) Traditional healers are more expensive than health clinics**

As previously discussed, suspect TB patients are charged a fee of 5 Dalasies at the chest clinic and, following diagnosis, medications are free of charge. Payments stipulated by traditional healers are frequently more exorbitant (up to the cost of a bull worth 3000 Dalasies in this survey) and can prove to be financially devastating for the patient who pays dearly for futile medications and services. This is particularly dangerous for women who are economically marginalized and have little time for treatments that do not work. It is additionally disconcerting because of the negative effects on diagnostic delay, increased rates of infection, and poor patient prognosis.

Consequently, if traditional healers are to be incorporated into the health care structure as part of TB management schemes, it may be difficult for programme coordinators to offer a financial reward for services that is comparable to the current market value for local remedies. Other critical issues that require deliberation in an effort to protect the integrity of the National TB Programme include the evaluation of traditional practices, quality control, and safety measures (Wilkinson, 1999).

**Theme 4:****Patient rapport with health care workers has a positive impact on care seeking****a) Satisfaction with treatment had positive impact on TB patients**

All but one patient reported satisfaction with their TB treatment following diagnosis. People described that their symptoms were reduced and/or eliminated

quickly and allowed patients to gradually return to their regular activities. The quick relief from coughing, body aches, fever, etc., served as an excellent incentive to continue with the DOTS treatment and follow-through with weekly clinic visits.

Positive accounts regarding interaction with the health staff in all three field sites suggests a cooperative and friendly atmosphere for patients receiving DOTS treatment. This is extremely important because the quality of encounters with health care workers (usually the LTIs in the Gambia) combined with time spent with TB patients can affect the number of programme defaulters (Thorson, 2003). For example, in Hurtig's study some defaulting patients had construed the structure of the supervised DOTS programme as the government's distrust in them (1999). These beliefs were further exacerbated by the lack of empathy sometimes shown by health workers (Hurtig, 1999). Instead, a focus on building an encouraging and constructive environment leads to patient agreement and increases adherence to treatment as seen in the responses presented here for this review.

#### **b) Good rapport with patients offered opportunities for health education**

As discussed in the research findings, the overall knowledge of TB was low and the level of formal schooling of the survey sample was minimal. Typically these shortcomings may lead to difficulties for health education efforts. However, the positive relationship between health care staff and TB patients established in the

Brikama, Farefenni and Serekunda clinics offered an excellent channel to provide health education to patients and their families. Patients and their close contacts in each of the 24 homes surveyed could correctly repeat instructions given to them at the clinics regarding the necessary lifestyle changes to reduce transmission levels and to enhance the patient's health.

To ensure compliance there has to be a reciprocated responsibility shared by patient and health care worker where the objectives need to be transparent and open with informed communication (Thorson, 2003). For instance, recognition of the importance of the *quality* of the initial patient contact needs to become a higher priority for planners. Auer presents anecdotal evidence that a thoughtful and respectful style of listening and interacting with patients improves TB prognosis (2000). This approach permits patients to speak candidly and facilitates a better understanding of each individual case by health care workers who can then appreciate the diverse array of influences that effect health seeking behaviour and treatment compliance.

Auer has also suggested that health care workers meet with family during clinic visits which enables the communication of improved health practices to more than one member of each household, thereby enforcing the diffusion of information and increasing TB awareness.

**Theme 5:  
The economic costs of being ill are far-reaching****a) Money problems translate into financial and emotional costs**

Perhaps because money represents a more tangible means for gauging socio-economic status and social standing, patients identified financial difficulties as the biggest obstacle of illness and this fixation often translated into increased anxiety for patients and their close contacts. Several patients mentioned that they feared not being able to provide food for their loved ones, clothe their children, and provide shelter for their families. Additionally, the financial costs of being ill are far-reaching for everyone but more so for women due to increased poverty, low social status, and elevated time constraints (Hudelson, 1996).

These relationships and concerns (previously outlined in Figure C) demonstrate the cyclical connection between being ill and being economically disadvantaged. People who are economically poor are prone to illness because of their reduced access to income and assets, overcrowded households, substandard living and working conditions, and low rates of education and literacy. The economic burden of TB creates barriers for prompt diagnosis. This may lead to continued transmission of the infection and lowered prognoses for patients, while compliance and improved outcomes are strongly associated with access to income. Being poor can cause illness, illness causes poverty, and this never-ending cycle causes a lifetime burdened with stress and the related emotional costs of not being able to provide for and/or care for family members, and a

decreased sense of self worth. For women, the stress of being sick is augmented by a dependence on marriage for economic stability.

This cycle exists irrespective of the presence of “low cost” TB medications and government subsidized programmes. Thus, it is evident that the characterization of “cost-effective” therapies needs to be expanded to appreciate the experience of the patient.

**b) Pre-diagnosis expenses can be severe**

It is important to note that a large proportion of patient expenditure occurs *before* the patient is actually diagnosed and started on antibiotic therapy. Patients reported they were less productive at home, lost time from work or were dismissed from their jobs. More money was spent on traditional healers and their related costs such as indigenous therapies and transport fares. Lack of patient knowledge about symptoms is a strong factor in this aspect and indicates the need for improved education activities which could lead to prompt diagnosis at Western clinics. Increased education efforts may also serve to eliminate unnecessary and costly visits to traditional healers, and traditional healers could be trained to redirect suspect TB patients to clinics at the time of their first consult.

**c) Transportation fees to and from clinics are accumulative and expensive**

Once diagnosed, patients learn quickly that, although medications are provided 'free of charge,' transportation fees to the clinics can be costly (Table 10). The patients in this survey reported that return fares to clinics via public transport or taxis can cost up to 112 Dalasies per visit. When multiplied by weekly visits over six months, these costs are expensive to patients and families who are already poverty-stricken and doubly burdened with the loss of the economic and/or domestic productivity of a loved one.

**d) Transportation times to and from clinics can be extensive**

Travel times can also have a compounding effect on TB patients in that it can take a long time to travel to clinics on foot, in places where road conditions are poor, or when the use of horse cart is the sole option. Although many Gambians live within a reasonable distance to chest clinics and health outposts, a distance of 8km (16km return) is still a significant barrier to access (Salanopini, 2000). As with transportation fees, the demands of DOTS treatment amounts to the accumulative loss of productive time away from work and a disproportionate loss of time with family.

In Hudelson's study in Nepal a successful alternative to health outposts was explored. By offering *mobile* clinics for TB patients it was possible to eliminate both transportation fees and times (1996). An additional advantage existed for

women who could skirt issues of time constraints and costs as they tended to visit the mobile service more frequently (Hudelson, 1996).

**e) Alternate ways to generate funds are often necessary for economic survival**

As seen in Table 12, many TB patients had to borrow money to help balance the costs of transportation fees and lost income. Family members also reported borrowing money and making lifestyle changes so to better manage with a sick patient at home. Many families were forced to sell assets such as their homes and property; some took on extra paid work such as selling crafts and produce at markets, while others resorted to giving up nutrient-rich foods in favour of a less expensive diet to help save money.

**f) Children often miss school to help compensate for lost productivity**

The removal of children from school to help out with domestic tasks and/or agricultural chores is another example of costly sacrifices made that are often detrimental to family life. In turn, the lowered educational status of the family's children propagates poverty and limits the family's chances for a more prosperous economic future.

The extreme financial responsibilities and time constraints put on the families of TB patients correspond to a health system designed to treat microscopic contagions, and not patients. As a result, the current system serves to fuel the

poverty-illness cycle, guaranteeing future generations of families encumbered by structurally-induced deprivation and perpetuating the persistence of the disease.

## CHAPTER 6: CONCLUSION

From a strictly biomedical standpoint, it is difficult to find fault with the Gambia's existing anti-TB strategy. Complete with free childhood vaccination programmes, nationwide chest clinics, and government-subsidized chemotherapies, the inherent expectation is the cost-effective eradication of pulmonary infection through the provision of inexpensive and accessible health care. Yet, the threat of TB infection remains despite the establishment of an ostensibly infallible system. The question remains – why don't patients take advantage of these numerous outlets to achieve better health? As demonstrated in this literature review and research project, the key to effectively address the deficiencies that hinder TB management protocols is to adopt a *pro-patient* perspective and consider the compilation of social, cultural and economic permutations that influence perceptions of health and well-being, guide health-seeking behaviour, and direct adherence to treatment.

This endeavour has succeeded in identifying core themes that validate the multidimensional nature of the influences that contribute to the persistence of TB in West Africa:

- a. Family and community perceptions influence the way people deal with illness
- b. Gender differentials influence perceptions of illness & health seeking behaviour
- c. The influence of traditional healers is important in Gambian society
- d. Patient rapport with health care workers has a positive impact on care seeking
- e. The economic costs of being ill are far-reaching

These results support the information observed in international contemporary research and complement the findings presented by the West African TB Initiative, the Medical Research Council, and the Gambia's National TB Programme. As a valuable sample of local insight regarding the patient's personal experiences dealing with the strengths and weaknesses of the current TB strategies, this study supports new proposals that seek to further highlight the realities of poor health as experienced by patients and their families.

Through the acquired appreciation of these constraints, it is possible to make an important association: from a human development position, the connection between poverty and illness is best illustrated through a broadened understanding of the concept of 'vulnerability.' In this context, vulnerability describes how people are prevented from accessing health services due to inherent social, cultural and economic structural limitations such as gendered power structures, reduced access to income, high levels of unemployment, low levels of education, and time-honoured dependencies on indigenous therapies.

This more holistic perspective has been recently adopted by the World Health Organization (2005) and epitomizes an onslaught of supporting materials that champion an interdisciplinary approach to healthcare that encourages patient-centred changes and flexibility in TB control strategies. By developing a socio-cultural perspective and by redefining "cost-effectiveness" to reflect all of the costs incurred by patients and their families, barriers may be reduced through

interventions that increase TB awareness, decrease delays in diagnosis, lower the number of health encounters, and reduce and/or eliminate travel distances.

Although a number of deficiencies have been identified in this report, it is also important to recognize the strengths so to focus on the potential of asset building at the local level. The Gambia is fortunate to already have an informal sector of community leaders that may enhance health education and awareness programmes. Traditional healers and NSGA's peer health counsellors have been proven to be a reliable, sustainable and culturally-relevant method of disseminating important health information to local communities and should be deemed a valuable resource in an integrated health care scheme. Additionally, as reports of TB related stigma were low, it should not be difficult to encourage increased self-presentation of suspect cases to clinics through community-oriented education programmes.

As applied to other health issues, the value of this people-centered perspective offers universal potential for increasing health overall by shifting the focus from restrictive biomedical and economic parameters to enhancing the quality of life for those who suffer from the related consequences of poverty and ill health. As Christian Liendhardt proposes, **“Health services and international agencies need to think not just how best to swallow pills but what is easiest for the patient (1999).”**

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**APPENDIX B:**  
**Questionnaire for TB patient**

Location of interview:.....	Number of languages spoken.....
Gender.....	Language preferred for interview.....
Age.....	Education.....
Ethnic group.....	Marital status.....

**Interview themes based on category:**

**We are interested in the working and economic conditions of your household. May we ask you some questions about these topics?**

What is your main source of drinking water (well, bottled water)?

What is your main occupation? What does this work involve (farmer, migrant worker, permanent employment, temporary employment)? Is it a paid job?

How many people live in your home?

How many bedrooms are there in your house? How many people sleep in each room?

Is your house well ventilated? How many windows?

Did you have to borrow money to begin/complete/continue your treatment and/or travel to clinic? If so, from whom did you borrow the money?

What are the terms of this loan? How will you pay the money back?

**We are interested in learning how you decided to come to the clinic:**

What were the initial signs and symptoms of your illness?

What did you know about TB before you were diagnosed?

When did you decide to seek medical attention?

Did you look for treatment somewhere else before you met with a doctor/nurse (initial consultation)?

(If traditional treatment was sought) Are traditional healers more expensive than the clinics?

Are you pleased with the treatment you have received at the clinic?

Have you ever been too sick to visit the clinic? Did you send someone else to collect your drugs?

(For wives) Were you obligated to gain spousal approval before seeking treatment?

**We would like to know more about how this illness affects the way Gambians live and socialise:**

What was your reaction when you were told that you had TB?

In your opinion, what are the worst physical symptoms of TB (i.e.: pain, fever, fatigue, etc.)?

How does illness affect your working life?

**For waged labourers:**

Will you return to work when your treatment is finished?

Are you paid while you are on sick leave?

**For Farmers:**

Is someone helping you with your land while you are sick? Is this person a friend? Family member? Employee?

Will you have to pay additional staff to work while you are sick?

How does this illness affect your social/family life?

Do you have children in school?

Do your children help you in your home/on the farm when you are sick? Do your children miss school to help out?

How long does it take you to travel to the clinic? By what means?

How much does transportation to/from the clinic cost?

Have you missed work due to your illness (due to symptoms, time to travel to clinic, side effects of medication)?

Does anyone else in your family/household have TB?

Did you tell your friends about your diagnosis? How did they react?

**We are interested in how Gambians perceive TB:**

What are the general perceptions of TB in your family? In your community?

Do some people hide their illness from their friends and family?

Some people believe that poorer people are more likely to get TB than people who are wealthy, what do you think?

Some people think that having TB is more difficult for women (men) than men (women). Do you agree?

Approximately how many months/days passed between the time you realized you were ill and the time you were diagnosed with TB?

During this time period, what did you do to make yourself feel better? Did you use traditional remedies? Visit a traditional healer? Visit a health care clinic?

(If patient visited a Western health care facility) How many times did you see a Western doctor/health care professional about your symptoms before you were diagnosed with TB?

(If treatment was sought from a traditional healer): Why did you seek treatment from a traditional healer before seeking help from a Western medicine clinic?

How much money did you spend on visits to a traditional healer (including transportation costs and medicine costs)?

How did you finance your treatment (i.e.: costs of traditional healer) prior to your diagnosis?

Method:	Check all that apply:	Approximate amount:
Own savings		
Transfers from relatives		
Bank loans		
Sale of property		
Sale of produce		
Other (specify)		

How much time did you miss from work/farming when you were sick before you were diagnosed?

How much income did you lose during the time you were sick before you were diagnosed?

How many days/months have you missed from work/farming since you have been diagnosed?

How much income have you lost since you have been diagnosed?

How did you finance your illness after you were diagnosed with TB?

Method:	Check all that apply:	Approximate amount:
Own savings		
Transfers from relatives		
Bank loans		
Sale of property		
Sale of produce		
Other (specify)		

Have you ever stopped your TB treatment? WHY did you have to stop (money, time, side-effects of drugs)?

In your opinion, what is the biggest financial challenge to being sick with TB?

If you could change anything about your TB treatment (how DOTS is implemented), what would you change?

**APPENDIX C:****Questionnaire for TB patient's spouse/relative**

Location of interview:.....  
 Gender.....  
 Age.....  
 Ethnic group.....

Number of languages spoken.....  
 Language preferred for interview.....  
 Education.....  
 Marital status.....

What was your reaction when your spouse/relative told you (s)he had TB?

(For husbands) Was your spouse obligated to seek your permission before she sought treatment/care for her illness?

How has this illness affected your social life?

If a person has TB, how does it affect his/her family?

Did you have to borrow money to support the family while your spouse/relative recovers?

Who did you borrow from? What were the terms of the loan? How will this money be paid back?

Have you sought alternate ways of generating extra funds (i.e.: second job)?

Has your domestic routine (daily habits) changed since his/her diagnosis? How? (new sleeping arrangements, separate dinnerware, etc.)

Have his/her domestic responsibilities been compromised since the illness came about? How has the household adjusted?

Do the children in the house have to miss school to help out around the house/farm?

**We are interested in how Gambians perceive TB:**

What did you know about TB before your spouse/relative was diagnosed? Where did you learn about TB?

Since your spouse/relative's diagnosis, have you learned more about the disease?

What are the general perceptions of TB in your family? In your community?

Did your spouse/relative tell his/her friends about their diagnosis? How did they react?

How do you plan to protect yourself and other members of your household against getting TB?

Do some people hide their illness from their friends and family?

Some people believe that poorer people are more likely to get TB than people who are wealthy, what do you think?

Some people think that having TB is more difficult for women (men) than men (women). Do you agree?

**APPENDIX D:**  
**(Photocopied) Letter from Burris Devanney**  
**(Executive Director of the Nova Scotia Gambia Association)**

**Evaluation of Performance: Heather Ann McPeake**  
**Nova Scotia - Gambia Association's Peer Health Education Program in The Gambia**

**Re: CIDA Awards Program for Canadians**

I am pleased to provide this evaluation of Heather McPeake's contribution to NSGA's Peer Health Education Program in The Gambia. Heather had been involved, through her CIDA Award, in an extensive research project on the relationship between poverty and tuberculosis in The Gambia. While I cannot comment on the research itself as NSGA was not involved in that aspect of Heather's work here, I can comment very favourably on her work with NSGA.

The NSGA's Peer Health Education Program aims at improving the health and well being of children and youth in The Gambia through empowering them with the knowledge, skills and confidence to take responsibility for their own health. This is being accomplished through the establishment of well informed, well trained teams of peer health educators in schools throughout the country. The peer educators develop and conduct an ongoing series of presentations to children and youth in their own schools and communities on the key health-related issues confronting these communities. They are trained in a variety of strategies to engage their peers in discussion and encourage healthful behaviour and attitudes. They also develop community outreach programs targeting neighbouring schools, out-of-school youth and the general public.

While the primary aim of the program is the prevention of HIV/AIDS, the peer educators are trained to make presentations on all of the other main health issues impacting on young people today, including sexually transmitted infections; drug and alcohol abuse; the harmful effects of tobacco use; diabetes; malaria; reproductive health issues; and tuberculosis.

Heather's work with NSGA was based upon her research into tuberculosis in The Gambia. Her primary tasks in the Peer Health Education program were as follows:

- develop a training module for tuberculosis in our Peer Health Education Program
- work closely with our permanent program coordinators and trainers to deliver this module to teams of peer health educators from selected senior and junior secondary schools on a trial basis
- evaluate the trial as a learning experience for the peer educators
- revise and improve the training module based upon this evaluation
- produce a training manual/information booklet on tuberculosis to be used by peer educators in their work of presenting this information to their peers

Our team of coordinators and trainers learned a great deal from Heather. She was very knowledgeable about TB in general and its prevalence in The Gambia, and was able to present this information clearly and graphically to any audience. She was very skilful in creating visually effective overhead transparencies and flip chart graphics. Our coordinators and trainers continue to use the materials that Heather created, and they have also learned from her example the methodology and value of colourful visual presentations. Thus she not only developed the training module but helped train our local staff in how to present the information themselves.

Heather was also most generous in the time she gave to helping our Gambian training team develop their own presentation skills. We were all very pleased with this. We were also pleased with the thoroughness with which she dealt with the topic. The TB information booklet which she

produced is well laid out and provides a complete description of symptoms, diagnosis, treatment and prevention. The booklet itself is a clear illustration of Heather's presentation techniques.

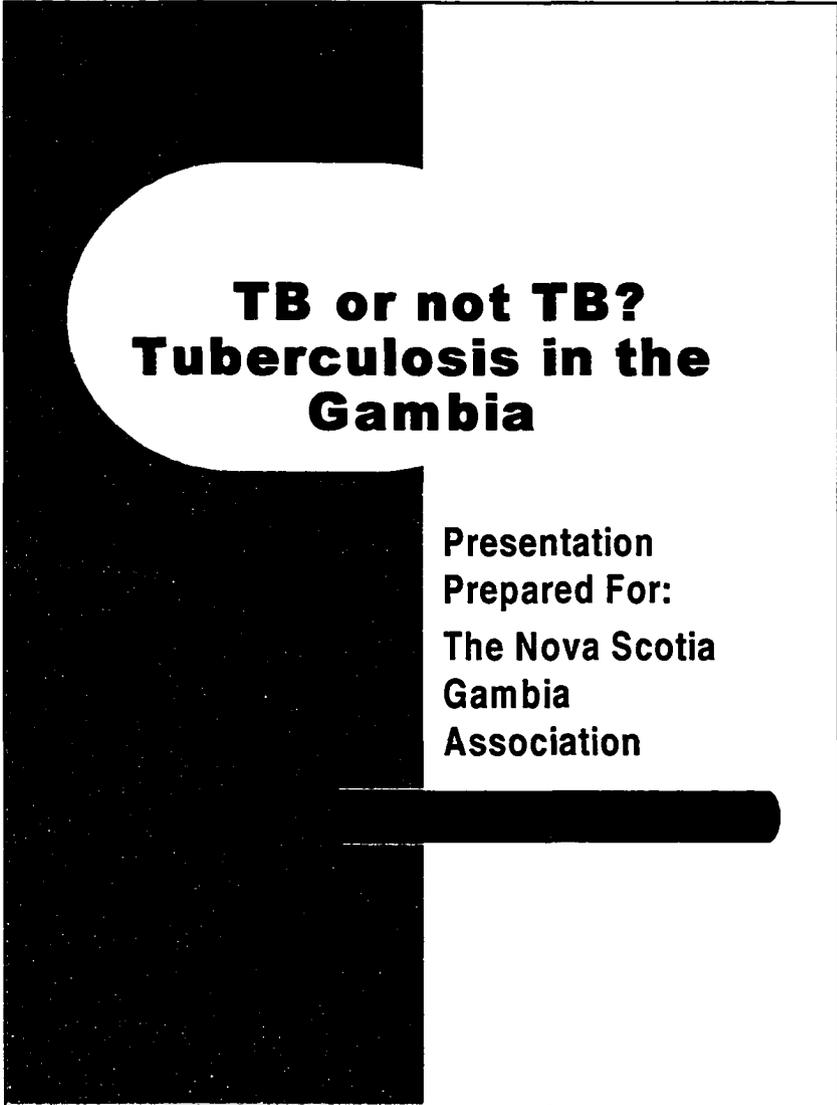
The booklet is currently in use not only by NSGA coordinators and trainers, but also by more than 1,000 peer health educators in the schools. TB is a serious problem in The Gambia, not only as an opportunistic disease that may infect persons living with AIDS but as a significant problem in its own right. There is no question that Heather has made a valuable contribution to the NSGA program and to hundreds of peer health educators in The Gambia who are now finding ways and means of sharing the information on TB with their peers.

We are most appreciative of the fact that the CIDA Award Program for Canadians has enabled NSGA to benefit from Heather's knowledge and research and her presentation skills and creative ability, as well as her good work ethic and generosity of spirit.

**Respectfully submitted by:**

**Burriss Devanney  
Executive Director**

**12 February 2003**



**TB or not TB?  
Tuberculosis in the  
Gambia**

Presentation  
Prepared For:  
The Nova Scotia  
Gambia  
Association

This segment of learning has been designed to accommodate various learning environments. Disks for the Microsoft PowerPoint presentation, plastic overheads, flipcharts, and information booklets have been made available for use by the NSGA and Peer Health Education counsellors.

**Presentation format and information booklet designed by:**



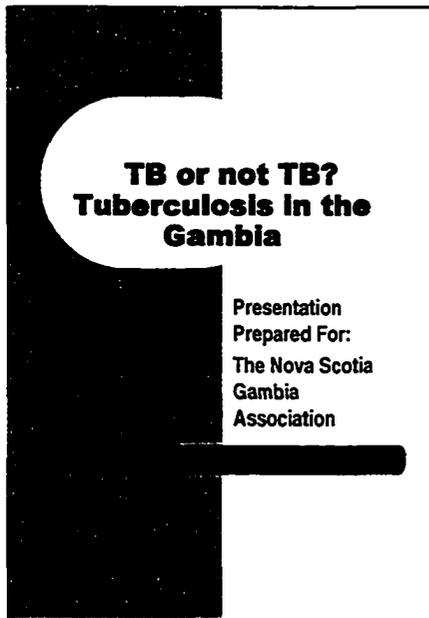
Heather McPeake  
Saint Mary's University  
Halifax, Nova Scotia  
Canada  
December 2001



## TB or not TB? NSGA Peer Health Education Program

### Slide #1:

### Introduction to TB Component



Hello! Welcome to the **NSGA Peer Health Education Program in the Gambia**. This component of the program will focus on a very important health topic: **tuberculosis of the lungs (TB)**.

Within this section you will learn some important definitions, statistics, and preventive practices to stop you (or someone you know) from becoming ill with TB.

This section of education involves a lot of what you have already learned from other parts of the Peer Health Education Program such as information on HIV/AIDS and the dangers of smoking. It is important to remember that a healthy lifestyle includes eating well, getting enough sleep, exercising, and knowing how to protect yourself and others from different types of diseases. Many of these concepts will be reviewed again here, along with some valuable information about TB.

**This segment of learning can be presented in a number of ways:**

- 1) If the equipment is available, “computerized” slides and notes have been prepared on a program called “**Microsoft PowerPoint**.” PowerPoint allows the person who is doing the presentation to use a computerized slide show to convey information. To do a PowerPoint presentation you will need a laptop computer and a special projector. (If this equipment is not available, copies of the slides and speaker’s notes have been made into this information booklet.)
- 2) **Overheads:** Copies of the PowerPoint “computerized” slides have been made into plastic overheads that can be used in classrooms where an overhead projector is available.
- 3) **Flipcharts:** One set of flipcharts is available from the NSGA, but you can create your own flipcharts based on material in this handout.
- 4) **Handouts:** Handouts and information booklets (such as this one) are available through the NSGA. The “key points” of each topic are summarized in the upper left hand corner of each page (as adapted from Microsoft PowerPoint).



A **mini-dictionary** containing words and acronyms relevant to this discussion has also been provided. Students will also be required to complete a **pre-test** prior to the presentation to test their current TB knowledge and then will be required to complete a **post-test** following the seminar to gauge what they have learned.



## TB or not TB? NSGA Peer Health Education Program

### Slide #2:

### Tuberculosis overview

#### Tuberculosis Overview:

##### Definition:

Pulmonary TB is a long-lasting lung disease caused by the mycobacterium tuberculosis and is easily spread from person to person. When treated early and properly, TB can be cured.

Learn the three C's of tuberculosis:

- 1) TB is a CHRONIC disease.
- 2) TB is a CONTAGIOUS disease.
- 3) TB is a CURABLE disease.

Tuberculosis of the lungs (pulmonary TB) is a chronic and contagious disease that is caused by a small bacterium known as *Mycobacterium tuberculosis* (a picture of the bacterium as seen with a microscope is shown on the insert on the left).

When we say that TB is a **chronic** disease, we mean that it lasts for a very long time.

When we say that TB is a **contagious** disease we mean that it is easily spread from one person to another. Therefore it can be very dangerous because everyone is susceptible to becoming sick.



Anyone can become infected with TB: men and women, young people and old people, black people, white people, rich people and poor people. Even celebrities can get TB! Some famous people who have had TB include **Desmond Tutu** and **Nelson Mandela** (right).

TB cases have been detected as far back as 2000 years ago and TB is still being found all over the world in North America, Africa, South America, Europe, and Asia. TB germs are **everywhere** – not just in developing countries as a lot of people might think.

When we say that TB is a **curable** disease, we mean that if a doctor or other health care professional treats TB properly and if patients follow the treatment, TB symptoms can be controlled and TB patients can recover from their illness.

HOWEVER, in order for TB to be managed effectively, it must be detected EARLY. If TB is identified too late, it can be **fatal**.

Take a minute now to learn the three **C**'s of tuberculosis:

- 1) TB is **CHRONIC**
- 2) TB is **CONTAGIOUS**
- 3) TB is **CURABLE**





**Slide # 4:**

**Scary TB Statistics**

**Scary TB Stats**

- 1/3 of the world is infected
- One person becomes infected every second!
- 8-10 million people develop symptoms
- 3 million/year will die
- TB is EVERYWHERE but 95% of cases are in developing countries
- >50% of cases will be in Africa
- 112/100 000 people in the Gambia (1999)
- That's at least 1527 Gambian TB patients!

Tuberculosis is a **global** epidemic that continues to grow and is gradually becoming more dangerous. Here are some scary statistics:

- It is estimated that between the years 2000 and 2020, nearly **one billion** people will be newly infected with TB and 35 million people will die from the disease (if they go untreated).
- Currently, reports show that approximately 1/3 of the world is infected with the TB bacterium!
- Because so many people are infected, it is easy to spread the

disease. In fact, it is believed that one person becomes infected with TB every single second!

- Of all the people who will be exposed to the bacteria, 8-10 million people will develop symptoms.
- Of these 8-10 million people who get sick with TB, 3 million will probably die.
- The bacterium that causes TB has been found throughout the world, but 95% of TB cases will be detected in developing countries.
- Of the 95% of cases found in developing countries, more than 50% of those new cases will be found somewhere in Africa.
- Here in **The Gambia**, TB has been found throughout the country – in cities and in rural areas. In 1999 a survey was completed and it showed that 112 people out of 100 000 have TB.
- **That means over 1527 Gambians have active TB!** (And those are just the people who were diagnosed! There are many more people in the Gambia who are sick with TB and who are infectious but they have not been diagnosed yet! They could be spreading the TB germ and they may not even know it!)

**SCARY STUFF!**



Slide #5:

**General TB symptoms**

Tuberculosis is **curable** yet thousands of people die needlessly every year. So remember: in order to **prevent** infection and to **cure** the disease, it is important to know the signs of the illness and know when to seek medical attention.

**If a person exhibits one or more of the following symptoms of illness, (s)he should visit a clinic for TB testing immediately:**

**General TB Symptoms**



- **Chronic cough**
  - 3 weeks or more
  - Especially after just waking up
- **Chronic weight loss**
- **Chronic fever (2 weeks or more)**
- **Night sweats**
- **General feeling of ill-health**
- **Chest or back pain**
- **Change in skin tone**
- **Coughing up blood (advanced)**
- **Voice grows hoarse (advanced)**

- **Chronic cough – especially after just waking up.** The cough may be “dry” (no sputum produced) or it may produce a green or yellow phlegm/sputum. A cough is considered **chronic** if it lasts for 3 weeks or more.

*cough because the bacteria damage the the production of excess amounts of mechanism may be due to tissue mucus, or a combination of both.*



**Note:** *People with TB tend to delicate lung tissue and stimulate mucus. The coughing irritation, an attempt to dislodge*

- **Chronic weight loss.** If a person loses a dramatic amount of weight (without the benefit of exercise or dieting) over a relatively short period of time then (s)he should go see a doctor. This weight loss is usually paired with increasing muscle weakness and fatigue.
- **Chronic fever lasting two weeks or more.** A person with a fever will have a body temperature of 38<sup>0</sup> or more, might feel hot to the touch, and/or may experience “chills.” Typically, TB patients experience fever in the afternoon.
- **Night sweats.** A person who is infected with TB may experience severe sweating during their sleep. This may or may not be accompanied with a fever.
- **General feeling of ill-health (or malaise).** An infection with the TB germ may leave the individual feeling like they are run down, or like they have a bad cold.
- **Chest and/or back pain.** Due to TB infection, a person may have difficulties or discomfort when breathing, talking, or completing daily activities.
- **Change in skin tone.** Individuals with black skin may take on a lighter complexion. This characteristic is usually more noticeable on the face. Try to compare the person’s skin colour with his/her family members.



TB Symptoms (Continued):



# SIGNS OF ADVANCED TB INFECTION

The following symptoms may indicate an advanced and more dangerous case of TB infection. Individuals exhibiting these symptoms should visit the nearest health care facility **IMMEDIATELY**:

- 1) **Coughing up blood (haemoptysis).** Sometimes a person with an advanced case of TB will cough up blood (sometimes just a few specks of blood are visible in the sputum but other times there may be a large amount of blood).



*Note: This should be a common rule. Coughing up blood may not always be an indication of TB infection but may signify some other infection or illness such as pneumonia. Whenever a person produces blood when they cough, they should visit a doctor as soon as possible!*

- 2) **Hoarse voice.** If a person's voice becomes chronically and seriously hoarse, (s)he should see a doctor without delay.



## TB or not TB? NSGA Peer Health Education Program

### Slide #6:

### TB infection requires medical attention!

infection  
requires medical  
attention!



- TB is curable but must be treated EARLY!
- TB-causing bacteria can only be cured by antibiotics!
- Home remedies and traditional treatments may treat the symptoms but will NOT cure TB!
- Know the signs and symptoms of TB!
- Close contacts of TB patient should also see the doctor.

If you or someone you know has one or more of the symptoms for TB, it is best to seek help from a medical professional as soon as possible.

**It is best to seek medical help quickly for two reasons:**

1) The sooner a person receives proper medical help, the sooner (s)he will get better.

2) The sooner a person receives proper medical help, the chances will be reduced that (s)he will infect others.

***Fast diagnosis is the best way to insure increased cure rates and decreased***

***infection rates!***

### What is meant by “proper medical treatment”?

TB infections can only be cured using a specially prescribed dose of antibiotics. Therefore it is only curable with **WESTERN MEDICINE**. In the Gambia, although there is a general service fee of 5 dalasies to be diagnosed at a hospital or clinic, these special anti-TB drugs are prescribed and given to TB patients for **FREE** by the Department of State for Health TB Inspectors and at all available government clinics. There are nine TB clinics across the country: Banjul, Serekunda, Brikama, Farefenni, Kerewan, Basse, 7?, 8?, 9? Some people who live far away from the clinics may be able to get their drugs from their village health care worker.



***Note:*** Although some traditional treatments may reduce some of the signs of TB, only specially prescribed antibiotics have the power to kill the germs that cause the disease. Using traditional medicines in place of Western remedies may prolong illness and encourage permanent damage to the lungs, increase a person's chances of dying from TB, and may increase the chance of infection for others.

### Be aware of TB's symptoms and know when & where to go for help.

It is also advisable that the patient's **close contacts** (for example, people who have been living in the same compound as the TB patient) should visit the doctor in order to rule out infection.



Slide #7:

TB Diagnosis

**TB Diagnosis**

Diagnosis may be achieved via one or more of the following tests:

- Sputum smear test
- Blood test
- Chest X-ray
- Urine test
- Mantoux skin test

Minor discomfort!  
Major benefits!



**How is TB diagnosed?**

When a person visits a health care professional with complaints of TB symptoms there are several tests that may be performed in order to make a proper diagnosis. Which test a patient is given may depend on a number of things such as a person's symptoms or the availability of testing equipment.

The most common test is called the **sputum smear test**. The doctor/nurse/inspector will ask the patient to cough-up some sputum into a container and this sputum sample will be tested in a laboratory for the presence of TB bacteria.

A test that reveals a "**sputum smear positive**" case of TB positively indicates infection. A TB patient's sputum may show up "**sputum smear negative**" for TB infection at the beginning of his/her illness but the patient could still be infected with the bacteria. Also, people with HIV or AIDS may also present as sputum smear negative but may still be infected with TB. Therefore, the individual should see the doctor again for another type of TB test that may include one or more of the following:



**Blood test.** Blood will be drawn from a vein in the patient's arm (near the elbow) and tested for TB. The patient should also ask for an **HIV test** because, as will be discussed shortly, people with HIV are more susceptible to TB infections. HIV can also be detected with a blood test.



**Chest X-ray.** This way the doctor can examine a person's insides and see if there are any signs of TB infection in the lungs.

**Urine test.** A patient suspected of TB infection will be requested to supply health care staff with a urine sample for testing in the laboratory.

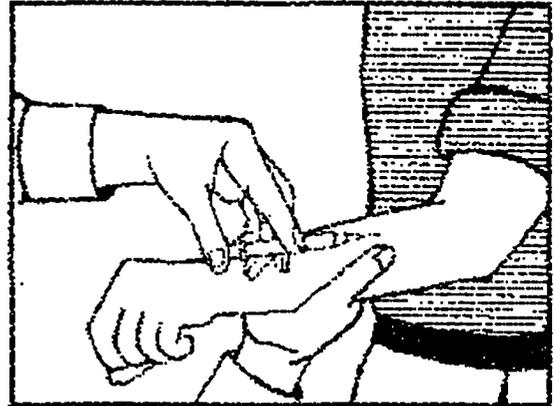


## TB or not TB? NSGA Peer Health Education Program

### TB Diagnosis (continued):

**Mantoux skin test** [*pronounced man-toe*]. The Mantoux skin test is often used in addition to other TB diagnostic tests. This test is designed to detect the presence of TB bacteria in your body. A small amount of harmless proteins similar to those found on the surface of TB bacteria is injected just below the skin on the forearm. If the surface near the injection becomes raised and red to a certain degree then it indicates either past or current infection with TB (the doctor/nurse will measure the circumference of the swelling 48 – 72 hours after the test is performed).

**Diagram of a health care worker administering a Mantoux skin test.**



**NOTE:** *People who do not currently have TB but have received the BCG vaccine against TB infection, have had TB before, and/or have been previously exposed to the TB bacteria may produce a positive test. Therefore a positive Mantoux test does not necessarily confirm TB infection. Also, a negative Mantoux test does not necessarily rule out TB infection. This is why the Mantoux test is often used in addition to other TB diagnostic tests.*

Sputum smear test  
Blood test  
Chest X-ray  
Urine test  
Mantoux skin test



All of these tests have their own minor form of discomfort but each test is quick and easy and the results far outweigh any pain endured!



**NOTE:** *Another important fact to remember is that all of these tests can be performed on pregnant women and on HIV infected individuals without doing them any physical harm.*





## TB or not TB? NSGA Peer Health Education Program

### Slide #8:

### WHO's DOTS Program

World Health Organization's  
**DOTS Program**  
Directly Observed Therapy Short-Course  
**TB Treatment**

- 95% cure rates
- anti-TB tablets (antibiotics)
- 3 times weekly for 6 months
- "Supervised swallowing"
- Minimal side-effects
- Confidential and FREE
- Prevents new infections
- Prevents MDR-TB
- *Generally, TB patients who take their medication are NOT contagious!*



#### How is TB treated?

In the Gambia, patients who test positive for TB infection are prescribed drugs in regulation with the World Health Organization's (WHO) drug treatment plan (drug treatment is sometimes also known as **chemotherapy** or **chemo-prophylaxis**). WHO has designed a program known as Directly Observed Therapy Short-course (or "DOTS").

WHO's DOTS program has been proven to be extremely effective with up to 95% cure rates for patients who comply with the program. However, in order for the program to be effective, TB patients have to take their drugs *properly!*

#### The DOTS system is fairly simple:

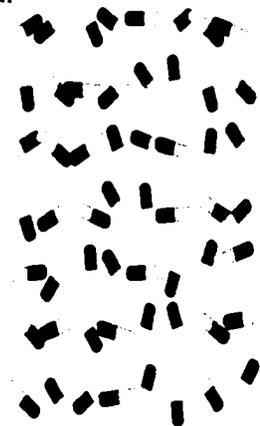
TB patients take antibiotics **three times a week** (usually Mondays, Wednesdays and Fridays) for **six months**. Sometimes people call the DOTS program "**supervised swallowing**" because TB patients are required to visit health clinics or hospitals to receive their drugs and swallow them under the supervision of health care workers. It is believed that close patient supervision will motivate patients to take their drugs properly. Additionally, DOTS enables health care staff to monitor TB cases in the country.

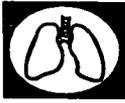
The antibiotics used in the Gambia are ethambutol, rifampicin, isoniazid and pyrazinamide. These pills are used in different combinations depending on the patient. The combinations may include up to 16 pills of four different types of antibiotics (the exact dosage depends on the patient's body weight). The combinations are as follows:

TB4 (maximum 16 tablets, 3 times a week for two months)

TB2 (maximum 8 tablets, 3 times a week for four months)

***All of those pills may seem like an awful lot to swallow but it is worth it!***  
***(TB patients often start to feel better within one the first week of taking antibiotics)***





## TB or not TB? NSGA Peer Health Education Program

### WHO's DOTS Program (continued):

When a patient is **sputum smear positive** they take the antibiotic combination known as **TB4**. Patients on **TB4** are considered to be **infectious** for the first month of treatment. During this time period (s)he should:

- ✓ Be given sick leave from work and/or school (health staff will provide a note),
- ✓ Be careful when coughing near others (i.e.: should cover their mouth),
- ✓ Collect their sputum in a container instead of spitting on the ground, and
- ✓ Stay away from those who are (or are suspected of being) HIV positive.

After two months of **TB4** treatment the patient will have another sputum test. If the sputum test is negative then the drug treatment will be reduced by one antibiotic to become **TB2**. Also, the patient will be permitted to go back to work or school (a note will be provided by the health care staff to confirm the patient's health status).

**Patients on TB2 antibiotics are generally not considered contagious!**

During treatment a person's sputum may be tested at least two more times to check to see that the antibiotics have worked. The WHO defines a "**cured TB patient**" as a patient who is **sputum smear negative** in the last month of treatment and on at least one other occasion.

In the Gambia, DOTS is a **confidential** and **free** service provided by the government. When the drugs are used properly (i.e.: the tablets are taken regularly and the prescription is followed to completion) there are minimal **side-effects**. For example, some people may have a mild upset stomach, and some may complain that their urine is tinted red. These conditions are *normal* when antibiotics are prescribed, although patients should visit their doctor if they become worried by any side effect of the drugs.

Unfortunately, antibiotics are not always used correctly and this leads to something called **Multi-Drug Resistant TB (MDR-TB)**. Drug resistance occurs when bacteria are permitted to "become accustomed" to the inhibiting effects of a drug due to misuse. MDR-TB is a global problem.

**Danger!**  
**MDR-TB Bacteria →**  
**Watch out!**



**NOTE:** *It is also extremely important for a TB patient to inform their doctor of his/her health history. Drugs that are prescribed for TB may be incompatible with drugs prescribed for other conditions such as HIV. Drug conflicts inside the body can be very dangerous!*



Slide #9:

**Risk factors for TB infection**

**Risk Factors**

- Age
- Alcohol abuse
- Smoking
- Conditions of poverty
- Gender
- MDR-TB & non-compliance to treatment
- Immune suppression
  - HIV
  - malaria
  - Diabetes
  - malnutrition

While **EVERYONE** is susceptible to TB germs, there are certain risk factors that may increase the chances of infection:

**Age.** Typically, those at the extremes of age (either very young or very old) experience a heightened risk of TB infection. However, it most often strikes people between the ages 15 and 35.

**Alcohol abuse.** People who abuse alcohol may be more prone to TB infection because alcohol can have damaging effects on the immune system. Also sometimes people spend more money on alcohol than on proper nutrition and malnutrition invites infection from germs.

**Smoking.** Tobacco damages lung tissue and destroys the body's natural immunity to TB.

**Conditions associated with poverty.** Although TB can strike rich people and poor people, certain factors that are related to poverty may increase the chances of infection. Some examples might include **malnutrition** (cannot afford proper food), **reduced access to public transport** (cannot visit clinics), **reduced access to education** (reduced literacy rates, cannot be trained on health education), **reduced access to health care** (live too far away from clinics or cannot afford health care fees), and **crowded living conditions** (reduced access to proper housing).

**Gender.** It is important to realize that illness has different outcomes for men and women. Although TB can infect both men and women you should be aware that:

- TB kills more women than any other infectious disease including malaria and AIDS.
- Although more cases of TB in men are reported in clinics, it is believed that due to socio-economic constraints, there are more women than men who have TB but they are unable to visit clinics for diagnosis. Can you think of what some of these constraints might be?
- “double” or “triple” workload (waged work + agricultural work + domestic duties)
- no time to seek treatment
- increased social stigma (e.g.: increased potential of divorce if ill)
- reduced decision making capacity (may need permission from spouse)
- reduced access to household funds (cannot afford travel/treatment fees)



**Note:** Over 70% of the world's poor are female and these women face the greatest obstacles to seeking health care and TB treatment.





## TB or not TB? NSGA Peer Health Education Program

### Risk factors (continued):

**MDR-TB and non-compliance to treatment.** Multi-drug resistance is a problem all over the world. The more strains of bacteria that become tolerant of the killing power of antibiotics, the more dangerous the threat of infection becomes.

Therefore, TB patients who do not comply with WHO's DOTS therapy regulations increase the risk of serious illness for themselves, and they also increase the chances for infection for other people.

**Immune suppression.** The body's natural immune system offers individuals a very powerful protective defence mechanism against certain viruses, bacteria and other environmental insults. However, certain conditions and lifestyle choices may reduce the body's ability to protect itself.

Smoking and alcohol abuse are two good examples of lifestyle choices with negative effects on immunity.

Some physical conditions that may reduce the body's ability to fight infection and recover from illness include:

**HIV**  
**Malaria**  
**Diabetes**  
**Malnutrition**



**Malaria reduces  
immunity to TB  
infection!**

It is important that people know how to prevent these conditions so that compound illnesses do not occur. For people who are already suffering from one of these conditions, it is important to protect themselves from opportunistic TB germs.

The condition that is known as **HIV-TB co-infection** is a particularly lethal combination. In Africa, HIV is the single most important factor determining the increased incidence of TB over the last ten years. Additionally, TB increases the chances of death for people with HIV.

# That brings us to our next topic. . .



## TB or not TB? NSGA Peer Health Education Program

### Slide #10: TB and HIV

#### TB and HIV

- Bacteria versus viruses
- HIV makes you more susceptible to TB
- TB increases HIV death rates
- TB is the only airborne disease that HIV/AIDS patients can spread to others
- Ask for an HIV test with your TB blood test
- Protect yourself!

When discussing HIV in the context of TB it can be a little bit confusing. HIV and TB are both dangerous infections on their own, but **HIV/TB co-infection** can be even more devastating.

#### Let's start with the basics:

It is important to understand that TB is a *bacterial* infection and HIV is a *viral* infection. While TB can be treated easily (and cured) with antibiotics, HIV is difficult to treat (even with antiviral medication), and HIV cannot be cured.



**NOTE:** *Antibiotics cannot treat viral infections! That is why it is important to visit your doctor to be properly diagnosed.*

TB is an opportunistic bacterial infection that preys upon people with weakened immune systems. People living with HIV/AIDS are more prone to TB infection because the HIV virus has compromised their immune systems. HIV will speed the progress of TB and TB will speed the progress of HIV. TB has become a leading cause of death of HIV+ people, it accounts for 15% of AIDS deaths worldwide.

You have been taught the fundamentals of HIV/AIDS transmission so you know that the HIV virus can only be spread through sharing needles, sexual contact and transmission from mother to her baby. **An HIV+ patient cannot transmit the HIV virus through casual contact with others.**

**HOWEVER.** . .TB is the only airborne disease that HIV+ patients can spread to others through casual contact. It is therefore important to remember that an increase in HIV cases ultimately leads to increased TB cases through opportunistic infection.

Because the risks of co-infection can be lethal, all patients who are being tested for HIV should also be tested for TB. Similarly, if a person thinks they might have TB and they have also been exposed to HIV, they should be tested for HIV.

Let's review the **ABC's** of HIV/AIDS protection and prevention:

**A**bstain from sexual contact & avoid intravenous drugs/shared needles!

**B**e faithful to a faithful partner!

Always use a **C**ondom!



**Slide 11:**

**Impact of Infection**

**Impact of Infection:**

- ↓ Personal health
- ↑ Risk to family health
- ↓ Economic development
- ↑ Orphaned children
- ↓ Education rates
- ↑ Death rates due to HIV
- ↑ multi-drug resistance
- ↑ Complications with malaria



It is important to realize the social and economic consequences of becoming sick with TB. Getting sick and showing symptoms of illness are really just the beginning of much bigger problems that can affect individuals, their family, and their community. **Consider the following:**

↓ **Personal health.** When a person becomes infected with TB (s)he will experience a decline in their personal health.



↑ **Risk to family health.** When that person lives with a group of people in an extended family situation or on a large compound, the health of others may be compromised.

↓ **Economic development.** When a person and/or family members becomes sick, it becomes difficult to work. When people cannot work at their jobs or on their farms the economic development of the community decreases.

↑ **Orphaned children.** When parents become sick with TB they increase the chances of leaving behind orphaned children.

↓ **Education rates.** Children orphaned due to TB, or children who have sick parents, often have to miss school because they have to help out at home, or on the farm, or even work outside the home to help pay for the lost wages of the parent.

↑ **Complications with malaria and ↑ HIV deaths.** TB is an opportunistic infection that may complicate malarial infections and increases the chances of dying due to HIV.



↑ **MDR-TB.** Finally, a lot of TB patients fail to take their antibiotics properly and this may lead to increased rates of MDR-TB, making it harder to cure and more expensive to import alternative drugs.



**Slide #12**

**Protect yourself and those around you**

**Protect yourself and those around you:**

**BCG vaccine:**

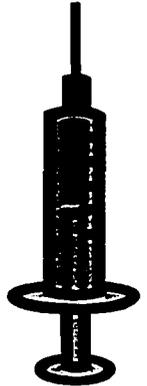
- BCG is an “attenuated” vaccine
- Have YOU been vaccinated? Check for your “TB Scar”
- In the Gambia, babies born in hospital usually get the BCG vaccine
- BCG is only 40% to 80% effective!!
- Protect yourself from TB infection regardless of vaccination history

In this section we will review the best methods of TB protection and prevention.

**BCG Vaccine:**

The first official line of protection against TB infection is the **BCG vaccine**. The BCG vaccine was developed eighty years ago in 1921 and has been used all over the world ever since.

The BCG vaccine is made from a form of bacteria discovered by two scientists named Dr. Calmette and Dr. Guerin (that’s why we call it the “BCG vaccine”).



BCG is what we call an “**attenuated**” vaccine. That means it is made with a strain of tuberculosis bacteria that has been weakened

to become harmless to humans. So, when the BCG is introduced to your body, it will not make you sick. Instead, your immune system will recognize the TB bacteria as “dangerous invaders” and learn to defend itself. This same concept is used with other vaccines such as the polio vaccine. This is also why people who have had the BCG vaccine will often have positive Mantoux skin tests (the Mantoux test will react to attenuated and live bacteria).

Have you been vaccinated against TB? It is easy to tell. Look for a “**TB scar**” on your upper arm. The scar should look like a small, circular indent on your skin. This is a good way for a doctor or nurse to tell if you have been vaccinated.

In the Gambia, babies born in the hospital are usually vaccinated using the BCG vaccine. Other people may receive the vaccine later in their life. Other people may NEVER be vaccinated for one reason or another.

The BCG vaccine is very **inexpensive** and is **widely available** throughout the world. However, although BCG coverage on a global scale has been quite high, the actual effectiveness of the vaccine tends to vary. In developing countries studies have shown that the ability of the BCG to protect people from becoming sick varies from 40% to 80%! **No one is protected 100%!** This means that even if you have been vaccinated against TB, you are still susceptible to getting the disease.

So, even if you have been vaccinated with the BCG vaccine, you still have to protect yourself against the bacteria that cause TB!

**Protection is inexpensive and easy.** Let’s review some basic protection strategies. . .



## TB or not TB? NSGA Peer Health Education Program

### Slide #13:

### Protect yourself and those around you

#### Protect yourself and those around you:

- Coughing, sneezing, and spitting can be dangerous!
- WASH YOUR HANDS!!
- Education
- Nutrition
- Ventilation
- Sunlight
- Separate sleeping quarters for TB patients
- Never share eating utensils or drinking containers!



It is now time to learn how to protect yourself and those around you from becoming infected with TB germs. **Protection is easy once you know how!**

**Action #1: Cover your mouth when coughing and sneezing!** If spitting is necessary, try to spit into a covered container or cup. Do not spit where people live, work or cook.

**Action #2: WASH YOUR HANDS!** This will protect you from TB and all kinds of other things. Always try to wash your hands with hot and soapy water before eating or touching your hands to your nose and mouth.

**Action #3: Education.** Learn how TB is prevented and educate your friends and family.

**Action #4: Nutrition.** Eat foods rich in vitamins and protein to keep your immune system healthy and to recover from TB infection faster. Peanuts, meat and fish are great immunity boosters!

**Action #5: Ventilation.** TB patients should spend as much time as possible outside or in well ventilated rooms to prevent the spread of germs to others.

**Action #6: Sunlight.** TB germs are *photosensitive* – they hate the sun's ultra-violet (UV) rays! TB patients are often advised to get plenty of sunshine to make them feel better. Plus, when the germs are expelled from a cough or sneeze into the sunshine they die almost instantly!



**Note:** The light from light bulbs does not have the same healing effects as the sun! Only UV rays can kill TB bacteria!

**Action #7:** TB patients should **sleep in separate rooms and in separate beds** from the rest of the family. This is because the TB bacteria live for a long time in dark rooms and because when people are sleeping they cannot cover their mouths when they sneeze and cough. It is best for TB patients to sleep alone.

**Action #8: Don't share cups or utensils.** Saliva can sometime contain droplets with TB germs, so it is advisable to avoid sharing drinking cups and eating utensils.



**Note:** Try to remember this rule for all social occasions!  
Not just when you know someone has TB.  
**You should always be suspicious that TB may be present.**



## TB or not TB? NSGA Peer Health Education Program

### Slide #14:

### Protect yourself and those around you

#### Protect yourself and those around you:

- Prevent HIV/AIDS.
- Maintain a healthy lifestyle.
- Adhere to DOTS.
- Don't smoke!
- If TB is suspected, visit your doctor as soon as possible.
- Early diagnosis = increased cure rates = decreased infection rates.



**Action #9: Prevent HIV/AIDS!** People with HIV get TB more frequently and people with TB and HIV can pass TB on to others.

#### **Action #10: Maintain a healthy lifestyle!**

**Y** Take care of your immune system: in order to stay healthy everyone should try to get moderate amounts of physical exercise, eat a nutritious diet, and try to get lots of sleep.

**Action #11: Adhere to DOTS.** If you or someone you know has been prescribed antibiotics according to DOTS, it is important to comply with the directives outlined by the WHO and the health care staff. Non-adherence to the orders may

result in chronic (or even fatal) infections and multi-drug resistance.

**Action #12: Don't smoke!** If you don't smoke don't start. If you do smoke – **QUIT!** Aside from being an ugly, addictive, expensive and cancer-causing habit, smoking damages the soft pink lung tissue with ugly black soot deposits. This soot makes it more difficult to fight infection, makes it more difficult to breath and it increases the chances of lung damage due to TB. *Also, second hand smoke can cause lung damage to people who do not smoke.*



**Note:** We can also say that, in the Gambia, smoking may cause **malnutrition**. This is because one of the effects of smoking is to reduce the appetite. Also, some people who only have a small amount of money may buy cigarettes instead of food to help them cope with the feeling of hunger.

**Action #13: See your doctor.** If you think you or someone you know may have TB, visit your doctor as soon as possible. Early diagnosis of TB cases is the best way to insure increased cure rates and decreased infection rates.

**Remember this equation:**

**Early TB diagnosis = ↑cure rates = ↓infection rates!**



What can the community do?



- Make sure everyone who shows TB symptoms is tested
- Make sure TB patients take their medicine correctly
- Make sure TB patients have proper nutrition
- Community support of TB patient
- Community education is crucial to TB reduction:
  - Increase support networks
  - Reduce stigma

What can the community do?

People who have been diagnosed with TB should not be alienated from the community.

In fact, there are lots of things the community can do as a group to help TB patients get better while also helping to protect the community against further infection. A little bit of **teamwork** will go a long way!



Community Checklist:

- ✓ Make sure everyone who has been in contact with the TB patient and/or shows TB symptoms is tested for the TB bacterium
- ✓ Make sure TB patients take their medicine correctly (three times a week for six months).
- ✓ Community members may also assist in the delivery of TB drugs to the patient's home and "supervise" the dosage.
- ✓ Make sure TB patients have proper nutrition so that the immune system can have a better chance of fighting the infection.
- ✓ Offer friendly support. TB patients do not have to be isolated from the community. Instead patients should be supported through positive encouragement and reassurance.
- ✓ Offer TB education in an effort to reduce TB. TB education not only increases valuable support networks for TB patients and their families, but it also helps to reduce the **social stigma** that is sometimes associated with certain contagious diseases.





**Slide 16:**

**Reducing the stigma of TB**

**Reducing the stigma of TB**



- The TB germ has no boundaries.
- TB can infect *anyone!*: men and women, teenagers, infants and elderly people.
- TB can infect people who are rich or poor.
- A community that gains an active interest in the health of individuals stands a greater chance of fighting group infection.

Although everyone is susceptible to TB infection regardless of where you live, how much money you have, or if you are a male or female, some people who think they might have TB may be too embarrassed to seek medical attention or feel uncomfortable sharing their TB diagnosis with their families.

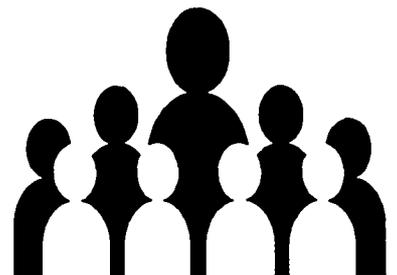
However, TB patients should not be stigmatised or alienated in their community. Instead they should be supported and offered encouraging messages.

A community that gains an active interest in the health of others stands a greater chance of resisting initial and/or recurring infection.

***Remember: One person infected with TB can infect 10 to 15 other people! Therefore, TB is a disease that affects the community! Not just the individual!***

**Help reduce the stigma of TB through peer education. Teach people that:**

- ✓ **The TB germ has no boundaries!**
- ✓ **TB may infect men, women, teenagers, infants and elderly people.**
- ✓ **TB can infect people who are rich or poor.**
- ✓ **TB can infect rural and urban communities.**
- ✓ **TB can infect both famous and non-famous people (remember Nelson Mandela?).**
- ✓ **TB exists in both developed and developing countries.**



***There is no reason to be ashamed or embarrassed about TB!***



**Review:**

- ✓ TB is chronic, contagious, curable
- ✓ TB symptoms
- ✓ TB infection requires medical attention
- ✓ TB diagnosis
- ✓ DOTS treatment
- ✓ Risk factors
- ✓ HIV and TB
- ✓ TB impact on communities
- ✓ TB protection and prevention
- ✓ Social stigma

**Slide #17:  
Review & Self-Test**

✓ **TB is a chronic, contagious, curable disease caused by a bacterial infection.** Can you name some ways to protect yourself?

✓ **Some common symptoms are cough, fevers, night sweats and chest pain.** Can you name some more symptoms?

✓ **TB infection requires medical attention!** Do you know what we mean when we say “proper medical treatment”?

✓ **TB diagnosis is cheap, quick and virtually painless.**



Can you name all five TB tests?

✓ **DOTS anti-TB therapy takes a long time to finish but is very effective.** Can you name some reasons why patients should act in accordance with to their treatment plans?

✓ **Patients who are taking TB2 antibiotics are not considered to be contagious.** What can a potentially infectious TB patient (TB4) do to protect others from infection?

✓ **Some risk factors to TB infection include age, gender and smoking.** Can you name some more?

✓ **An HIV+ patient cannot transmit the virus through casual contact with others but can transmit TB to others fairly easily.** What is the main difference between HIV and TB infection?

✓ **TB impacts communities by increasing complications with HIV and malaria and by decreasing economic development.** What are some other impacts of TB infection?

✓ **You can protect yourself against TB infection by washing your hands and by covering your mouth when coughing and sneezing.** Can you name some more protection strategies?

✓ **TB infection has no boundaries.** Can you think of some ways to reduce the social stigma of TB infection?



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