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**An exploration of the causes, manifestations
and consequences of tuberculosis stigma in
an urban district in Ghana**

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Dedication

This thesis is dedicated to my children Kwaku, Sefakor and Senanu for allowing me to embark on this PhD program that took me away from them for more than three years! Thanks for your patience and understanding!

Abstract

This thesis used a qualitative research approach to explore the causes, manifestations and consequences of tuberculosis (TB) stigma in an urban district in Ghana. It examined reasons why TB is stigmatised and elucidated how TB stigma manifests within the community setting and the healthcare system. It also explored the feelings and experiences of TB patients, to highlight how the fear of stigmatisation may affect case finding and treatment adherence.

Twenty eight focus groups (6 with patients, 6 with health workers and 16 with community members) and 121 individual interviews (66 with community members, 34 with patients and 21 with health staff) were conducted. Data were analysed using Grounded Theory techniques and procedures.

Eleven causes of TB stigma were identified: fear of infection; physical frailty of TB patients; association of TB with HIV/AIDS; perceived causes and spread of TB; outdated societal practices about TB; public health practice and discourse; attitudes of healthcare workers towards TB patients; health staff's own fear of TB; self-stigmatisation by TB patients; judgement, blaming and shaming TB patients; and past experiences with TB. Elements of physical and moral threats were identified in all these causes of TB stigma. The threat the disease poses to community members led to imposition of socio-physical distance, participatory restrictions and

rules for unexpected interactions on those suffering from TB in society. Within the healthcare system, the threat of TB affected the attitudes and behaviours of healthcare workers towards TB patients and TB work. Health managers also sited TB units/wards in isolated parts of the hospital, and failed to provide adequate tools and equipment, support and supervision to enable the provision of quality TB services. The fear of stigmatisation made the patients deny the obvious symptoms of the disease, and report to the hospital only after prolonged period of self-medication in the community. When diagnosed, they cried, questioned how they got the disease, contemplated committing suicide and were mostly isolated within the family and community.

For everyone, the threat of TB underlies their beliefs, attitudes, actions and behaviours when interacting with TB patients. It also forms the basis of avoidance of social interactions, and attitudes and practices of healthcare workers towards TB patients.

The TB control programme should encourage open discussion about TB in the community and tailor health education messages to the community's understanding of the disease. TB services should be completely integrated into the general healthcare system and community members involved in activities of the TB control programme. Regular refresher courses in TB control and management should be organised for health professionals and a national guideline for the prevention of TB in health workers developed.

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List of publications arising from this thesis

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List of abbreviations

NTP	National Tuberculosis Control Programme
WHO	World Health Organisation
TB	Tuberculosis
SAEM	Shama Ahanta East Metropolitan (district)
DOTS	Directly Observed Treatment, Short-course
HIV	Human Immunodeficiency Virus
AIDS	Acquired Immune-deficiency syndrome
CAQDAS	Computer-assisted Qualitative Data Analysis Software
HCWs	Healthcare workers
PTB	Pulmonary tuberculosis
EPTB	Extra-pulmonary tuberculosis
BCG	Bacillus Calmette-Guerin
IUATLD	International Union against Tuberculosis and Lung Disease
MDGs	Millennium Development Goals
PPM-DOTS	Public-Private-Mix Directly Observed Treatment, Short-course
CB-DOTS	Community-based Directly Observed Treatment, Short-course
CHPS	Community-based Health Planning and Services
PAS	Para-aminosalicylic acid
DOT	Directly Observed Treatment
IE&C	Information, Education and Communication
CDU	Communicable Diseases Unit
S	Streptomycin
R	Rifampicin
H	Isoniazid
Z	Pyrazinamide
E	Ethambutol
T	Thiacethazone

Chapter 1 : Introduction

This thesis is an exploration of the stigma attached to tuberculosis (TB). It examines reasons why TB is stigmatised, how TB stigma manifests within the community setting and the healthcare system, and the effects stigma has on the patients, with focus on health seeking behaviour and adherence to treatment.

The purpose of this introductory chapter is to provide a synopsis of the focus of the study and to define the terms and boundaries of the thesis. The chapter introduces the problem of TB stigma and explains how I became interested in studying the topic. It states the aim of the thesis and presents a brief overview of the chapters presented in the thesis.

1.1 Defining terms and setting parameters

For the purpose of this thesis, the type of TB being discussed is pulmonary tuberculosis (PTB). It is referred to in the local Twi language as “*nsaman wa*”, meaning ghost cough. Thus when the respondents talk of TB, they are referring to the pulmonary type of the disease. A *TB patient* as used in this thesis refers to a person diagnosed with TB, and either receiving or having completed treatment at the time the research was conducted. No attempt was made to categorise the patients into stages of treatment. The term *community* is used in this thesis to refer to a geographical location within the study setting.

1.2 The problem of TB stigma

Ghana launched a National Tuberculosis Control Program (NTP) in 1994, based on the World Health Organisation's (WHO) Directly Observed Treatment, Short-course (DOTS) strategy. To date, the strategy has been implemented throughout the country with coverage of over 80.6% (WHO, 2005).

More than a decade after implementation of TB control activities throughout the country, case detection rate in 2006 was 31%, far below the target of 70% (NTP-Ghana, 2006, WHO, 2005). Many experts on TB control think that the low case detection may be attributed to the reliance on passive means of making a diagnosis of TB. This means that individuals recognising their symptoms as due to TB self-report to the hospital for diagnosis. As a result, socio-cultural factors that influence illness experience and hence the behaviour of people in society may affect their desire to seek medical help (Somma et al., 2008).

The stigma attached to TB in most societies has been identified as one important socio-cultural factor that can influence the illness experience of those affected by TB in society (Somma et al., 2008). This is because stigma as a socially constructed phenomenon can shape the attitudes and behaviours of community members towards those affected by the disease in society (Crocker et al., 1998, Goffman, 1963, Jones et al., 1984). In other words, the expectation and/or actual experience of negative attitudes

and behaviours, for example, fear of stigmatisation, may result in concealment of the obvious symptoms of the disease and this can lead to a delayed health seeking and diagnosis.

Furthermore, because the process of diagnosis of TB may take a considerable length of time, often involving multiple contacts with varied categories of health workers, sometimes in different health institutions, any obstacle encountered may have a significant effect on the motivation to seek help. Moreover, because health professionals are in a “power category” within any social setting, when they identify and label a person as diseased, and define the disease with negative attributes, it can be recognised by society with discriminatory consequences for persons afflicted (Goffman, 1963).

Except for one study in Botswana that reported the absence of stigma among TB patients in a developing country (Steen and Mazonde, 1999), the existence of stigma attached to TB in most societies in developing countries is recognised, and has been documented as a major global cause of the limitations of TB control efforts (WHO, 2003, Weiss and Ramakrishna, 2001, Weiss et al., 2006, Lawn, 2000, Heijnders and Van Der Meij, 2006, Balasubramanian et al., 1999). The association between TB and HIV/AIDS is worsening the plight of many sufferers, particularly in high HIV/AIDS prevalence countries, and this often result in increased stigmatisation of TB patients (Dick et al., 1996, Bond and Nyblade, 2006,

Godfrey-Faussett and Ayles, 2003, Van Rie et al., 2008). For example, in Thailand, the association between TB and HIV/AIDS affected the ability of patients to adhere to the prescribed TB treatment regimens because TB patients were often suspected of having HIV/AIDS as well resulting in increased stigmatisation of TB patients (Ngamvithayapong et al., 2000).

Consequently, there has been increased concern in recent times to understand the stigma attached to many diseases and conditions of public health importance, including TB, to enable institution of appropriate interventions and to minimise the impact of stigma on sufferers (Weiss et al., 2006, Heijnders and Van Der Meij, 2006, Weiss and Ramakrishna, 2001).

1.3 How I became interested in the topic

I received my undergraduate and postgraduate trainings in medicine and public health respectively. Both fields are dominated by a positivist perspective on research. Thus, before conducting this research, my theoretical inclination was more towards a bio-medical view of understanding medical issues and problems.

Prior to enrolling on the PhD program I worked as the TB Clinician/Coordinator for the Western Region of Ghana. In the course of my work, I identified many problems with the TB control programme; key

among these was low case detection rate coupled with a high rate of defaulting from treatment.

I used a quantitative research approach to investigate the reasons for defaulting from treatment. A key finding was that patients who reported having problems with others (community members, friends, family members and health staff) were more likely to default from treatment than those who did not experience any problem (Dodor and Afenyadu, 2005).

In addition to the study findings, my interaction with patients and their family, and observation of attitudes and behaviours of community members and health workers towards TB convinced me that the stigma attached to the disease may not only affect adherence to a TB treatment regimen, but also the motivation of people to seek medical help when suffering from symptoms suggestive of TB.

I therefore decided to do further research, using a qualitative research approach to explore the determinants of TB stigma and to understand how attitudes and behaviours of community members and health workers towards TB may hinder people from coming forward to be tested for the disease. Such understanding can help to identify the components of stigma in both the community setting and healthcare system so that appropriate interventions can be proactively put in place to reduce it. Such strategies may help to achieve the Millennium Development Goals (MDG) and the

Stop TB partnership targets of halving TB mortality and prevalence by 2015 (WHO, 2008b).

1.4 Aim of this thesis

This thesis aims to explore, identify and describe the causes of TB stigma and to elucidate how it operates in the community setting and healthcare system to affect the motivation of people to seek help as well as adhering to prescribed treatment regimens.

1.5 Overview of thesis

Seven chapters follow this introductory chapter.

Chapter 2, *Background to tuberculosis*, provides background information on TB and control activities. After a brief history of TB and the clinical course of the disease, the chapter charts the development of global TB control activities and examines the effects the HIV/AIDS epidemic has on TB incidence and mortality. The limitations of the DOTS strategy for TB control, particularly the neglect of the social milieu in which TB patients access TB services, are highlighted, and the importance of understanding the stigma attached to TB to help improve case finding and treatment adherence emphasised.

Chapter 3, *Stigma, definitions and concepts*, examines the concept of stigma, emphasising the aspects that are relevant to TB. The origin,

conceptualisations and categorisation of stigma are discussed. The functions stigmatisation serves in society as well as the interaction between stigmatised and non-stigmatised individuals are also examined.

Chapter 4, *Tuberculosis stigma*, provides a brief overview of previous research done on the topic. The chapter highlights the gaps in the literature, the relevance of the current work and ends by stating the research questions this thesis provides answers to.

Chapter 5, *Subjects and methods*, explains how the research was carried out. It outlines the principles of qualitative research, and explains and justifies the data collection methods used. It also provides detailed information on the study setting, data collection and analysis, and ethical and practical issues that arose during the research process. The chapter ends by discussing how validity and reliability of the findings of this research can be assessed.

Chapter 6, *Findings*, presents the results under four sections. The first section outlines the causes of TB stigma identified in the data, whilst the second and third sections examine how TB stigma manifests in the community setting and healthcare system respectively. The last section expounds the effects stigma has on TB patients, particularly, health seeking and treatment adherence.

Chapter 7, *Discussion*, uses the stigma theory to examine the findings. The main finding is that TB is stigmatised because it poses physical and moral threats to this Ghanaian society. Other characteristics of the disease as well as activities of health workers enhance the threat TB poses to others. The consequences of stigma on the patients are also highlighted.

Chapter 8, *Conclusions*, discusses means of tackling the stigma attached to TB in Ghana and outlines possible future research works that emanated from this study.

The appendices that follow contain the interview schedules, invitation letters and reprints of papers published from this research.

1.6 Summary and conclusion

This introduction chapter has provided an overview of the problem of TB stigma globally and has emphasised the importance of the topic for the TB control programme. How I developed interest in the topic was stated and an overview of each chapter provided. The next chapter provides background information on TB.

Chapter 2 : Background to Tuberculosis

2.1 Introduction

This chapter provides background information on TB and control activities. A brief history of TB, the natural course of infection, clinical presentation, and diagnosis, with a focus on developing countries, are outlined. The development of the World Health Organisation's (WHO) Directly Observed Treatment, Short-course (DOTS) strategy and the National TB Control Programme (NTP) in Ghana will be examined. The impact of the advent of HIV/AIDS on global incidence of TB, particularly, in sub-Saharan Africa will also be highlighted. The chapter ends by pointing out the limitations of the DOTS strategy, particularly the low case detection rate in sub-Saharan Africa and states the importance of understanding TB stigma to help put in place interventions to encourage those suffering from TB to come forward to be tested for the disease.

2.2 History of TB

Tuberculosis is one of the oldest documented infectious diseases and remains a major public health problem today. The evolutionary origin of the causative organism, *Mycobacterium tuberculosis*, is uncertain. It was believed to have originated in prehistoric humans as a zoonotic infection transmitted from tuberculous animals most probably cattle, between 8000 and 4000 BC (Bloom, 1994). However, a recent analysis of genetic data based on tubercle bacilli from East Africa has shown that *M. tuberculosis*,

has a progenitor species about 3 million years old (Gutierrez et al., 2005). Indeed, signs of tuberculosis have been identified in the spines of Egyptians and South American mummies dated over 6000 years old (McKinney et al., 1998).

Different names have been used to describe tuberculosis. The Greek poet Homer described it as “a grievous consumption that separates soul and body” (Gallagher, 1969 p.167). Hippocrates (470-376 BC) called it phthisis; English speaking people called it consumption, and later the “Captain of all the Men of Death,” and “The Great White Plague.” The enlarged cervical lymph nodes were called “Scrofula” or “The King’s Evil” (Myers, 1970 p.10). The disease also had significant social impact in history and was prominent in arts and politics. For example, Botticelli’s Venus is a popular painting depicting a pale beauty to signify the disease that would take her life at the age of 23 and the self-entrusted power of 18th century English royalty to heal the disease by the touch of their hands (McCray et al., 1997).

The cause of the disease was shrouded in mystery and it was believed to be an inherited disease for a very long time (McKinney et al., 1998). A few people, however, suspected the contagious nature of tuberculosis. Italy and Spain, for example, had regulations to prevent its spread as early as 1699. Patients so afflicted were strictly isolated, and when they died, their

bedding and the doors to their rooms were burned and their rooms were re-plastered (Dowling, 1977).

In 1722 Benjamin Marten, an English physician, explicitly said that the disease might arise from a micro-organism, which may be an airborne contagion. His idea of germ theory was mocked at that time (McKinney et al., 1998). In 1865, Jean-Antoine Villemin went on to demonstrate that the disease could be transmitted using sputum or caseous tissue from a patient to animal. This was widely discredited at that time (McKinney et al., 1998). In 1882, Robert Koch, a German physician and microbiologist was able to identify and isolate the causative organism *M. tuberculosis* (McKinney et al., 1998).

Antonin Marfan suggested the existence of acquired immunity to tuberculosis as early as 1886, but it was not until 1919 that Calmette and Guerin succeeded in making a stable vaccine (BCG) against the disease. Benjamin Weill-Halle and Raymond Turpin used this vaccine for the first time in 1921 (McKinney et al., 1998). Following the initial success, its use spread throughout Europe and to other continents in the world. In the 1940s, the WHO started promoting mass vaccination with BCG in its campaign to control the disease (Raviglione and Pio, 2002).

Drugs that were used in the treatment of other diseases were also tried on tuberculosis. For example, cod liver oil, prescribed for rheumatism in the late eighteenth century, was later given for tuberculosis (Dowling, 1977). In

the absence of effective drugs, other measures were tried, including urging patients to move to warmer climates. A movement towards high altitude, where the air was believed to be beneficial, began in 1859 with establishment of a sanatorium for patients suffering from pulmonary tuberculosis by a German physician, Herman Brehmer (Dowling, 1977). Later, surgical resection of the affected parts of the lung became the predominant practice in most parts of the world (Dowling, 1977).

In 1939, Selman Waksman attended a congress of microbiologists in New York City, where he was intrigued by Alexander Fleming's description of his experiments. Although he had made earlier observation that avian tubercles were inhibited or killed in septic soils, he failed to follow this up (McKinney et al., 1998). In 1943, Albert Schatz, a student of Selman Waksman, extracted streptomycin from soil fungus and showed it to be active against the tubercle bacilli in vitro, leading to its administration for the first time to a human patient on November 20, 1944 (McKinney et al., 1998). Around the same period, Jorgan Lehman, noticed that synthetic para-aminosalicylic acid (PAS) inhibited the growth of the tubercle bacilli in vitro and used it to treat tuberculosis in guinea pigs. It was first successfully used in the treatment of tuberculosis in a human patient in 1944 (McKinney et al., 1998).

The modern era of treatment of tuberculosis began in 1946, when streptomycin was demonstrated to be efficacious against the disease

(McKinney et al., 1998). In 1952, isoniazid became available, and in 1965, rifampicin was also found to be as effective as isoniazid, making tuberculosis curable in the majority of patients (Mandell and Bennett, 2000). The discovery of these drugs ushered in the concept of combination chemotherapy, dubbed, 'short course' with a duration of not less than 6 months (Harries and Dye, 2006).

With the availability of effective drugs and a vaccine it was assumed that it would not take a long time for tuberculosis to be eliminated from the world. This idea was captured in the words of Selman Waksman:

“But most importantly, the ancient foe of man, known as consumption, the great white plague, tuberculosis, or by whatever other name, is on the way to being reduced to a minor ailment of man. The future appears bright indeed, and the complete eradication of the disease is in sight” (McKinney et al., 1998 p.126)

Despite the successes in the battle against TB over the years, more people are now suffering from the disease than any time in history. From late 1970s and early 1980s to date, the world has witnessed a second pandemic of TB, particularly in developing countries affected by the HIV/AIDS epidemic.

2.3 Natural history of TB infection

Patients with open pulmonary tuberculosis (PTB) are the most important source of infection, the risk of infection being determined by how infectious

the source is, the closeness of the contact, and the immune state of the host (Harries and Dye, 2006). The initial infection occurs by the inhalation of droplets containing the bacilli when a PTB patient coughs, sneezes, spits or speaks. These infectious particles are generated in large numbers and can remain suspended in the air for long periods. The small sizes of the droplets allow them to bypass the protective barriers in the throat and reach the alveoli where they get deposited. The infectivity of a patient depends on the number of viable bacilli produced during coughing or sneezing. When the patient produces sufficient bacilli to be visible on microscopic examination of sputum, it is referred to as a smear positive case (Enarson et al., 2000). Such patients are most important in the spread of the infection.

As with many infectious diseases, the events following such infection vary from person to person. Local multiplication of the bacilli at the site of implantation leads to the formation of a small lesion termed the Ghon focus. From this focus bacilli are carried through the lymphatic systems to adjacent lymph nodes where multiplication of the bacilli continues. The resulting lesion consisting of the Ghon focus and the enlarged regional lymph nodes is termed the primary focus (Collins, 1997).

The presence of bacilli in the lungs usually stimulates a cell-mediated protective immune response, which is due to activation of macrophages by chemical mediators called lymphokines released by T-lymphocytes

attracted to the site of infection. Activated macrophages and lymphocytes form a compact aggregate around the bacilli thereby creating the histological structure termed the granuloma (Collins, 1997).

Of those who become infected, 80-90% will never become ill with tuberculosis unless their immunity is seriously compromised later in life. The bacilli remain dormant within the body and their presence is indicated by a significant size of reaction to a tuberculin skin test (Collins, 1997). In this group of infected individuals, there may eventually be reactivation of such dormant lesions in about 5% of them, leading to post-primary tuberculosis several years or even decades after the initial infection. Alternatively, post-primary tuberculosis may be due to exogenous re-infection (McKinney et al., 1998).

However, in the remainder of those infected, the disease process may progress in one or more ways to give rise to overt primary tuberculosis. In these individuals, bacilli may spread from the primary complex to other sites by the lymphatic or blood streams. This may lead to tuberculous meningitis, which may occur about three months after infection, or to progressive lesions in bones, joints or the kidney, which are usually detected a year or more after infection (Collins, 1997).

About two-thirds of all untreated smear-positive cases of PTB will die within 5-8 years of developing the disease (Harries and Dye, 2006). Most of those who survive beyond 8 years develop dormant TB, whilst a few

continue to excrete the tubercle bacilli in their sputum (Harries and Dye, 2006, Enarson et al., 2000).

2.4 Aetiology of tuberculosis

The causative organism of tuberculosis, *M. tuberculosis*, belongs to the family Mycobacteriaceae, and the order Actinomycetales. The bacillus is aerobic, non-spore forming and non-motile, with a high cell wall content of high molecular weight lipids. It measures between 1µm to 4µm in length and 0.3µm to 0.6µm in diameter (Brooks and Jawetz, 1995).

Mycobacteria are classified as Acid and Alcohol Fast (AAFBs), because they cannot be decolourised by acid or alcohol after using basic dyes to stain them. This property depends on the integrity of the waxy envelope. They grow very slowly, with generation time of about 18 hours. They tend to be more resistant to chemical agents than other bacteria because of the hydrophobic nature of the cell surface. The cell walls can induce delayed hypersensitivity (Brooks and Jawetz, 1995). The Ziehl-Neelsen technique of staining is employed for the identification of acid-fast bacteria.

2.5 Clinical presentation of TB

Tuberculosis can affect any organ in the body and hence can present in different ways. The diagnosis of the disease is based on clinical presentation and the use of certain investigative tools. The clinical

presentation can be broadly grouped into constitutional, pulmonary and other symptoms (Grange, 1996).

2.5.1 Constitutional symptoms

Common symptoms of tuberculosis include fatigue, loss of appetite, irritability and weight loss. There is usually a low-grade fever, which persists for weeks and becomes marked as the disease progresses. Night sweats may accompany the fever. It should be noted that the absence of fever or other symptoms does not however mean the absence of the disease.

2.5.2 Pulmonary manifestation

In pulmonary tuberculosis, there is usually a progressive cough with production of sputum, which may be blood stained in 8% of adults with active disease (Lutwick, 1995). There may be localised or generalised chest pain and breathlessness when a massive amount of lung tissue is involved.

2.5.3 Other symptoms

The disease may present in many other forms because it can affect virtually any organ in the body. Under such circumstances, the manifestation will depend on the organ involved.

2.6 Investigation of TB

Table 1 summarises some of the investigative methods used in the diagnosis of tuberculosis and identifies the advantages and disadvantages of each, emphasising methods that are relevant to developing countries.

Table 1: Investigative methods used in the diagnosis of tuberculosis

Type(s) of test	Advantages	Disadvantages
Sputum smear microscopy	Smear microscopy is the only means by which the diagnosis of PTB can be confirmed in most developing countries. It efficiently identifies the most infectious cases. It is cheap and affordable and can be performed with minimal skill.	May be problematic depending on the competence of the laboratory staff. No bacilli may be found in the sputum of advanced HIV positive patients. Can not be used in children since they cannot produce sputum. It is not sensitive and may pick other mycobacteria species.
Sputum culture	This is the definitive way of making a diagnosis of TB. When sputum smear is negative, culture may be positive. It is commonly used in monitoring drug sensitivity patterns in recurrent TB, and community prevalence of drug-resistant TB.	It needs skilled laboratory facilities, which may not be available in most developing countries. It is very slow and takes 4-8 weeks to get results. It is very expensive and may not be affordable to most developing countries. Only in 50% (higher in good laboratories) of cases is it possible to isolate the bacilli from the sputum.
Radiological test	Very efficient in the diagnosis of TB when used by trained medical officer. It identifies sputum negative cases missed by sputum microscopy. Very useful in the diagnosis of tuberculosis in children since they cannot produce sputum.	It is unreliable; abnormalities identified on a chest radiograph may be due to TB or a variety of other conditions. Individuals previously treated for TB may show signs of the disease on radiographic examination. Advanced HIV-positive individuals may not show the classical pattern of TB on chest radiograph.
Tuberculin test	Very useful in measuring the prevalence of TB in the community, especially if not vaccinated with BCG. Very valuable in making diagnosis in a young child at an age when fewer children in the community will normally have a positive test. A strong positive test is a point in favour of tuberculosis.	A positive test may not be caused by TB and a negative test does not always rule it out, especially in HIV positive. It may be negative in malnutrition or other diseases even though the person may have TB. Its use is very limited in high-prevalence countries where about 50% of the adult population are infected with TB. It is not routinely available in many peripheral health institutions; it is expensive, has a very short expiry date, must be kept protected from light and heat and requires some technical skills in its administration and reading.
Others-Biopsies of lymph nodes, laryngeal swabs, and immunological tests etc.	These tests are very useful in skilled hands since they are very fast and specific. Immunological tests, for example, are very useful in patients who cannot produce sputum. They are very useful in research work on TB.	Most of the tests are expensive and cannot be afforded by most developing countries. Technical skills are needed in their performance and this may not readily be available in low-income countries. Expensive equipments are needed for most of these tests and this limits their use developing countries.

2.7 Progression of global TB control

Prior to the growth of major urban cities, the disease was believed to be endemic with cases appearing sporadically. The incidence increased rapidly as a result of the industrial revolution, which led to over-crowding and unhygienic living conditions which favoured its spread (McKinney et al., 1998). It was estimated that, in the 17th and 18th centuries, tuberculosis was the cause of about a quarter of all deaths in adults in the UK (Mandell and Bennett, 2000). This was followed by a decline in the incidence of the disease in most industrialised countries. The decline was attributed to improvement in public health, hygiene, nutrition, and living conditions in most cities in the mid-1800s (McKinney et al., 1998). During the 1950s, TB rates had dropped by 75%, and TB hospitals in most developed countries closed their doors for lack of patients (McCray et al., 1997).

Between 1948 and 1963, when effective chemotherapeutic agents were discovered, vertical TB control programmes were established in developed countries, which further resulted in a marked decline in the incidence of the disease. However, when this was implemented in the developing world, where the burden of the disease was highest, this did not result in the same decline as witnessed in the developed countries (Raviglione and Pio, 2002).

The global approach to the management of health services shifted to primary health care between 1970s and 1980s, and so TB control programmes became incorporated into general health-service delivery (Raviglione and Pio, 2002, Harries and Dye, 2006). These reforms affected TB control programmes negatively, particularly in the developing world (Bess, 2000, Weil, 2000). The resultant neglect of TB control activities, coupled with the advent of HIV/AIDS pandemic in the 1980s, resulted in a sharp increase in TB notifications globally. Sub-Saharan Africa, where the HIV/AIDS epidemic was highest, saw TB case notifications increase dramatically, estimated at 5-8% per year (Narain et al., 1992). Over the period 1990-99, eight million out of the estimated 88 million new cases of TB and 2.9 million of the 30 million people predicted to die of TB was attributable to HIV infection (Dolin et al., 1994).

The dissolution of the former Soviet Union, which was accompanied by a major socioeconomic crisis and collapse of the health service, also led to an increase in the number of TB cases in that region (Raviglione and Pio, 2002, Dye, 2006). Most industrialised countries saw increased notifications of the disease in large towns and cities around the same period (Raviglione et al., 1995, Rieder et al., 1989). Furthermore, the fall in socioeconomic conditions in most parts of the world, and the accompanying poverty, malnutrition and overcrowding, favoured the spread of the disease (Raviglione and Pio, 2002). An assessment of the TB crisis in 1990 showed that nearly 8 million cases and 2.9 million deaths

occurred worldwide (Sudre et al., 1992). In 1991, it was estimated that 1.7 billion people (a third of the world population) were infected with TB, with over 95% of the estimated number occurring in the developing world (Kochi, 1991).

Meanwhile, in the late 1970s, despite the fading interest on the part of the international community in TB control activities, the International Union Against Tuberculosis and Lung Disease (IUATLD) focused on the development of an appropriate model for National TB Control Programmes in developing countries (Enarson, 1995). The model was developed in Tanzania, in collaboration with the Tanzanian Government and other stakeholders, and was then applied in other countries. In 1989, the World Bank assessed the model and found it to be the most cost-effective health intervention in developing countries. It was later accepted by WHO as an appropriate model for TB control.

Inspired by the results of the implementation of the IUATLD model, and the resolve to contain the disease globally, the WHO took an unprecedented step and declared tuberculosis a global health emergency in 1993 and set a target of detecting 70% of new infectious cases and curing 85% of those detected by 2000 (WHO, 2003). The proposed strategy recommended for TB control was branded Directly Observed Treatment, Short-course (DOTS), which has five key components:

- Government commitment to sustained TB control activities.
- Case detection by sputum smear microscopy among symptomatic patients self-reporting to health services.
- Standardised treatment regimen of six to eight months for at least sputum smear positive cases, with directly observed therapy (DOT) for at least the initial two months.
- A regular, uninterrupted supply of all essential anti-TB drugs.
- A standardised recording and reporting system that allows assessment of treatment results for each patient and the TB control programme performance overall (WHO, 2003, p.19).

The adoption of the DOTS strategy by the international community injected a new enthusiasm into TB control efforts. It also helped to focus attention and strictly monitor progress so as to achieve the set targets (Raviglione, 2003). The number of countries that adopted the DOTS strategy continued to grow throughout the 1990s, reaching 119 by the end of 1998 (WHO, 2000b). Despite the rapid adoption and implementation of the DOTS strategy globally, by 1997 it became evident that the 2000 targets, especially the target to detect 70% of infectious TB cases, could not be achieved (Raviglione, 2003) and so were deferred to 2005. Even so, the targets were not reached by the revised date (WHO, 2000a, Dye et al., 2007).

Starting in 2000, targets for global TB control have been integrated into the Millennium Development Goals (MDGs). MDG 6 Target 6.C is to halt and reverse incidence of TB by 2015 (UN, 2008). The *Stop TB Partnership* has also set two additional impact targets, which are to halve prevalence and death rates by 2015 compared with their level in 1990 (Dye et al., 2005). The outcome targets first set by the World Health Assembly in 1991 were that DOTS programmes should detect at least 70% of new smear-positive cases and to successfully treat at least 85% of detected cases. All five targets have been adopted by the Stop TB Partnership and, in 2007, were recognized in a World Health Assembly resolution (WHO, 2008b).

2.8 TB Control in Ghana

As was mentioned in Chapter 1, Ghana launched a National Tuberculosis Control Program (NTP) in 1994, based on the WHO's DOTS strategy, and set the same target: to detect 70% of people with infectious TB and successfully cure 85% of those detected by 2008 (NTP-Ghana, 2006). According to the WHO, Ghana is among countries in which the DOTS strategy has been implemented, covering over 80.6% of the population (WHO, 2005).

Although statistics on the disease are not accurate, it is estimated that Ghana has 123 smear positive PTB cases per 100,000 population per year. Thus with an estimated population of 20 million, 25,000 smear-positive PTB cases are expected every year (NTP-Ghana, 2006).

However, in 2006, only 31% of the estimated number of PTB cases were detected, and the cure rate for 2005 was 66.7% (NTP-Ghana, 2006).

To help to improve the TB situation in the country, the NTP came out with two strategies for the expansion of DOTS: inclusion of private practitioners in TB control, “Public-Private-Mix DOTS” (PPM-DOTS) and expansion of the TB programme to the community, “Community-based DOTS” (CB-DOTS) (NTP-Ghana, 2006). The PPM-DOTS started on a pilot basis in the two largest metropolitan districts of the country (Accra and Kumasi) in 2003, and is being expanded to other parts of the country, including Shama Ahanta East Metropolitan (SAEM) district in 2008. The CB-DOTS incorporates all the recommendation of the WHO and is in consonance with the Ghana’s national policy on Community-Based Health Planning and Service (CHPS), which seeks to improve access and expand coverage of health services in the country (NTP-Ghana, 2006).

However, studies conducted in other developing countries have reported that a substantial proportion of patients, especially women, opted out of the community DOTS program because of stigma and concerns about neighbours getting to know of the diagnosis (Balasubramanian et al., 1999, Ngamvithayapong et al., 2001). It is therefore important to take into consideration the stigma attached to TB in society and to put interventions in place to reduce it so as to make the PPM-DOTS strategy acceptable and more appealing to the community members.

2.9 Impact of HIV infection on TB control

HIV infection is a potent risk factor for TB and the association between the two diseases has presented a grave public health threat, particularly in sub-Saharan Africa and in urban towns and cities in the developed world (Corbett et al., 2003, Schluger and Burzynski, 2001, Godfrey-Faussett and Ayles, 2003, Lawn et al., 2006, Maher et al., 2005, Sonnenberg et al., 2004). The prevalence of HIV among adults is strongly associated with TB incidence rate in a population; when HIV infection rates are high, TB incidence also increases. The WHO has estimated that one-third of people living with HIV/AIDS worldwide are infected with TB, and in 2007, estimated that 1.37 million (14.8%) of the estimated 9.27 million new cases of TB were HIV positive, with the African Region accounting for 79% of patients who are co-infected with TB/HIV globally (WHO, 2009).

In HIV infection, there is gradual destruction of the immune system making it difficult for the body to defend itself against infection. The HIV virus progressively depletes CD4+ T-lymphocytes and makes them dysfunctional. This, coupled with defective macrophages and monocytes, places the patient at a high risk for primary and reactivation tuberculosis (Davies, 1994). In the pre-HIV/AIDS era, it was estimated that the lifetime risk of development of active TB in an individual infected with the tubercle bacilli was 5%-10% (Schluger and Burzynski, 2001). However, people who are HIV-positive and infected with TB are up to 50 times more likely to develop active TB in their lifetime than people who are HIV-negative

(WHO, 2008a). Since the containment of TB infection in an individual depends on intact cellular immunity, HIV has now emerged as the most important risk factor for the progression of dormant tuberculosis infection to clinical disease (Narain et al., 1992).

The diagnosis of TB in HIV-infected individuals is also often challenging. The nature, presentations, and the clinical and radiological features of TB depend on the degree of immuno-suppression. In HIV infected individuals with relatively good immunity and CD4+ cell counts, and a low viral load, the manifestations and presentation of the disease are similar to those in HIV negative individuals (Zumla et al., 2000). However, because the HIV virus suppresses the immune system, in advanced stages of HIV infection there is often atypical presentation of the disease. Therefore, the patients do not normally produce sufficient tubercle bacilli to be seen on sputum microscopy. Furthermore, advanced HIV infected individuals often do not show the classical picture of TB on radiographs (WHO, 2003). This makes the diagnosis of smear-negative pulmonary TB difficult, especially in developing countries where other advanced and alternative means of diagnosis are limited (Harries et al., 1999a). Thus the proportion of all reported forms of pulmonary cases that are smear-negative tends to be higher in African countries that have higher prevalence of HIV infection (WHO, 2008b).

There is also considerable evidence that TB patients who are infected with HIV are more likely to die, during and after treatment, compared to HIV-negative patients (Connolly et al., 1998, Ya Diul et al., 2001, Ackah et al., 1995, Elliott et al., 1995). Tuberculosis has therefore become the leading cause of death among people who are HIV-positive, accounting for up to half of all AIDS-related death worldwide (WHO, 2008a).

The advent of HIV/AIDS is also shifting the balance between men and women in the 15-24 years age group who are diagnosed with TB. This is because HIV infection tends to be higher among women of this age group resulting in increases in the prevalence of TB in this age group in African countries (Harries and Dye, 2006).

2.10 Summary and conclusion

TB is an ancient disease but remains a public health threat today. Despite the availability of effective drugs and control programmes based on the DOTS strategy, the global targets for TB control were not reached, and have been postponed twice (Elzinga et al., 2004). The DOTS strategy has failed to contain the ever increasing number of TB cases, particularly in sub-Saharan Africa, mainly because of the effects of the HIV epidemic in the region (Lawn et al., 2006). A major set back to the success of the DOTS strategy is the low case detection rate. The global case detection rate in 2006 was 61%, with the Africa Region recording the lowest of 46% (WHO, 2008b). In Ghana, the case detection rate in 2006 was 31%, far

below the 70% target (NTP-Ghana, 2006). It is therefore important for DOTS programmes in the Africa Region to improve case detection if the global targets are to be achieved (Dye, 2006, WHO, 2008b, Elzinga et al., 2004).

One reason identified as underlying the failure of the DOTS strategy to achieve the set targets is the neglect of important social factors that facilitate access and adherence to treatment (Lienhardt and Ogden, 2004). One such social factor identified as contributing to the low case detection rate in most developing countries is the stigma attached to the disease in most societies; a situation which may be aggravated by direct observation of treatment (DOT), especially in the presence of HIV infection (Balasubramanian et al., 1999, Lawn, 2000, Nyblade, 2006). It is therefore very important to understand how stigma operates within the community setting and the healthcare system to affect the motivation of people to seek help when suffering from symptoms suggestive of TB. The concept of stigma is examined in the next chapter.

Chapter 3 : Stigma, definitions and concepts

3.1 Introduction

This chapter focuses on the concept of stigma. Because most of the research done on stigma pertains to attributes such as membership of a racial group, homosexuality and mental health, their applicability to TB is not always clear. This has, therefore, constrained the review and made it very selective, emphasising aspects that are relevant to TB stigma. The chapter highlights the social origin of stigma as well as the variation between cultures of attributes regarded as stigmatising. Various conceptualisations of stigma and the organisation of stigma into meaningful types and categories are discussed. The functions that stigmatisation serves in society, and the theories espoused to justify it, are examined. The chapter ends with examination of interactions between stigmatised and non-stigmatised individuals, focusing on the perspective of the stigmatised individual and the strategies used to overcome stigmatisation.

3.2 What is stigma?

The term 'stigma' is derived from the Greek word referring to a tattoo mark, usually impressed upon people, using a hot iron, to show that they were devoted to the services of the temple (Whitehead et al., 2001). It was later secularised to designate the marking of an individual as a slave or criminal and to expose something unusual and bad about the moral status of the

person bearing the mark (Goffman, 1963). Today, the term is used loosely to apply more to the disgrace of possessing the unacceptable attributes than to the bodily evidence of it (Goffman, 1963).

Stigmatisation is considered to be a set of social processes with the key step being the recognition of something different in the person (Smith, 2002). Society has a way of categorising and assigning expectations to its members (Goffman, 1963). There are also rules regarding the norms and processes of dealing with problems of daily life. If a rule is broken during interactions between individuals in society resulting in abnormal situation, it can be labelled as stigma (Bennstam et al., 2004). When people perceive individuals as possessing socially unacceptable attributes, they assign negative qualities to the person and this results in intense devaluation of the individual. Thus the term stigma connotes a moral judgment of an individual and often results in complete devaluation of the person. The basis of the devaluation is the observation that the person possesses certain devalued social attributes, such as, membership of a devalued racial group or unacceptable sexual preference.

The attributes considered as stigmatising and the context in which the devaluation of the individual occurs are defined by the social environment, and not by nature (Crocker et al., 1998, Goffman, 1963, Dovidio et al., 2000, Jones et al., 1984). Thus any discussion of socially inferior attributes must take into consideration the social norm since stigma is generally

associated with inferior attributes which are commonly regarded as norm infractions (Page, 1984).

The attribute regarded as a sign of disgrace and the extent of the disgrace varies historically and continues to vary between cultures (Scambler, 1984, Whitehead et al., 2001). This occurs because stigma, as a socially constructed concept, evolves with society and characteristics seen as stigmatising at one time in history may be normal at another period (Dovidio et al., 2000). Similarly, some illnesses and conditions have been used from time to time to mark people out as set apart from normal people (Davey and Seale, 2002). Thus, characteristics seen as stigmatising vary from one culture to another, and depend on what is defined as normal at a particular time in history.

3.3 Conceptualisations of stigma

Ervin Goffman (1963) is widely cited for providing very insightful exposition which conceptualises stigmatisation as complete devaluation of an individual who possesses a deviant attribute. According to his view, society has a way of establishing means of categorising persons and the characteristics felt to be common and accepted for members to possess. The attributes society expects the person to possess is the 'virtual social identity'. As we interact with the person, the attributes we discover that the person possesses is the 'actual social identity'. When any member of society is seen to possess attributes (actual social identity) that make him

different from societal expectations, usually a less desirable one (virtual social identity), the person is “thus reduced in our minds from a whole and usual person to something tainted and discounted” (Goffman, 1963, p. 12). The individual’s social identity is spoiled and he/she is assumed to be incapable of fulfilling the role requirement of social interactions. Thus, the discrepancy between the characteristics and attributes that we expect ordinary members of society to have and what they actually possess is stigma (Goffman, 1963).

Following Goffman’s work, Jones and colleagues used the term ‘mark’ to refer to a range of conditions considered deviant by a society that might initiate the stigmatisation process. They propose that stigmatisation occurs when a mark (deviation from a norm) possessed by a person links him/her to dispositions that discredit the bearer. They pointed out that such a mark of deviance initiates an attributional process through which people interpret other aspects of the person, and respond to the stigmatised individuals on the basis of their stigma at the expense of their individuality (Jones et al., 1984).

Crocker and colleagues also conceptualised that “stigmatised individuals possess (or are believed to possess) some attributes or characteristics that convey a social identity that is devalued in some particular context” (Crocker et al., 1998, p. 505). They posited that although there is often an objective trait, behaviour or characteristic of an individual that makes it

possible for him/her to be stigmatised, it is the conviction held by others, or the stigmatised individuals themselves that leads to stigmatisation. Thus “the problem of stigma does not reside in the stigmatising attribute, or the person who possesses that attribute, but rather in the unfortunate circumstances of possessing an attribute that leads to devaluation in a particular social context” (Crocker et al., 1998, p. 506). They also mentioned the role of power in the process of stigmatisation and hinted that being in a position of power decreases one’s vulnerability to being stigmatised

Link and colleagues also pointed out that six interrelated components must converge to produce stigma:

- “People identifying and labelling human differences”.
- “Based on dominant cultural beliefs, link the labelled individuals to undesirable characteristics; usually to negative stereotypes”.
- “Placing labelled persons in distinct categories, leading to some degree of separation of ‘us’ from ‘them’.
- “Emotional reactions, such as, anger, irritation, anxiety, pity and fear are involved in identification of human differences, the linking of those differences to undesirable attributes and separation of identified persons into ‘us’ and ‘them’”.
- “Experiencing of status loss and discrimination by the labelled person that lead to unequal outcomes. This may occur in the form of

individual discrimination or structural discrimination, in which institutional practices work to the disadvantage of the stigmatised groups, even in the absence of purposeful discrimination by individuals”.

- “Access to social, economic and political power that allow full execution of the above mentioned components” (Link and Phelan, 2001, p.367, Link et al., 2004, p.513).

However, there is a contrary view from evolutionary scholars on the variation of stigma from culture to culture. Such scholars point out that the attributes that are stigmatising do not vary from one culture to another, but are similar across cultures. They argue that because humans everywhere are endowed with the same psychological systems, there is commonality across culture in what attributes are stigmatised (Kurzban and Leary, 2001, Park et al., 2003). They propose that characteristics that lead to stigma-based social exclusion are derived from evolved adaptations designed to cause people to avoid interactions that are likely to impose fitness costs. They emphasised that, given the potential cost of interacting with individuals who are diseased, it would be adaptive to a population to readily identify diseased individuals and to avoid contact with them. From this perspective, stigmatisation is a functional means of avoiding individuals who might pose some sort of interpersonal danger, and this is the same across many cultures (Kurzban and Leary, 2001, Park et al., 2003).

Nonetheless, even if the ability of humans to stigmatise or exclude others is an evolved adaptation mechanism, it is cultural beliefs that influence and determine which attributes are singled out and provide the specific context of the stereotypes that are attached to those stigmatised attributes (Major and O'Brien, 2005). It can be argued, therefore, that the features that emerge as cues to the unusualness of an individual may be different across different cultural environments (Park et al., 2003)

3.4 Organisation of stigmas

Stigmas are usually organised into meaningful categories that capture the various ways in which stigmatising characteristics differ from each other (Crocker et al., 1998). Ervin Goffman categorised stigmas into three main types:

- *Abominations of the body*, which are physical characteristics which convey a devalued social identity, such as, physical handicap and disfiguring body conditions.
- *Blemishes of the individual character*, which are related to ones personality or behaviour and are perceived as weak will, such as, dishonesty, mental disorder, and unemployment.
- *Tribal stigmas*, which are familial, or passed from generation to generation, and include membership in a devalued race, nation or religion (Goffman, 1963, p. 14).

Goffman indicated that if the stigma the individual possesses is already known or evident on the spot, then it is referred to as *discredited stigma*. On the other hand, if the attribute is neither known already by those present nor is it immediately perceived by them, then it called *discreditable stigma* (Goffman, 1963).

Jones and colleagues also identified six dimensions of stigma, namely:

- *Concealability*, which refers to the extent to which the stigmatising attribute is hidden or visible to others as well as the extent to which the person will want to conceal it from others. This depends on the nature of the stigmatising mark such that those who are able to conceal their condition often do so. For example, homosexuality can be seen as a concealable stigma since the individual can hide that fact from others
- *Course of the mark*, this refers to whether the mark will become more salient or progressively debilitating over time and examines what the anticipated social consequences of the outcomes are. Irreversible conditions tend to elicit more negative attitudes from others. For example, someone with severe burn scars may heal over time while someone with leprosy may have the condition getting worse over time.
- *Disruptiveness*, this refers to the degree to which the stigmatising condition interferes with the flow of interpersonal interactions or

communication within the social network. An example of disruptive stigma is certain forms of mental illness that affect the ability of the individual to have uninterrupted communication with others.

- *Aesthetics*, this reflects the subjective reactions to the unattractiveness of the stigma. That is the extent to which the signs and symptoms of the condition make the person repellent, ugly or upsetting in some way. Facial deformities fall under this dimension of stigma.
- *Origin*, of the stigmatising mark refers to the aetiology of the circumstances that led to the condition and the way the person is perceived to be responsible for the mark. Perceived responsibility for the condition carries great influence in whether others will respond with unfavourable views and/or punishment towards the stigmatised person. For example, HIV/AIDS and obese individuals are often held responsible for the condition.
- *Peril*, the perceived danger of the stigmatising conditions to others, and if so, how imminent or serious it is. It also deals with the extent to which social groups can be threatened by the condition. Individuals with tuberculosis and certain forms of mental illness are usually considered to be a threat to others (Jones et al., 1984, p. 24).

Stigma is also classified into whether actual stigmatisation or discrimination took place or it is based on the anticipation of discrimination. When people

with stigma are discriminated against on the sole ground of their social unacceptability or inferiority, it is called “*enacted stigma*.” On the other hand, the shame associated with possessing the negative attribute in question is “*felt stigma*”; it is an oppressive fear of enacted stigma (Scambler, 1984).

3.5 Functions of stigma

Stigma is usually denounced by everyone yet practiced by all (Crocker et al., 1998, Crandall, 2000). As the experience of stigma is universal and stigmatising attributes and characteristics can be found in every society, it is possible that stigmatisation has some value for those who stigmatise (Crocker et al., 1998). Indeed, those who stigmatise others are conscious of what they are doing and usually base their actions on certain moral, ethical, legal and social beliefs which enable them to continue to stigmatise with a clear conscience (Crandall, 2000).

As mentioned earlier, many functions of stigma have been discussed in the literature but their applicability to TB is not always clear. The next section examines functions that are relevant to TB stigma.

3.5.1 Promotion of self-enhancement

Crocker and colleagues pointed out that stigmatisation may enable individuals to believe that they are better than those they stigmatise, and this may enhance their self-esteem (Crocker et al., 1998). They posit that

in-group members may derogate those who belong to another group (out-group) so as to enhance their personal self-esteem. The in-group members usually achieve this by creating a lower group to which they compare themselves, using the principles of downward comparison (Wills, 1981). According to the principles of downward comparison, when individuals find themselves in situations that threaten their self-esteem, they tend to compare themselves with a less fortunate other, and this enhances their self image (Wills, 1981). By so doing, the in-group members feel superior and this can be used to justify the stigmatisation of the out-group members (Crocker et al., 1998, Hinshaw, 2006).

3.5.2 Promotion of in-group enhancement

Another function of stigmatisation is the promotion of the superiority of one group over another (Crocker et al., 1998). Humans are, and have always lived in groups since this helps to pool and share resources so as to enhance chances of survival (Neuberg et al., 2000). Group living encourages the formation of social identity with in-group members (Hinshaw, 2006). However, as one develops strong affiliation to the in-group, it can fuel the devaluation of the out-group (Hinshaw, 2006). This is done by favourably comparing the in-group with the out-group so as to affirm the superiority of the in-group and thus enhance the social identity of the in-group members. This strategy is also used by the in-group to justify stigmatisation of the out-group and to affirm the superiority of their collective social identity over the out-group (Crocker et al., 1998). The

demonstration of the superiority provides the opportunity to justify the discriminations and prejudices against the out-group. It therefore means that anything that threatens the survival of the in-group relative to out-group will lead to an increase derogation of out-group members (Hinshaw, 2006).

3.5.3 System justification

System justification principles tend to utilise the belief by the majority of people that the existence of hierarchy in society serves a useful purpose. Such approaches posit that through our observation and experience of social arrangements, we perceive and develop stereotypes about stigmatised groups and use this to explain their low social status in society (Crandall, 2000). System justification is achieved by creating unifying ideologies that are made to appear as authentic to defend the superiority of the out-group as well as to prevent inter-group conflicts (Crocker et al., 1998).

Individuals with higher social status in society may capitalise on the existence of group inequalities to stigmatise those of lower status and to justify the advantageous position they occupy in society (Crocker et al., 1998). It also makes them feel that they benefited through fair schemes and that they deserve the privileged status they occupy in society (Crocker et al., 1998). In other words, the presence of hierarchy in every society is used by those who have higher status to continue to suppress those who

do not have status and use it to justify their position as fair and deserved (Hinshaw, 2006).

Similarly, the belief in a just world, that is, bad things do not happen to good people or people get what they deserve and deserve what they get, as developed by Lerner 1980 (quoted in Crocker et al., 1998 p.509, Crandall, 2000 p.129), can also serve as a myth that can be used to justify the stigmatisation of others. This is because collective beliefs are always given moral authority, creating the avenue to view stigma as an infringement of a social norm (Goffman, 1963). People with stigma challenge our belief in a just world and make us question the validity of the existence of a just world (Jones et al., 1984). However, because we have spent our entire individual and collective lives coming to accept such beliefs, when faced with any challenge, instead of questioning the validity of our beliefs, we almost always tend to uphold them. We do so because such ideologies create the avenue for us to hold individuals responsible for their predicament. It also makes us attribute their situations to controllable factors and use it to justify the way we treat the stigmatised (Crocker et al., 1998). Blaming the victim, and attributing the control and responsibility of the stigmatising attribute to the stigmatised, allows us to show less sympathy towards the person (Crandall, 2000).

The Protestant work ethic, which posits that the success of an individual depends on hard work and determination, can also be used to justify the

stigmatisation of those who occupy lower status in society. By using such ideologies, the marginalised and stigmatised in society are deemed to be responsible for their position because they failed to adhere to the symbolic value of society (Crandall, 2000, Crocker et al., 1998). System justification can be used to explain the consensus within a society on what attributes are stigmatised and why stigmatised individuals also tend to accept their stigmatised status in society (Crocker et al., 1998, Hinshaw, 2006).

3.5.4 Terror and anxiety management

Jones and his colleagues argue that every society ascribes to a shared system of meaning through which they perceive, identify and categorise the world around them. This collective understanding of how things work becomes accepted as the reality and forms the basis of how the members look at issues. This 'symbolic universe', as it is referred to by Berger and Luckmann, (1966) (quoted in Jones et al., 1984 p.82) becomes the frame of reference through which every aspect of social life is interpreted and given meaning. They point out that this shared system of meaning protects the members of the society from outside threats and enables the members to develop a stable relationship with the world around them. It also helps to ward off the fear of what they do not understand. Moreover, because the shared system of meaning is often taken for granted and accepted as the reality, when members of society encounter any challenges to what they have come to accept as the reality, this creates panic and anxiety within them (Jones et al., 1984).

It is also claimed that stigmatisation helps humans manage the perception of anxiety when faced with circumstances that remind them of life and death (Hinshaw, 2006, Crocker et al., 1998). The terror management theory (Rosenblatt et al., 1989), offers explanations by positing that humans have very sophisticated minds that enable them to be attentive to the disorderly and meaningless world that we live in, and this makes us aware of the inevitable nature of death, which can occur prematurely and unexpectedly. However, such consciousness causes a lot of anxiety and terror. In an attempt to shield members of a culture from the anxieties, we ascribe to cultural conceptions that give protection against human vulnerability and death. Such ideologies help us to deal with the anxiety of living in an uncertain world because they enable us to impose order and meaning on the chaotic world around us. The cultural worldview provides security to those who live by the standards and values it espouses (Rosenblatt et al., 1989).

Therefore, when we encounter individuals who do not conform to our worldview, they remind us of the senseless and meaningless world we live in, and threaten our belief in a perfect and valid world. The fear of death threatens and disrupts the normal order that we have come to accept as the way things are in society. Thus, stigmatising attributes call into question the validity of what we have come to accept as reality and arouse in us awareness of death. It also reminds us of those things that we have

devoted our entire individual and collective efforts to exclude from our consciousness (Jones et al., 1984).

3.5.5 To deter threats to group living

Neuberg and colleagues assert that stigmatisation is to ward off factors that threaten the ability of humans to live in groups (Neuberg et al., 2000). They indicated that group living promotes the survival of people and gene transmission. By living in groups, and pooling and sharing resources, the needs of the members can be better met than through individual efforts. This requires truth telling and trust so as to create common group identity as well as stable bonds within the group. It also requires the members to reciprocate the efforts of others and this is known as norm reciprocity.

However, this propensity to group living also provides the opportunity for some members to exploit the group's resources to their advantage (Batson, 1998). Those who exploit the efforts of the group to their advantage have the propensity to survive and transmit their genes at the expense of those who contributed the resources. Such exploitation can undermine group cohesion. Moreover, it is also not possible for every member of the society to equally reciprocate the investments of others.

There must therefore be mechanisms to enable identification and labelling of those who exploit the group's resources or those who are unable to reciprocate the norms of others and deny them the group's protection, and

expel the individuals from the group if necessary. Stigmatisation, according to their view, serves that purpose; it is a response to the presence of those who threaten coherent group living. Thus, people will stigmatise those with characteristics that will hinder group living (Neuberg et al., 2000).

3.6 Interactions between stigmatised and non-stigmatised individuals

Interactions between stigmatised and non-stigmatised individuals are often characterised by uncomfortable moments and this can generate a lot of anxiety for both parties. During the interactions, both stigmatised and non-stigmatised individuals focus on what they say, do and the implications of their actions (Goffman, 1963), and this creates anxiety during the interactions. The possibility of encountering such interactions can lead both stigmatised and non-stigmatised individuals to adjust their lives so as to avoid meeting each other. Indeed, Goffman pointed out that stigmatised individuals do avoid interaction with non-stigmatised (Goffman, 1963). The non-stigmatised may also avoid the stigmatised individuals, especially if there is a genuine reason to do so (Hebl et al., 2000)

Two features of stigma have been identified as very important during such interactions: controllability and disruptiveness (visibility) of the stigma (Crocker et al., 1998, Hebl et al., 2000). Stigmatising attributes are controllable when the stigmatised individual is viewed as responsible for the stigma or when the stigma could be eliminated by the behaviour of the

stigmatised individual (Hebl et al., 2000, Crocker et al., 1998, Jones et al., 1984). Controllable stigmas tend to elicit more hostility from non-stigmatised individuals. The disruptiveness or visibility of stigmas are those stigmatising attributes such as, race and disfiguring conditions that are immediately visible to the non-stigmatised individual (Jones et al., 1984, Crocker et al., 1998). It also immediately reveals how dangerous the stigmatising attributes are to the non-stigmatised (Hebl et al., 2000).

The sources of anxiety experienced by non-stigmatised and stigmatised individuals during contacts with each other are many and varied, and depend on the context of the interactions. Some of these sources are examined briefly.

3.6.1 Sources of anxiety for non-stigmatised individuals

Societal norms and expectations dictate that interactions among members in society occur between non-stigmatised individuals. Therefore when it becomes necessary for non-stigmatised individuals to interact with stigmatised individuals, this necessitates changes to the social norms and expectations. The disruption, which often results in the development of new ways of interaction between the two can generate anxiety for both parties (Hebl et al., 2000).

The non-stigmatised may experience fear in the interaction because the stigmatising attribute may pose a danger. The fear may be either physical

or social. In physical fear the non-stigmatised may be afraid of the possibility of contracting the stigma from the stigmatised, as in most contagious diseases, while in social fear the anxiety is the loss of social status through association with the stigmatised. Both physical and social fear can make the non-stigmatised to avoid association with the stigmatised.

When non-stigmatised individuals are aware of the devalued social identity of the stigmatised, this can either consciously or unconsciously activate cultural stereotypes about the stigmatised, and can influence the behaviour of the non-stigmatised towards the stigmatised (Crocker et al., 1998). There is also the tendency for the non-stigmatised individual to interpret the stigmatised person's past and present in terms of the stigma (Jones et al., 1984). Attempts to suppress such ideas can create anxiety for the non-stigmatised individual and this can result in awkward moments during interactions.

Non-stigmatised individuals also assume that the stigmatised are bitter and unhappy about their stigma. Accordingly, non-stigmatised individuals try not to mention the stigmatising attribute during the interactions so as to avoid offending the stigmatised, and this often creates anxiety for the non-stigmatised individual (Hebl et al., 2000).

3.6.2 Sources of anxiety for stigmatised individuals

Individuals who possess stigmatising attributes are conscious of the fact that they may be targets of prejudice and discrimination, and this shapes and defines their day to day activities (Jones et al., 1984, Goffman, 1963, Crocker et al., 1998). Moreover, because of the ever-present possibility of being stigmatised, they are always careful in interactions with non-stigmatised individuals and this result in uncomfortable and awkward moments. The experiences of others may also affect the stigmatised individual's sense of vulnerability to stigmatisation (Crocker et al., 1998).

Furthermore, based on dominant cultural beliefs, stigmatised individuals are aware of the fact that they possess a stigmatising attribute (Crocker et al., 1998, Goffman, 1963, Major and O'Brien, 2005). Consequently, when interacting with non-stigmatised individuals, the stigmatised individuals will be concerned with the salience of the stigma and will want to minimise and reduce attention to it so as to normalise the interactions (Jones et al., 1984). However, individuals with visible stigmas can not use concealment to cope with the stereotypes, prejudice, and harassment that their stigma may trigger (Crocker et al., 1998). Under such circumstances, the stigmatised will experience stigma threat, and may feel anxious that their behaviour may confirm what others already believe about them. As a result, the stigmatised is very careful during such interactions, looking for meaning and intents in the statements of the non-stigmatised person, and may also be concerned with damage to his/her self esteem during the

interactions (Crocker et al., 1998, Goffman, 1963). They may also get confused about the behaviour of the non-stigmatised and wonder whether what they say or do is dependent on their social identity or personal qualities (Crocker et al., 1998, Major and O'Brien, 2005).

3.7 How stigmatised individuals manage awkward moments

The strategies used by stigmatised individuals to handle the uncertainty and anxiety surrounding social interactions with non-stigmatised individuals are many and varied. However, only those that are relevant to TB stigma are discussed. The discussion is organised around the following strategies: information management (or passing); situation management (covering) (Goffman, 1963 p.58), and withdrawal (Jones et al., 1984).

3.7.1 Information management (passing)

The deliberate concealment of information about the stigmatising attribute so as to promote normal interaction with others is called 'passing' (Goffman, 1963). This strategy is used when the stigmatising attribute is not immediately visible or known by others (discreditable stigma) before the stigmatised encounter them. Under such situations management of information about the stigmatising attribute becomes a central issue. The goal of passing is to keep the stigma hidden. Because all humans will like others to see and interact with them as normal individuals in society,

almost all stigmatised persons who get the opportunity to pass will do so (Goffman, 1963).

Some of the passing techniques used by the stigmatised are to conceal or avoid the stigma symbols. The stigma symbols are signs which draw the attention of others to the stigmatising attributes possessed by stigmatised individuals. For example, name changing and rejection of structures that can make others associate the stigmatised to the negative attribute is employed to contain the effect. The use of dis-identifiers sometimes occurs with concealment of stigma symbols. It is a situation where the stigmatised dresses or uses other items to prevent others from identifying him (Goffman, 1963).

Another strategy is to present the signs of their stigma as a sign of another attribute, one that is less significantly a stigma (Goffman, 1963). A TB patient, for example may attribute the obvious signs and symptoms of the disease to another disease that is less stigmatising and this may delay treatment seeking.

The stigmatised may also pass by categorising those around them into two groups: a large group to whom they tell nothing and a small group to whom they tell all and upon whose help they then rely. They may also maintain physical and psychological distance from others. By avoiding others, stigmatised individuals can avoid the possibility of giving out personal information. By keeping relationships distant, he/she ensures that time will

not have be spent with others, since the more time spent together, the more chance of unanticipated events that may necessitate disclosure of his/her secrets. By maintaining physical distance, the individual can restrict the tendency of others to build up a personal identification of him/her. By residing in a region with a mobile population, he can limit the amount of continuous experience others have of him (Goffman, 1963).

3.7.2 Situation management (covering)

Covering involves strategies aimed at keeping the stigmatising attribute from looming large in particular interactions. When the stigmatising attribute is readily visible or known by others (discredited stigma), before the stigmatised meet them, the goal is to manage smoothly and comfortably the interaction by withdrawing covert attention from the stigma. For people who possess visible stigma that provides the primary schema through which everything about them is understood by others, their concern in such interaction is to minimise others noticing their stigma (Jones et al., 1984, Goffman, 1963).

The techniques employed in covering are sometimes similar to what is employed in passing since what will conceal a stigma from the unknowing person may also ease matters from those in the known (Goffman, 1963). Some of the covering techniques are, avoiding the display of attributes associated with the stigma, making efforts to keep communication during such encounter normal, giving others the chance to adjust before reacting

and acting as if efforts of others to ease things are effective and appreciated.

3.7.3 Withdrawal

Because interactions between non-stigmatised and stigmatised individuals are often characterised with strain, conflict and discomfort, the stigmatised may tend to rely on few individuals who handle their interactions smoothly and do not cause much stress to him/her (Jones et al., 1984). When these individuals are not available, the stigmatised may resort to social isolation instead of the risk of problematic interactions (Jones et al., 1984). Thus the TB patient may choose the company of family members and close friends who he/she feels comfortable interacting with, and to isolate him or herself if they are not available so as to avoid the contempt of others. The stigmatised may also choose the company of individuals who share the same stigmatising attribute with him/her. However, restricting one's interactions only to those who share the same stigmatising attributes may not fulfil one's social needs (Jones et al., 1984).

3.8 Summary and conclusion

This chapter reviewed the concept of stigma. It has shown that the process of stigmatisation leads to systematic exclusion of individuals from social interaction because they possess an attribute that makes them different. It has elucidated the various forms of stigma and emphasised that stigma is socially constructed and varied across time and culture. During

socialisation, members of a society gain some understanding of attributes considered stigmatising. They will therefore be in position to compare their own attributes with existing stigma types and conclude that they are stigmatised. Thus, the stigmatised individual is constantly aware of being vulnerable to stigmatisation, and has to devise means of making interactions with the non-stigmatised as smooth as possible. The stigma attached to TB is briefly examined in the next chapter.

Chapter 4 : Tuberculosis stigma

4.1 Introduction

This chapter examines previous research done on TB stigma. It is not intended to be a full literature review, but to briefly look at what is known about the topic. It describes what has already been done and outlines the approach adopted in this thesis. The chapter ends by stating the research questions that this thesis provides answers to.

4.2 Previous research on TB stigma

Review of the literature has shown that TB stigma is often an incidental finding from studies with a focus on identifying problems of the TB control programmes so as to devise measures to improve access to TB services. The studies are usually designed to examine the social environment from which the patients access TB services, including the views and perspectives of the communities in which the patients reside. As a result, the studies often focus on issues such as health-seeking behaviours of the patients, their experience of the disease and reasons why they default from treatment. Others also examine societal perceptions and attitudes towards the disease and those affected in society. Consequently, the findings usually confirm the existence and the effects of TB stigma rather than what causes it.

One effect of TB stigma reported in these studies is the ability of stigma to affect health-seeking behaviour of individuals with symptoms suggestive of TB. This happens because stigma makes people hesitate or choose not to disclose their symptoms to family members, friends or neighbours for fear of being ostracised and may also attribute the obvious symptoms of TB to some minor conditions, such as, common cold or an ordinary cough (Dick et al., 1996, Liam et al., 1999, Johansson et al., 1999, Weiss and Ramakrishna, 2001, Macq et al., 2005, Liefoghe et al., 1997). Stigma also affects the quality of life of TB patients and makes them feel sad, lacking in confidence and depressed (Hansel et al., 2004, Macq et al., 2005, Weiss and Ramakrishna, 2001). Consequently, the patients usually go through a lot of emotional suffering which in turn results in self-medication as a way of reducing the impact of the contempt of others (Dick et al., 1996).

Furthermore, because stigma is closely associated with the perception by others that infected/affected people place others at risk of infection (Johansson et al., 1999), many patients are not accepted or treated well by health workers, friends, and their family members (Balasubramanian et al., 1999). Patients then suffer in silence and do not ask for appropriate support. As a consequence, they often default from treatment and continue to spread the disease in the community (Dodor and Afenyadu, 2005, Lawn, 2000, Jakubowiak et al., 2007).

4.3 Identified causes of TB stigma

Notwithstanding, these studies that focused on improving TB services did identify some causes of TB stigma. The beliefs about the transmission and curability of TB, which is often a reflection of the way society understands the disease, has been reported as a cause of TB stigma (Liefoghe et al., 1997, Meulemans et al., 2002, Liefoghe et al., 1995, Jaramillo, 1999, Rajeswari et al., 2005, Ngamvithayapong et al., 2000, Khan et al., 2000, Xu et al., 2004, Bennstam et al., 2004, WHO, 2003). Indeed, in Cali, Columbia, it was documented that 23% of 399 study participants based their stigma on scientifically unfounded beliefs about the transmission of TB, for example, eating and drinking from plates and cups used by a TB patient (Jaramillo, 1999). Such stigmatising cultural meanings can have serious impact on the illness experience of patients and can worsen the social suffering of the individual even more than the symptoms of the disease (Weiss and Ramakrishna, 2001).

Other researchers have also reported that females and older patients are more stigmatised than males and younger patients (Meulemans et al., 2002, Liefoghe et al., 1995, Long et al., 2001, Atre et al., 2004, Ngamvithayapong et al., 2000, Eastwood and Hill, 2004, Hoa et al., 2004, Ngamvithayapong et al., 2001, Balasubramanian et al., 2004, Johansson and Winkvist, 2002, Somma et al., 2008). The attitudes and practices of health workers and the association of TB with HIV/AIDS have also been

identified as causes of TB stigma (Liefoghe et al., 1995, Hansel et al., 2004, Sengupta et al., 2006, Bond and Nyblade, 2006).

4.4 Gaps in the literature

In spite of the recognition that TB stigma has a negative effect on TB patients and the control programmes, the causes have not been well explored. As mentioned in the previous section, because of the focus of previous research, the findings only documented the existence and consequences of TB stigma. To date, there are very few published studies that are designed to examine in detail the causes of TB stigma.

Two published precedent studies focused on exploring the causes of TB stigma have been identified. One of the studies explored the stigma of TB in Nicaragua (Macq et al., 2005). The study identified and highlighted two sets of contradictory feelings and attitudes that underlie the behaviour of people towards those affected by TB in society: people were afraid of getting infected and do not trust the patients but they sympathised with their predicament and supported the patients (Macq et al., 2005). The second study conducted in Nepal identified four causes of TB stigma: fear of infection; link between TB, poverty and low caste; belief that TB is a punishment for sins committed; and blaming TB patients for acquiring the disease through certain unacceptable lifestyle behaviours, such as, smoking cigarettes and drinking alcohol (Baral et al., 2007).

However, these studies did not adequately examine TB stigma through the “lens” of the stigma theory so as to help to provide a framework within which the relevant components of TB stigma can be elucidated and to identify how it may manifest within the community setting and healthcare system to affect patients. Such a framework will help to provide the understanding needed in the development of strategies to counteract the effects of stigma on TB patients.

4.5 Research questions

In the light of the above stated gaps, this thesis sets out to address the following research questions:

- Why is TB stigmatised and what are the causes?
- How does TB stigma manifest within the community setting and healthcare system?
- How do TB patients respond to TB stigma and what effects does it have on health seeking behaviour and adherence to TB treatment?

4.6 Summary and conclusion

In this chapter, the focus of previous research on TB stigma was briefly outlined and gaps identified. It was emphasised that most of the findings confirm the existence and the consequences, rather than the causes of TB stigma. The chapter also discussed two previous works that are related to

this research, and stated the research questions. The next chapter examines the methodology adopted in this research.

Chapter 5 : Participants and methods

5.1 Introduction

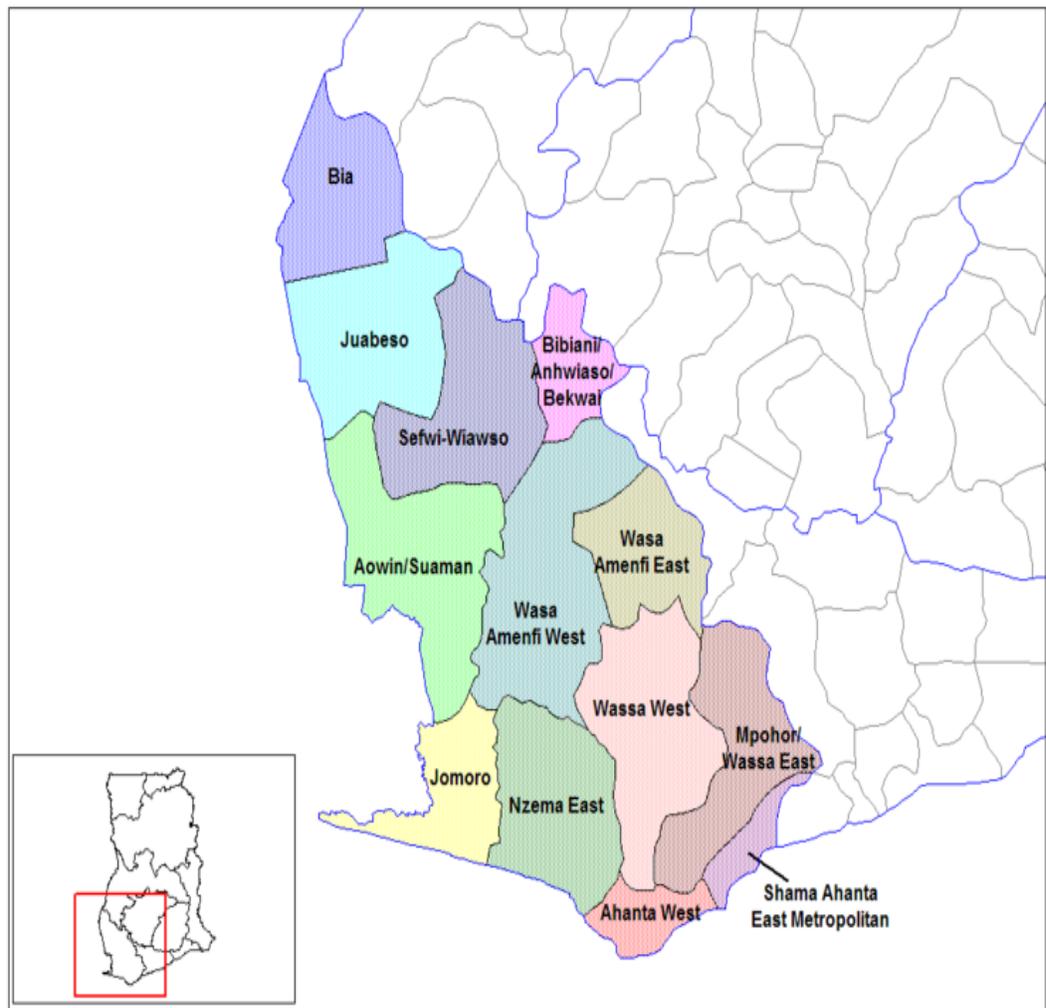
This study uses data from focus groups and individual interviews to analyse the stigma attached to TB in a Ghanaian society. Having set out the research questions at the end of the previous chapter, this chapter examines the theoretical underpinning of the research project. It spells out the overall research strategy, describes the data collection methods and explains how the data were analysed. Ethical and practical issues that arose during execution of the project are also examined. The chapter ends by discussing how validity and reliability of the findings presented in this thesis can be assessed.

5.2 Study setting

The data were collected in the Shama Ahanta East Metropolitan (SAEM) district in the Western Region of Ghana between January and August 2005. The SAEM district is located on the western coast of Ghana, about 200 kilometres from Accra, the capital of Ghana. The capital town of the SAEM district is Sekondi-Takoradi (see Figure 1). It is the third largest metropolitan district in Ghana, with a population of about 360,000. The most common occupations of the populace are agriculture and fishing, which employ about 29%. There are four government hospitals, including the Effia-Nkwanta Regional hospital, which provides health services to the

people in the metropolis. The services of these hospitals are supplemented by more than 30 private hospitals and clinics.

Figure 1: A Map of Western Region showing Shama Ahanta East Metropolitan district



Source: http://upload.wikimedia.org/wikipedia/commons/a/ac/Western_Ghana_districts.png

This district was chosen for the study because of its metropolitan nature and the fact that ethnic groups from most parts of the Western Region and Ghana as a whole can be found there. Also, more than half of industries within the Western Region are located in this district. The nature of the work in these industries puts the workers at risk of developing respiratory diseases, including TB. Furthermore, there have been reported instances of unpleasant behaviours toward TB patients in some industries and companies within the district which anecdotally can be attributed to TB stigma.

5.3 TB diagnosis and treatment in Ghana

As was mentioned in Chapter 1, Ghana launched a National TB Control Programme in 1994. Under the NTP structure, TB treatment centres are located in all regional, district and mission hospitals throughout the country. TB diagnosis and treatment are provided free of charge to all patients. However, patients who need supplementary drugs, for example blood tonics, analgesics and cough mixtures, pay for these.

TB is diagnosed among patients self-reporting to the out-patient-department of healthcare facilities in the country. Individuals who present with a cough lasting two weeks or more undergo sputum smear microscopy and chest x-rays. Those found to have TB are then referred to the treatment centres where they are registered and started on anti-TB treatment.

During the 'intensive phase' of treatment (first two or three months), patients who live in communities far away from the treatment centre are supplied with their drugs and then referred to a health facility near their place of residence for daily 'direct observation of treatment' (DOT). Patients living near the treatment centres are expected to attend every morning for DOT. About 90% of patients are managed daily on this ambulatory basis for the entire intensive phase of two months. However, patients who are severely ill or have other medical complications that will not permit ambulatory treatment are admitted to the hospital for treatment.

The 'continuation phase' of treatment (the last four or five months) is unsupervised and requires all patients to report to the treatment centre once a month. This enables review of progress of treatment to be made as well as to supply the medication for the next month.

The treatment regimens used throughout the country are those recommended by the WHO (WHO, 2003, NTP-Ghana, 2006). Briefly, these treatment regimens are as follows. All new cases (Category I): sputum smear-positive PTB; smear negative PTB; and extra pulmonary tuberculosis (EPTB), are given a 6-month regimen consisting of two months of daily supervised rifampicin, isoniazid, pyrazinamide, and ethambutol followed by four months of isoniazid and rifampicin

(2HRZE/4HR)*. Previously-treated TB patients (Category II): relapse; treatment failure; and treatment after default, are given an 8-month regimen consisting of three months of daily supervised rifampicin, isoniazid, pyrazinamide and ethambutol, supplemented by streptomycin during the first two months, followed by five months of daily rifampicin, isoniazid and ethambutol (2SRHZE/1RHZE/5RHE). Children less than 12 years (Category III) are given a 6-months regimen, consisting of two months of isoniazid, rifampicin and ethambutol and four months of isoniazid and rifampicin (2HRZ/4HR).

5.4 Research approach adopted

As no prior information was available about the nature of TB stigma in Ghana, there was the need to explore the issue and so a qualitative research approach was adopted. This approach is useful in the exploratory stages of a research project where it can help to clarify the research question, aid conceptualisation and generate hypotheses for later research (Creswell, 1998, Sofaer, 1999). It permits the exploration of relevant issues pertaining to common experiences of affected individuals (Bowling, 1997), and enhances the capacity to understand how and why similar events are often interpreted in a different, sometimes conflicting manner by different stakeholders (Sofaer, 1999). Thus, qualitative research provides a rigorous

* S= Streptomycin; R = Rifampicin; H = Isoniazid; Z = Pyrazinamide; E = Ethambutol; T= Thiacethazone. Numbers before the letters indicate the number in months of the phase of treatment

descriptive base upon which subsequent explanatory research can be based (Murphy et al., 1998).

Qualitative research can also be used to discern and understand what lies behind any occurrence about which little is known and can be important in gaining fresh and original views on things about which quite a bit is already known (Strauss and Corbin, 1998). It has particular strengths in exposing facts that are discrepant with the researchers' prior assumptions and is well suited to answering questions that seek to understand why things happen rather than quantifying them (Murphy et al., 1998). It also allows a more in-depth discussion of issues, thereby providing elaborated detail of phenomena that are difficult to convey with quantitative methods using standardized questionnaires (Liefoghe et al., 1997).

Qualitative research usually studies people in their natural settings, and attempts to understand events in terms of the meanings people make of their social world and how they interpret that world around them (Denzin and Lincoln, 1998, Pope and Mays, 2006). The approach provides rich descriptions of phenomena, and enhances the understanding of issues in context (Sofaer, 1999). By examining participants' behaviour in context, the researcher is in a position to draw conclusions about such meanings, which may then be tested empirically (Murphy et al., 1998).

Qualitative research seeks to understand issues from the perspective of the society, organisation or setting and resists the tendency to impose

meanings on issues. It examines and explains the culture and behaviour of humans and their groups from the view point of those being studied (Bryman, 2004). It also helps to clarify the values, languages, and meanings attributed to the various roles played by people in a society (Sofaer, 1999).

It allows the adoption of a flexible framework for data collection and analysis- emergent design. This means that, rather than being fixed at the outset, the study design can be modified as the research progresses in response to the researcher's understanding of the issues (Lincoln and Guba, 1985). This is a key attribute of qualitative research because the researcher does not usually have a complete understanding of the issue under investigation, and because the aim is to learn from every step, as deeper understanding is gained, this is used to modify the study design (Dahlgren et al., 2004).

For example, at the initial stages of the research project, heads of health institutions within the SAEM district, as well as the regional and district directors of health services were among prospective interviewees. However, since the focus was to comprehend the depth rather than breadth of TB stigma, and the fact that data analysis is more effective if there is a limited body of data to work with (Silverman, 2006), the idea was later dropped as the sample of interviewees grew and provided deep insights on the issue. Also, in the course of implementation of the project,

some questions on the interview guides were removed, modified or new ones added to reflect the growing understanding of the topic. The adoption of this emergent attitude helps the researcher to remain flexible and this is one of the strengths of qualitative research.

5.5 Data collection method

People's knowledge, views, understandings, interpretations and experiences are linked to the social milieu and the appropriate way to generate data on these is to interact with them, talk to them, and gain access to their account and expressions (Mason, 1996). Moreover, because knowledge and evidence are situated in a particular context and depend on interaction between the interviewer and interviewee(s), the researcher needs to adopt a flexible and sensitive approach during each interaction (Mason, 1996). Thus interviewing techniques that encourage informants to express their ideas and point of view in their own words, based on their own priorities, are generally preferred to asking them to respond to survey designers' assumptions about what is or is not important in the context of the research (Murphy et al., 1998). Since the aim of the study was to explore the nature of TB stigma from the perspectives of the patients, healthcare workers and community members, individual interviews and focus groups were used.

5.5.1 Individual interviews

An individual interview is an open-ended and discovery oriented method and is an excellent tool when exploring the perspectives of others (Guion, 2006). People are experts on their own lives and so are the best to report their experiences (Darlington and Scott, 2002). An individual interview helps people to report their experiences and also assists the researcher to understand the meaning people make of their lives from their own perspectives (Britten, 1995). Moreover, because the interview is face-to-face and flexible during data collection, areas to be explored and the direction of discussion can be varied, thus allowing both parties to clarify what they do not understand there and then. This helps the interviewer and interviewee to explore the meaning of questions and answers together (Darlington and Scott, 2002, DiCicco-Bloom and Crabtree, 2006). It also has the advantage of being able to let the interviewee talk about past and future events, and by interviewing different people, a range of perspectives can be provided about the same phenomenon (Darlington and Scott, 2002).

5.5.2 Focus groups

Unlike individual interviews, focus groups involve more than one interviewee, during which a specific topic is explored in depth. This means that instead of asking each person to respond to a question in turn, the participants are encouraged to talk to one another, ask questions,

exchanging anecdotes and comments on each others experiences and view points (Kitzinger, 1995). It is quick and a convenient way to collect data from several people simultaneously, and is specifically designed to yield information on the community's beliefs, values and understanding of health problems (Morgan, 1998). It provides the opportunity to study ways in which individuals collectively make sense of a phenomenon and constructs meaning around it and has proved to be very useful in gathering information on sensitive topics (Morgan, 1998).

Focus groups take advantage of communication between research participants in order to generate data (Kitzinger, 1995, Morgan, 1996). The group interactions create cross-flow of communication and this helps the participants to explore and shed light on their views in ways that would not be possible using one-to-one interviews (Kitzinger, 1995, Kitzinger, 1994). After hearing others speak, the participants are stimulated into thinking more deeply about the topic, probe each other's views, build new ideas and alter existing ones. This allows the researcher to develop understanding of why people do what they do, and reveal variations in perspective and extent to which any offered view is shared.

The group context also encourages the participants to explore issues of importance to them, in their own vocabulary, generating their own questions and pursuing their own priorities (Kitzinger, 1995). It also helps the researcher to appreciate the many forms of communication that people

use in day to day interactions, including jokes, anecdotes, teasing, and arguing (Kitzinger, 1995). Gaining access to such a variety of communication is useful because people's knowledge and attitude are not entirely encapsulated in reasoned responses to direct questions (Kitzinger, 1995). The context of focus groups reflects the processes through which meaning is constructed in everyday life, and may thus be more naturalistic.

The sessions are informal and participants are encouraged to discuss their perceptions on a specific topic. The informal setting is believed to make participants feel at ease, encouraging them to express their views freely (Punch, 1998). It also takes the pressure off participants to respond to every question, and they are able to choose the manner in which and when to respond to any question. Moreover, hearing others talk about their experiences may enable participants to feel comfortable about sharing their own experiences (Darlington and Scott, 2002).

A potential disadvantage of focus groups is the possibility of peer pressure by some participants during the discussion, which may make them to remain silent about some views or readily agree with more dominant views in the group (Darlington and Scott, 2002). There is also a potential for embarrassment when sensitive issues are being discussed making participants to be reluctant to share their personal experiences (Darlington and Scott, 2002). Furthermore, confidentiality is compromised because

apart from the researcher, other members of the group will also hear what was said (Kitzinger, 1995).

5.6 Initial preparations

5.6.1 Identifying the study population

Qualitative research is about finding the meaning people attach to what they do and why they do it. This means that, for participants to be able to provide full and relevant descriptions, it is important that they have significant experience with the issue under study. The sampling strategy was therefore guided by the research questions as well as by practicality. A purposive sampling strategy was adopted, focused on individuals, groups and settings that could provide relevant information on the topic (Darlington and Scott, 2002). This strategy allowed decisions about the sampling to be reviewed during the research process and to stop recruiting more participants when data saturation was reached.

Two broad groups of people can be identified around the TB patients: community members and healthcare workers. Within the community, there are three sub-groups: family members, friends, and community members not related to the patients. Among the healthcare workers, three sub-groups can be identified: healthcare managers, health personnel working outside the TB control programme, and those involved in providing care for TB patients.

5.6.2 Contacting and selecting community participants

There are five sub-districts within the SEAM district, each with a number of communities or villages. The sub-district capital and another community with a high number of TB cases were purposely selected, making a total of ten communities. However, data were collected in nine communities because of logistic issues and the fact that saturation was reached. Each of the selected communities was visited and meetings held with the Assembly Man or the Unit Committee Leader (elected community leaders who represent the community at the District Assembly) to explain the purpose of the study. They were then asked to identify about 15-17 males and females who they believe have never had TB to participate in the study.

5.6.3 Contacting and selecting healthcare workers

Seven government health institutions provide TB services in the SAEM district. However, only four offer both in-patient and out-patient care. These four were purposely selected because their personnel may have a more comprehensive (in-patient and out-patient) experience of caring for TB patients. At each of these health institutions, the head of the facility was asked to identify appropriate persons from the three groups that work with TB patients: health managers, healthcare workers involved in the TB control programme, and those in other units of the hospital to participate in the study. Because experience with TB was a major criterion for

participation in the study, more personnel were recruited from units where TB patients are more likely to be seen. For example, because internal medicine wards usually attend to more TB cases than obstetric and gynaecological wards, the number of study participants from the former was more than the latter. Invitation letters (see Appendix 2) explaining the purpose of the study were sent to the identified healthcare workers to participate in the study.

5.6.4 Contacting and selecting TB patients

The health personnel in charge of TB patients in the selected institutions were contacted and asked to select the TB patients using the institutional TB registers. Because considerable experience of living with TB was considered very fundamental for effective deliberation on illness experience, only patients who had had at least two months of treatment or completed the entire TB treatment not more than a year earlier were recruited to participate in the study. Selected patients who were still receiving treatment had the purpose of the study explained to them at the clinic. Those who had completed treatment were traced to the addresses indicated in the TB register to explain the purpose of the study to them.

5.6.5 Developing interview guides

Different interview guides (see Appendix 1) were developed for the three groups of research participants; TB patients, healthcare workers and community members. However, the questions asked or the issues

explored during the individual interviews and focus groups were the same for each group of research participant. The guides explored possible issues and factors that may underlie the reasons for stigmatisation of TB and how this may affect patients in terms of treatment adherence and coping with the disease.

The interview guides were not rigidly adhered to, but served as a guide for a structured conversation and to ensure all topics were covered. The questions were based on the literature, and were grouped into sections. The first section explored general knowledge, attitude and beliefs about TB and experiences with the disease, whilst the second explored possible reasons for seeing TB as a shameful disease. The third section explored the perception of TB patients as a 'risk' to others and feelings and reactions when interacting with TB patients. In addition to the above general themes, certain issues that were peculiar to healthcare workers and TB patients were also explored. These included perceptions about posting of health workers to TB units/wards and treatment seeking behaviour, feelings, experiences, and coping strategies of TB patients.

As the research progressed, the interview guides were reviewed and modified; new questions were added, some re-framed and others removed when deemed unnecessary. For example, questions exploring the causes of TB and availability of social support for patients were included in the initial guides. However, in the course of the research, it was realised that

the community participants' knowledge of TB became evident as they answered or discussed other issues and patients also talked freely about the availability or otherwise of any social support during the illness period.

5.6.6 Recruiting and training research assistants

Three research assistants were recruited and trained to help with data collection. They participated in a one-week training session on qualitative research organised by the funding agency for members of teams awarded research grants. They conducted some of the individual interviews but I personally moderated all the focus groups. During the focus group sessions, they recorded the discussions on audio tapes and also took notes.

5.7 Data collection

Data were collected in two stages: the focus groups were conducted first and later the individual interviews. The selected participants in each study group were divided into two. Between 8 and 12 took part in the focus groups whilst the rest were involved the individual interviews.

5.7.1 Healthcare system

Both the focus groups and individual interviews were conducted in the English language. The decision to use English was because all health workers have at least a secondary-level education, and speak and read English. Moreover, English is the official language for all workers in Ghana.

Six focus groups (1 with health managers, 1 with staff providing services for TB patients, and 4 with general staff) and 21 individual interviews (16 females and 5 males) were conducted with healthcare workers. The focus groups were held within the hospital premises, and the number of participants ranged between 8 and 12 individuals, with each session lasting for 1-2 hours. Details of the participants are shown in Table 2.

Table 2: Background information of healthcare workers

Group	No. per group	Age range	Unit (number)
Health Managers	8	30-59	X-ray 1; Labour Ward 2; Nursing Training College 1; Medical Ward 2; Nursing Administration 1; Surgical Ward 1
TB unit Staff	12	25-59	Chest Clinic 7; Injection Room 3; Laboratory 2
General staff Group 1	9	27-49	Consulting Room 1; Medical Ward 3; Dispensary 1; Nursing Administration 1; Reproductive and Child Health 1; Paediatric Ward 1; Laboratory 1
General Staff Group 2	8	28-48	Psychiatry 1; Labour Ward 1; Medical Ward 4; Consulting Room 1; Nursing Training College 1
General Staff Group 3	12	26-57	Surgical ward 2; Medical Ward 3, Casualty 1; Theatre 1; Labour ward 1; Reproductive and Child Health 2; X-ray 1; Injection Room 1
General Staff Group 4	10	24-59	Medical Ward 2; Reproductive and Child Health 1; Laboratory 3; Paediatric Ward 1; Surgical Ward 1; Casualty 1; Nursing Administration 1

5.7.2 TB Patients

The focus groups and individual interviews were conducted in the local language (Twi) because most of the patients do not understand and speak English. This was to help encourage free expression of opinions and ideas.

Thirty four individual interviews (24 males and 10 Females) and six focus groups were held with TB patients in the hospital premises. Each focus group session lasted for 1 to 2 hours and comprised of 8 to 12 individuals. Details of the focus group participants are shown in Table 3.

Table 3: Background information of TB patients

Group	No. per group	Age range (mean)	Occupation (number)
Female group	8	23-55	Trader 2; Hairdresser 1; Seamstress 1; Fishmonger 1; Unemployed 2; Student 1
Male group 1	9	26-58	Mason 1; Electrician 1; Fisherman 1; Shoemaker 1; Carpenter 1; Painter 1; Labourer 1; Trader 1; Unemployed 1
Male group 2	12	14-46	Salesman 1; Electrician 2; Farmer 1; Labourer 2; Student 1; Plumber 1; Quarry Worker 1; Unemployed 3
Mixed group 1 (10 Males & 2 Females)	12	21-69	Security 1; Retired 2; Quarry Worker 1; Bookbinder 1; Driver 1; Unemployed 5; Sailor 1
Mixed group 2 (8 Males & 4 Females)	12	17-52	Truck pusher 1; Trader 1; Student 1; Hairdresser 1; Seaman 1; Tailor 1; Unemployed 6
Mixed group 3 (10 Males & 2 Females)	12	27-56	Quarry 1; Farmer 2; Painter 2; Driver 1; Seaman 2; Electrician 1; Seamstress 1; Salesman 1; Fishmonger 1

5.7.3 Community setting

As mentioned in the previous section, the local language (Twi) is widely spoken and understood by most of the community members and was used for both the focus groups and individual interviews.

Sixteen community focus groups and 66 individual interviews (37 females and 29 males) were conducted at venues in the community. The focus groups were held for males and females separately so as to avoid male dominance in the discussions, except in one community where because of the small number of participants, both genders were combined. Because participation was voluntary, the number in each group varied, ranging between 9 and 12 participants and each session lasted 1-2 hours. Detail background information on the focus group participants is shown in Table 4.

Table 4: Background information of community participants

Community	No. per group	Age range	Occupation (number)
Community 1			
Males	11	23-52	Teacher 3; Trader 2; Driver 3; Student 2; Fisherman 1
Females	11	23-58	Trader 7; Hairdresser 1; Seamstress 3
Community 2			
Males	9	21-45	Fisherman 5; Student 2; Mechanic 1; Tailor 1
Females	12	21-46	Trader 9; Fishmonger 2; Hairdresser 1
Community 3			
Males	12	34-74	Farmer 4; Fisherman 2; Carpenter 1; Driver 1; Teacher 1; Unemployed 1; Retired 1; Weaver 1
Females	12	25-85	Trading 5; Fishmonger; 1 Unemployed 6
Community 4			
Males	12	27-62	Self-employed 3; Carpenter 2; Unemployed 3; Driver 1; Mason 1; Steel Bender 1; Labourer 1
Females	11	20-55	Trader 8; Seamstress 1; Unemployed 2
Community 5			
Males	11	30-50	Carpenter 4; Tailor 2; Steel Bender 1; Bar attendant 1; Driver 1; Unemployed 1; Retired 1
Females	11	28-54	Trader 7; Fishmonger 3; Teacher 1
Community 6			
Males	11	21-66	Carpenter 2; Teacher 1; Electrician 1; Salesperson 2; Social Worker 1; Self-employed 1; Security officer 1; Messenger 1; Retired 1
Females	12	19-45	Trader 7; Seamstress 2; Hairdresser 1; Chemical Seller 1; Unemployed 1
Community 7			
Males	11	30-71	Building Contractor 1; Security Officer 1; Retired 3; Labourer 1; Driver 1; Teacher 1; Trader 1; Unemployed 2
Females	10	26-75	Trader 4; Unemployed 6
Community 8			
Males	12	30-60	Fisherman 5; Farmer 1; Retired 1; Carpenter 1; Railways 2; Unemployed 2
Community 9			
Mixed (6 Males & 3 Females)	9	20-60	Driver 1; Seamstress 1; Accountant 1; Electrician 2; Technical Officer (health) 2; Factory worker 2

5.8 Data analysis

5.8.1 Data transcription

After each data collection activity, the research assistants (RAs) used the recorded audio tapes and field notes to literally translate and transcribe verbatim all the interviews into English and later word processed. Immediately after that, I used the audio tapes and field notes to cross-check the transcripts to ensure that they were accurately translated and transcribed to preserve the meanings of participant's words and statements. Where there were any discrepancies, these were discussed with the RAs so as to help improve subsequent transcriptions.

5.8.2 Computer-assisted qualitative data analysis software (CAQDAS) packages

Recently, there has been an increase in the use of computer-assisted qualitative data analysis software (CAQDAS) packages to facilitate qualitative data analysis. Indeed, the UK Economic and Social Research Council recognised the importance of CAQDAS in facilitating qualitative data analysis and recommended in their revised guideline for training of graduate students that students should have skills in the use of CAQDAS packages (Bringer et al., 2004). This development has however, resulted in a lot of debate among qualitative researchers about the advantages and disadvantages of using CAQDAS (See Murphy et al., 1998, Silverman, 2006, Gibbs, 2002, Bryman, 2004). The key issue of concern is the

changes CAQDAS packages have brought to bear on qualitative data analysis and how this may affect the quality of the analytic process (Bringer et al., 2004). It is therefore important to discuss some of the concerns raised about the use of CAQDAS and outline how it was used to facilitate the analytic approach adopted in this thesis.

Among the issues raised in the literature against the use of CAQDAS packages is the fact that by transforming data analysis into rigid and automated processes, such packages create a distance between the researcher and the data. And since qualitative data analysis is making meaning from texts in a particular context, the use of CAQDAS removes context and meaning from the text during the analysis. Another concern is that CAQDAS packages promote certain theoretical perspectives and analytic techniques at the expense of others. This may therefore encourage researchers to adopt a perspective simply because they are supported by the chosen package instead of basing such decisions on the research questions. Others also think that such packages impose a narrow approach to the data analysis and the ability to use such packages to count the frequency of occurrences of certain words in the text may lead to quantification of qualitative data resulting in wrong and inappropriate conclusions.

On the other hand, researchers who argue in favour of the use of CAQDAS packages point to the speed with which large volumes of data can be

handled, giving the researcher sufficient time to explore various analytic options available. They emphasise that CAQDAS packages facilitate the coding and retrieval process and enable patterns in the data to be compared, thereby allowing meaningful analysis to be done, using for example, stored characteristics such as gender and professional affiliations of the study participants. Furthermore, such packages improve collaboration between research team members. They also enable consistency in the coding process, help enhance transparency of qualitative data analysis and make the process of analysis clearer to those who seek to understand how conclusions were reached.

NVivo 2.0 (QSR International Pty Ltd., Melbourne, VIC, Australia) was used to facilitate data analysis in this thesis. The decision to use this package was based on the nature of the research topic: exploration of the causes of TB stigma in the community setting and healthcare system and its effects on TB patients. As such, a research perspective that permits exploration of ideas and theory building was needed. The Grounded Theory procedures and techniques was therefore adopted since it facilitates exploratory research (Strauss and Corbin, 1998), and is supported by the NVivo software (Gibbs, 2002).

NVivo was invaluable in terms of ordering the data and keeping track of the coding process. The use of the software facilitated constant comparison between interpretations and illustrative statements from the original text. It

also allowed the search for contradictory instances to guard against data misinterpretation and to ensure that the findings are grounded in the data. This was done by clicking, for example, a word in a statement and this opens up the whole text in the original interview.

5.8.3 Getting started with NVivo

After editing and formatting the transcripts, the documents were imported into NVivo for analysis. In NVivo, a project refers to a collection of stored information, such as, transcripts, background data, and personal notes etc. for analysis. From within the project, documents can be opened, edited, coded and analysed.

The analysis involved looking for concepts or ideas (called 'nodes' in NVivo) in the data and seeking to understand their differences and similarities as well as how they link and relate to each other. NVivo distinguishes three ways of keeping nodes: free nodes, tree nodes and case nodes (Gibbs, 2002, Richards, 2005). The free nodes are the simplest, standing on their own, usually in a list, with no relationship to other nodes. Tree nodes, on the other hand, are organised into hierarchy and can be used to demonstrate the relation between nodes. Free nodes can be made into tree nodes and vice versa, a process which is analytic in nature. Case nodes are used to organise coding about cases; they can refer to all the text for a particular case or can be used to organise these cases into types. For example, healthcare workers working in the TB

control programme could be labelled as a case node to which all texts can be coded.

5.8.4 Coding the data

Coding is an analytic process through which a researcher identifies one or more discrete passages of text that in some sense, exemplify the same theoretical or descriptive idea (Gibbs, 2002). It is also described as the assignment of meaningful tags or labels, either descriptive or inferential, to information compiled during a study (Miles and Huberman, 1994).

Initially, the transcripts were read through, line by line, to identify key nodes (themes) talked about by the participants. The identification of the nodes was guided both by the words of the participants and also from reading other research work on the concept of stigma in general, and particularly TB stigma. Personal knowledge and experience of working in the TB control programme, particularly with patients and their experience of the disease as well as the local culture was also relied on. The identified nodes were used to develop a coding framework for coding the data. The coding process involved reading the transcripts, linking and connecting texts to the nodes they represent. If new nodes were identified while coding latter transcripts, they were added to the coding framework. Previously coded transcripts were then checked to identify texts representing the new nodes and coded appropriately.

Attributes on certain variables, such as, gender, age, and responses to certain questions (e.g. would you marry a TB patient?) that were felt might have some influence on the analytic process were created. In NVivo, attributes are associated with a document or set of documents and regarded as data about the data (Gibbs, 2002). For example, the attributes gender and type of interviewee can be used to search for patterns and variations in the data.

A research journal was also kept in which 'memos' about thoughts and comments while editing and coding were written. A memo is the record of the researcher's analysis, thoughts, interpretations, questions, and directions for further data collection (Strauss and Corbin, 1998). Although such memos are essentially notes to the researcher, they are seen as a way of theorizing and commenting about the general development of the analytical framework (Gibbs, 2002) as well as recognition of the preconceptions and/or biases of the researcher.

5.8.5 Developing analytic schemes and models

As the analysis progressed, themes that were identified as belonging to each other were organised into discrete categories and subcategories, using their various properties and dimensions (Strauss and Corbin, 1998). This was done through manipulation and organisation of free nodes into tree nodes, resulting in the creation of a hierarchy of nodes containing categories and subcategories. For example, at the beginning of the coding

process, a free node called 'TB shameful' was created to which statements and reasons for regarding TB as a shameful disease were coded. In the course of coding, it was noticed that the participants mentioned various reasons why TB is regarded as a shameful disease. These texts were retrieved and read through to identify the various reasons given. These reasons then become subcategories or children, as they are called in NVivo, and were organised and hierarchically arranged under the parent node 'TB shameful'.

Various searching strategies available in NVivo for searching nodes and text were also used to explore any developing analytic schemes and concepts. Both simple and Boolean (and/or) search terms were used together with the NVivo attributes. After the search, the texts were retrieved and read through, constantly comparing their meaning and contexts, to identify any common and recurring patterns in the data. For example, a search was conducted using the attributes 'past experience with TB' and 'marrying a TB patient' to ascertain whether past experience with TB (that is, if the respondent knew someone, either family member, close friend or community member who had had TB) have any influence on the decision to either agree to marry a TB patient or consent to such a union involving other family members.

As the analysis progressed, quite a number of phenomena were recognised as related to each other. Diagrams of the relationships between

the elements of the emerging models were created, and search conducted on their nodes. After the search, the texts were retrieved and examined repeatedly to ensure that the data supported the emerging conceptual model. This enabled the construction of a holistic mental picture of how each element might relate to the others. This process of identifying phenomena and searching for the relationship between them was repeated over and over until a particular phenomenon emerged as central to the research topic. This central phenomenon was recognised because it appeared high up in the coding tree and linked many other elements of the models (Gibbs, 2002). It brings together most of the elements of the study and was made the pivot around which the findings of this research are constructed.

5.9 Ethical issues

Ethical approval was obtained from the Ghana Health Service Ethical Review Committee. Other ethical issues that arose in the course of executing the study are considered here.

At the beginning of each data collection session, the purpose of the study was explained and verbal consent obtained from every participant to tape-record the discussions. For patients in particular, it was made clear to them that participation in the study is voluntary and refusal to take part would not affect their access to services offered by the hospital.

No form of inducement was used to entice the participants to partake in the study. However, refreshment was provided after the focus group sessions. Healthcare workers and TB patients who travelled to the regional hospital to participate in the focus groups were also reimbursed with the cost of travelling. To help protect the identity of the patients and prevent questioning by community members, both the focus groups and individual interviews for patients were held within the hospital premises.

During data collection, a sensitive approach was adopted because in-depth interviewing and focus groups are intrusive in nature, especially when patients are discussing their personal experiences of the disease. Although the research study did not require names and details of individual participants, presentation of a large section of data was avoided so as to prevent the possibility of readers identifying the person speaking in the quote. Moreover, no identifiable records, such as, name and hospital, were kept on the tapes or written in the transcripts. The recorded audio tapes were listened to only by the RAs and me.

5.10 Rigour of data collection methods and analysis

Although the concepts of validity and reliability have their roots in quantitative research and therefore hold particular meaning in that paradigm, the underlying concerns are important to qualitative research. However, because different theoretical assumptions underlie quantitative

and qualitative research, it is appropriate to address measures taken to ensure validity and reliability of the findings presented in this thesis.

In qualitative research, the concept of 'validity' refers to the extent to which the researcher adequately represents the reality of the people being studied, whilst 'reliability' refers to the degree of consistency of the research findings (Richards, 2005, Gibbs, 2002). As David Silverman argues, research findings can be said to be reliable, and the interpretations and conclusions valid only when the researcher can demonstrate to readers that appropriate methods of data collection and analysis were used (Silverman, 2006).

In this study, validity was ensured by providing step-by-step explanation of the data collection and analysis processes to help readers to understand and judge how conclusions were arrived at. Practical and ethical issues that arose during the research process and how they were addressed were logically documented. Detailed information on how access was gained and means of data production was provided. Coding and categorising of the data were adequately explained. Rigour of data analysis was ensured by reading and rereading of the transcripts to generate a coding framework. Then, passages from the transcripts were sorted into categories, and examined for similarities in meaning and grouped into themes. The themes were then constantly and carefully compared with the data until a core category emerged that integrates several concepts. The cycle between

interpretation and data helped to develop categories that are grounded in the data. To help readers to assess whether interpretations were based on the data or not, sufficient segments of texts or quotes that relate to the interpretations are used (see next chapter).

Furthermore, it has been suggested that the assistance of others can be enlisted to code segments of the data and when the results are comparable, then coding reliability is achieved (Cutcliffe and McKenna, 1999, Morrow, 2005, Murphy et al., 1998). However, it is worth noting that because every researcher brings his/her background into the coding and analysis process, such an exercise may not necessarily guarantee reliability in the coding (Richards, 2005). Thus, it is unlikely that two people will arrive at the same categories and interpretations since each person brings his or her background into the analytic process (Cutcliffe and McKenna, 1999). Coding reliability was enhanced through the following procedure. As my understanding of the data grows, previously coded segments of the data were re-visited and re-coded to ensure reliability in coding. Although the evolving nature of the coding framework may not lead to the same results, it allowed re-coding of those segments to bring it inline with what was being coded at the time.

Credibility of research findings can also be enhanced through prolonged engagement with the field and familiarity with the study setting. This is because it helps the participants to feel comfortable and to share their

story with the researcher (Creswell, 1998, Stiles, 1993). As mentioned in Chapter 1, my job as TB clinician/coordinator in the region enabled me to have prolonged interaction with the patients and the community members. This helped the patients to relax and share their feelings and experiences. It also allowed me to identify any contradictory perspectives and cross-check them from the participants.

The technique of triangulation was also used to improve the rigour of the findings. This entails using multiple and different data sources, methods, investigators, and different theoretical perspectives in the study of a social phenomenon (Bryman, 2004, Flick, 2006). In this study, findings from different data collection methods (focus groups and individual interviews) and sources (TB patients, healthcare workers and community members) were triangulated to provide a broader understanding of TB stigma and to strengthen the credibility of the interpretations. Triangulation also helped to provide a further level of perspective than may be available using either of the data collection methods, for example, individual interviews alone (Frey and Fontana, 1991). The combination of the two data collection techniques in the different settings and participants enhanced the understanding of how TB stigma is constructed in different ways in different contexts. Through this, patterns of convergence or corroboration of the overall interpretation was enhanced making the findings more comprehensive. It also helped to identify the context-specific nature of the different accounts.

5.11 Summary and conclusion

This chapter outlined the methodology used in this thesis. It emphasised that because no prior information was available on TB stigma in Ghana, a qualitative research approach was adopted. The chapter also stated that the selection of the study participants and data collection methods were geared toward exploring TB stigma in both community and health system. It also documented how data were collected and analysed. Ethical issues that arose during the research process and how they were solved as well as issues of validity and credibility of the findings were also discussed. The results of the analysis are presented in the next chapter.

Chapter 6 : Findings

6.1 Introduction

Having explained the methodology in the previous chapter, this chapter outlines the findings. Because similar questions and issues were explored during the focus groups and individual interviews, the findings are combined, and presented in four sections. In section one, the causes of TB stigma identified in the data are explored, whilst the manifestations of TB stigma in the community setting and within the healthcare system are examined in sections two and three respectively. Section four examines the effects of TB stigma on patients. The qualifiers used to express approximate proportions of less than 50%, 50-80%, and more than 80% of respondents who expressed the same ideas are 'some', 'majority', and 'most' respectively.

6.2 Section A: Causes of TB stigma

Eleven causes of TB stigma were identified in the data:

- Fear of infection
- Physical frailty of TB patients
- Association of TB with HIV/AIDS
- Perceived causes and spread of TB
- Outdated societal practices about TB
- Public health practices and discourse

- Attitude of healthcare workers towards TB patients
- Health staff's own fear of TB
- Self-stigmatisation by TB patients
- Judgement, blaming and shaming TB patients
- Past experience with TB

With the exception that few women in both community focus groups and individual interviews were sympathetic and accommodating when talking about relating to people with TB, there were no marked differences in the findings by site and sex.

6.2.1 Fear of infection

The main cause of TB stigma identified in the data is the fear of infection. TB was described as a dangerous and highly infectious disease that is spread through the air as well as by personal contact with individuals affected with the disease. This fear was expressed by both community members and health workers. Because of the fear of infection, certain behavioural expectations from TB patients were pointed out:

...if the TB patient goes to any public place, he/she has to sit quietly; should not dance among the crowd, or be shouting and talking like others do... He/she should carry his/her cup or buy the sachet (bottled) water. Because as we said, it's an airborne disease and as he/she shouts the germs can enter someone for the person to develop TB... (Male, community focus group)

...in the lab, we normally have an opening prayer before starting work and we begin with singing. The disease can spread to others during singing. So what we normally do is that we tell them (TB patients) that 'don't join us; you stay where you are and sing'. I mean we are very conscious of the disease when singing... (Laboratory staff, focus group)

6.2.2 Physical frailty of TB patients

The concept of physical frailty refers to the obvious signs and symptoms of the disease. According to the majority of the participants, the extreme weight loss seen among TB patients, coupled with a persistent cough, and sometimes coughing up blood, makes them feel very uncomfortable around TB patients, heightening their fear of the disease.

...a person with TB is emaciated and cannot walk; the ribs are out like someone who is lifting iron rods; he is wasted and carries a handkerchief to cover the mouth everyday... (Male, community focus group)

Some of the TB patients also agreed that the features of the disease make them feel ashamed. One patient described what he went through when trying to buy food:

...I went to buy from a woman selling food; when she saw the way I looked, she just asked me to move back a little and said 'bring your money for me to serve you; don't come here to spoil my market'...(Female patient, individual interview)

6.2.3 Association of TB with HIV/AIDS

Although it was not asked, the majority of the participants in the communities, and sometimes the TB patients, associated TB with HIV/AIDS, citing common physical signs and symptoms shared by both diseases, particularly, extreme weight loss. This was evident in the way most community members usually described TB patients as very emaciated, coughing up blood and looking like HIV/AIDS patients. Some community members also indicated that they were aware of the fact that TB and HIV/AIDS are linked, and usually likened individuals in the community with TB to those infected with HIV:

...my landlord's child from Abidjan suffered from the condition... he coughs continuously and persistently and lost much weight and we thought he had HIV/AIDS ... (Male, community individual interview)

Some of the patients were also aware of the association between TB and HIV/AIDS. Consequently, they indicated that losing excessive weight leads people to diagnose TB patients as having HIV/AIDS, and this was a major concern to them:

...when I was informed of the diagnosis, I was shocked because I heard that the disease is usually associated with HIV/AIDS. I was praying that I do not develop AIDS. Because when you loss weight people will think you have got another disease; people will think you have AIDS... (Female patients, individual interview)

No such association between TB and HIV/AIDS was identified in the statements and words of healthcare workers.

6.2.4 Perceived causes and spread of TB

Various beliefs about the causes and spread of TB were identified: germs in cough; stepping in sputum; sharing cooking utensils/plates/cups with a TB patient; dusty work environment; hard physical labour and spiritual or evil forces. Such multiple interpretations of the causes and spread of the disease can lead to stigmatising behaviour as evident in most community discussions:

...it can be transmitted through sharing cups and spoons. When the TB patient spits around and you step in or coughs, it gets into the air; it is germs which is airborne so it can cause another person to get it ... (Female, community focus group)

It is also believed that there is a spiritual type of TB, which comes from the devil, witchcraft or evil forces. This form of TB could also be “inflicted” upon a relative by the ghost of a family member who died from the disease. This spiritual TB, referred to as ‘*nsaman wa*’, literally ‘ghost cough’, is usually acquired when relatives shun and refuse to care for a family member who has the disease. When the person dies, his/her ghost ‘sends’ the disease to the relative(s) who shunned and refused to care for him/her. It is only family members of the dead person who usually get this type of TB; ‘outsiders’ are not affected. Such a belief points to the ambivalent

perception about the infectiousness and cause of the disease as well as the perception that stigmatising behaviour itself can lead to TB:

Respondent 1: I hear TB is infectious but I do not believe it

Respondent 2: It is infectious but it depends on one's character

Facilitator: Can you explain why you are saying getting infected depends on one's character?

Respondent 2: It depends on how you treat the sick person; if you care very well for him or her, you will be free but if not, you will get infected.

Respondent 3: When you neglect and shun the person you will get infected.

Respondent 4: What you are saying is true (referring to the previous speaker) because a lady was admitted at the hospital with TB and one of the children neglected her. The lady asked of that child and said if she dies, she will infect her with the disease. The lady died and that daughter is suffering from TB and she looks very bad. When she went to the hospital and took an X-ray, she was told that the whole lungs were damaged; she coughs very seriously (Female, community focus group).

6.2.5 Outdated societal practices about TB

Certain historical practices, although no longer in use, were mentioned frequently by the community participants as making suffering from TB shameful. They indicated that such practices heighten their fear of TB:

...in the past, when anyone developed that disease, they were normally taken to a distant place or behind the house, where a structure is built for them to stay in until either they are cured or die from the disease... (Male, community focus group)

6.2.6 Public health practice and discourse

The majority of the community members and TB patients pointed out that certain public health practices and exclusionary policies of health workers made suffering from TB shameful and enhanced the fear of the disease.

6.2.6.1 Isolation and exclusionary practices

The community members pointed out that doctors give the disease very strange names and indicated that, in most hospitals, those who have TB are confined somewhere. They stated that TB patients are usually separated from other patients and sometimes relatives are not allowed to see them. They also mentioned that when the health team is on ward rounds, by the time they get to where the TB patients are, most of them will be in gloves and masks. To them, TB patients are separated by the health workers because it is not a disease you can go out in public with:

...when you have TB and report to the hospital you are isolated to a place where many people will not see you; that is why it is a shameful disease... (Female, community individual interview)

6.2.6.2 Inaccurate health education messages

Inaccurate health education messages by health professionals were mentioned by the community participants as the basis of their attitudes and behaviours towards TB patients. Common among such messages is the avoidance of household items used by TB patients:

...the doctors made us aware that the disease is infectious, and that no one should use a cup used by the sick person; the patient should be isolated and his plates separated from those used by the rest of the household... (Male, community focus group)

6.2.6.3 Food safety and hygiene practices

Within SAEM district, individuals who want to sell, especially cooked food, are made to undergo medical examinations. Such prospective sellers are screened for various diseases, such as, typhoid fever, worm infestations and TB. Such an exercise by the health authorities was often alluded to as making TB a shameful disease. It was also cited as the reason why the community members are usually antagonistic towards those they suspect to be suffering from TB, and are selling:

...it is because of this disease that the City Council people (referring to the environmental health unit) ask those selling food to go for a check up to ascertain whether they have TB or not. You will only be given the certificate to sell food when you are not having TB, so that you don't contaminate the food and transmit the disease to a lot of people... (Male, community focus group)

6.2.6.4 Prohibition of full burial rites

In the past, full burial practices were prohibited by health professionals for community members who died from communicable diseases, such as, cholera and TB. Although this is no longer practiced, it was often referred to by the participants as making suffering from TB shameful:

.... at times, when someone dies from TB, they (health workers) don't allow the family to bring the dead body home. They do everything at the hospital and then move straight to the cemetery for burial... (Male, community focus group)

6.2.7 Attitudes of healthcare workers towards TB patients

Most of the community members pointed out that the attitudes and behaviours of health workers towards TB patients, especially the way they relate to, and treat those with the disease, make it shameful. They reported various incidents they had witnessed or were aware of, involving different categories of health professionals shouting at TB patients, asking patients not to sit among other out-patients, moving away when the patients approached them and standing at a distance when talking with the patients. A community member who had had TB narrated what she felt when she was diagnosed with the disease:

...I ever had that disease; initially I did not know it was TB; I easily got tired and lost a lot of weight and was wondering what was wrong with me. I went to the hospital...When you report to the doctor he makes sure you do not come near him; so I realized that TB patients are not considered as human beings...(Female, community focus group)

6.2.8 Health staff's fear of TB

The majority of health staff expressed feeling of fear when interacting with TB patients. They said that because of the fear of getting infected they feel very uncomfortable and terribly afraid when interacting with the patients.

When taking blood sample, for instance, they were in a hurry to finish and pray that the patient would not cough during the procedure or asked the patient to cover the mouth when coughing:

... I know TB patients are very difficult to work with. I heard of a TB patient who tried to infect a nurse by spitting onto her bread and the nurse got infected. I am really afraid to work among such patients. If I am asked to go there (referring to the TB unit) it will be a big problem for me, but I will agree and put in measures to prevent me from getting infected... (Medical ward staff, focus group)

6.2.9 Self-stigmatisation by TB patients

It was pointed out that the manner in which those who have TB behaved contributed to the shame associated with the disease. The participants said that TB patients were ashamed and usually hid the diagnosis from close relatives and friends, and sometimes found it difficult to come out and interact freely with other members in the community. However, the patients claimed they behaved that way because when others got to know of the diagnosis, they would not come near them. To the patients, if you have TB, you are shunned and devalued by society:

... I did not inform anyone because I know how human beings behave; before you are aware, everybody will isolate themselves from you. So there is no need to help people to shun you... (Female patient, focus group)

...people have different opinions about TB, so I did not tell anyone. But they noticed that I was sick and had loss a lot of weight. Anytime they ask me, I just tell them that I am sick and go to the hospital for treatment. I did not inform anyone that I have TB... (Male patient, individual interview)

6.2.10 Judgement, blaming and shaming TB patients

According to some of the participants, the patients lead certain 'socially unacceptable lifestyles', such as smoking cigarettes and cannabis, drinking alcohol and the use of hard drugs such as cocaine, resulting in the development of TB:

...those who usually drink 'akpeteshie' (locally brewed alcoholic liquor) and smoke cigarette and wee (cannabis) get TB because they pass it from one person to another and use the same glass... (Male, community individual interview)

They accused and blamed TB patients for deliberately spreading the disease to others, and at the same time expected them to be responsible for taking measures to prevent the spread of the disease to others. They pointed out that TB patients should go to the hospital for treatment and also take the prescribed drugs so that the disease does not spread to others. They also expected the TB patient to isolate him/her self from people and not eat with them. When TB patients cough in public, they are expected to cover their mouths, have containers to put the sputum into and use their own cups and plates when eating to prevent spreading the

disease to others. When a patient failed to adhere to these behavioural expectations, it is taken as an intention to infect others:

...some TB patients are very wicked and try to infect others with the disease. At CDU (Communicable Diseases Unit), they are not allowed to spit around and are given containers for their sputum but when they come home, some spit around indiscriminately... (Male, community focus group)

...because the patients know that others can get the disease when they (TB patients) share things with them or when the patients cough on you this makes them (TB patients) to develop wicked ideas. If one of them is among us now and there is water in the fridge, he wouldn't mind going to pick it; they will do everything possible for you to get it... (Paediatric ward staff, individual interview)

6.2.11 Past experiences with TB

Most community members indicated that they knew someone who had had TB or was suffering from the disease. They mentioned mostly close relatives, siblings, friends and children. According to most of them, the persons they knew with the disease died. For some, more than two people from the same family had died of TB. Because of such experiences with the disease, some community members were of the view that TB is difficult to cure or can not be cure completely, because infection with TB invariably led to death:

...one of my uncles had it and when he was about to die he coughed severely and vomited blood; and when we got there, he was lying dead in the pool of blood... (Female, community focus group)

...as for TB, no matter what you do, it will kill you! Even if the person is given all kinds of drugs and is cured, it will reoccur and kill you; so I don't believe that treatment can completely cure it... (Female, community individual interview)

6.3 Section B: Manifestations of TB stigma within the community setting

This section examines the manifestations of TB stigma in the community setting. The findings are presented as a set of three intertwined themes: participatory restrictions; socio-physical distance; and rules and codes for unavoidable interactions.

6.3.1 Participatory restrictions

At the core of feelings towards TB in the community is the fear of infection; this fear underlies attitudes and behaviours of the community members towards those affected by TB in society. The majority of community members indicated that because TB is highly infectious, they were afraid of getting infected when interacting with the patients. Because of fear of infection, they pointed out that TB patients should not be part of society and should therefore be separated from the rest of society. They indicated

that once they become aware that the person has TB, they will not get close or share activities with the person:

...it can affect us when we talk or do things in common with them; so those visiting or staying around TB patients should be careful so that they don't get infected... (Female, community focus group)

...the disease is infectious so the patient should have separate eating plates and drinking cups. He/she should also have a container for the sputum and discard it into a gutter. The sputum contains germs which are very strong and when he/she spits on the ground and someone steps in, the germs can enter the person and cause TB. So the TB patients should have separate things... (Male, community individual interview)

They stated that when someone develops TB, the person must seek treatment immediately and insisted on the exclusion of TB patients from the rest of society. They advocated for admission of TB patients to the hospital for treatment and said that they are in favour of the use of isolation wards in hospitals since this was the practice in historic times:

...in the 70's, I was young and we lived near Cape Coast hospital; TB patients had an isolation ward so I think it should be continued. Because when they come out others may get infected. They may use a glass to drink alcohol and I may not be aware that the person has TB and drink from the same glass... (Male, community focus group)

...they should be admitted; the government has prepared a place for them (TB patients). When you go to Effia-Nkwanta hospital, they have a place where they are admitted and treated until they get well... (Female, community individual interview)

However, a few individuals in the community were of the view that participatory restrictions are not good for the patients. They pointed out that, when the sick person is isolated, the resulting loneliness is sufficient to kill the patient. More so, when the patient is on treatment, he/she is no longer infectious so others can interact with the patients without fear.

6.3.2 Socio-physical distance

6.3.2.1 Marrying a TB patient

The majority of the community members said they would not marry a TB patient and would also not encourage any family member to enter such a relationship. The main reason given for this position is the fear of infection. They indicated that in the event that the partner is spared, the children born to such a couple could get infected:

...I would not marry or encourage my child to marry a TB patient because we all want peace; TB is like AIDS, when you have it there is no peace; so I would not allow such marriage...I can't marry him because I can get infected; even if that did not happen the children we may bring forth can get infected... (Female, community individual interview)

Some of the community members also pointed out that TB imposes a lot of economic burden on a marriage because the patient does not have the energy to work to raise money to support the spouse. Moreover, the patient is not able to perform his/her expected roles in marriage leaving such duties for others to perform:

...if your wife develops the disease, she has no strength to do anything to help you; she can not cook for the family, somebody else must be there to take care of the children, so it is a problem to us... (Male, community focus group)

The outcome of treatment is another reason given for not accepting TB patients as marriage partners. Having seen or heard of many people who died from TB in the community, they pointed out that they can not guarantee what may happen in the course of treatment. Furthermore, the extreme weight loss and the persistent cough, and sometimes coughing up of blood, do not make TB patients presentable marriage partners. For some, the fact that TB patients are shunned in the community and the observation that some of them have HIV/AIDS means that when you marry a TB patient, you will be associated with the shame the disease brings:

...I would not marry a TB patient because people will be pointing fingers at me, saying "that is the wife of the TB patient"... (Female, community individual interview)

Only a few people said they would marry a TB patient. Such individuals pointed out that marriage is based on love. Moreover, because there is

cure for the disease, they will ensure that the patient is treated, after which they can get married:

...there are certain qualities you will have seen in the person before deciding to marry. These qualities will not disappear because of TB, so allow the person to take treatment for about a year and marry after that... (Male, community focus group)

6.3.2.2 TB patients selling in the community

The majority of the community members are of the view that TB patients should not sell in the community because they can infect others. They indicated that if the patient is selling food and coughed during the preparation, those who purchase the food item may become infected when they eat it. They insisted that if they see any TB patient selling food, they would report to the police or sanitary inspectors for the person to be arrested and dealt with accordingly:

...If I see a TB patient selling, if he/she does not take care I will report him/her to the police because he/she can destroy the whole community. If she has to sell, she should not sell food because she can cough unto the food and spread the infection to those who eat it... (Female, community individual interview)

Some of the community members were of the view that it is not only food items that can transmit the disease. They pointed out that, irrespective of what the patient is selling, because the process of bargaining involved talking, which could lead to coughing, those coming to purchase the item

can be infected. As far as they are concerned, selling and TB does not go together so they would not buy anything from a TB patient:

...TB patients can decide to sell any items, but as for me, no matter what they are selling, I would not buy from them; even if it is unpeeled orange; because they can cough onto it when peeling it and can transmit the disease to me... (Male, community focus group)

However, some of the community members were of the view that because of financial difficulties, when the patient is on treatment, selling should be permitted. Such community members pointed out that only items that are cooked before consumption and products that are not consumed (e.g. sandals, clothes, books and charcoal) should be sold:

... I would buy tuber foods like cassava, plantain, and cocoyam, because they are peeled and cooked before eating; we have been made to understand that cooking kills germs so I can buy such foods items from the person... (Male, community focus group)

6.3.2.3 Selection of TB patients to represent the community

The majority of the community members said they would not agree to the selection of a TB patient to represent the community in any official capacity. They were of the view that the disease is infectious and talking usually leads to coughing. They pointed out that the patient could start coughing during the speech and would end up not just infecting the dignitaries but disgracing the community as well:

...the cough can be continuous for about 30 minutes and if this should happen at the function, it would be a disgrace to us. Even if there is a prize they want to give to us, because of his excessive coughs, they won't give it and this will make us lose something valuable... (Male, community focus group)

Some also pointed out that the patients usually look very wasted and do not have the strength to stand for long periods; he/she may fall down and die in the process. To them, TB patients should not come to public places and it will be a shame for the community to select such a person to represent them:

...when you are choosing a person for such a function, he/she should be handsome and a person with TB is emaciated and won't fit for selection because people might think he is a sicklier... (Female, community focus group)

Only a few people were of the view that if the TB patient is knowledgeable and competent, they could approve the selection of such an individual to represent them:

...if the person has good knowledge of the work he/she is supposed to do, I don't have any problem with that. We could choose a healthy person to represent us and the person might not work... (Male, community individual interview)

6.3.3 Rules and codes for unavoidable interactions

Whenever it becomes unavoidable to interact with someone with TB, for example, when sitting close in a car, at a funeral gathering, or playing draughts, the majority of community members indicated that they would cover their mouth with a handkerchief, turn their head or sit in the opposite direction of the wind from the patient to avoid inhaling the air. If they are onboard a vehicle, and find out that the person sitting next to them is a TB patient, they may either refuse to board the car, alight before reaching their destination, or would not utter a word to the patient because in an attempt to respond to anything they say, the patient might cough and infect them:

... I would alight when such a person sits by me; because the disease is through the air and I would by all means breathe. Besides, by the time we get to Accra, the person would have talked and because it is in the air, it can stay in the car and can infect us, so I would alight... (Male, community focus group)

When a TB patient joins the community members at any function, he/she is expected to abide by certain 'codes of conduct'. Most of the community members said the patient should cover the mouth when coughing or turn the face in the opposite direction to those around him/her. They maintained that TB patients should not spit on the ground because if anybody steps on the spit in bare feet, the person may get the disease. The patients should have a container with a lid into which they put their sputum for disposal. The patients should have their household items, such as cups and plates,

separated from the rest of the households'. If the patients eat any food, they should not give the leftovers to anybody, especially children, since this will be taken as intention to infect others:

... I know a man who deliberately wanted to infect others. He leaves his left-over food for the children. When people are around he coughs continuously and spits indiscriminately. Sometimes some of the TB patients have the intention to infect others... (Female, community focus group)

6.4 Section C: Manifestations of TB stigma within the healthcare system

The manifestations of TB stigma within the healthcare system are discussed in this section. The findings are presented as three inter-related themes: behaviours towards TB patients; administrative procedures and policies of healthcare managers; and attitudes towards TB work.

6.4.1 Behaviours towards TB patients

6.4.1.1 Diagnosis of TB: the onset of fear

The majority of the health workers (HCWs), particularly, those working outside the TB control programme, expressed fear of infection when interacting with TB patients. The fear usually intensified after the diagnosis of TB was confirmed, and resulted in a change in the way they interacted with the patients. They indicated that upon confirmation of the diagnosis, they were usually afraid and felt very uncomfortable around the patient, and sometimes might refuse to go near them. If the diagnosis is made

while on admission, the patient is either immediately isolated or moved to the end of the ward. In health institutions where the TB unit is detached from the main hospital building, the attending doctor(s) will be followed everywhere with the laboratory results to have the patient transferred:

...as soon as the diagnosis is made, they don't want the patient to sleep at the ward again. They will immediately transfer the patient to CDU (Communicable Diseases Unit); even as late as 5 pm, you will see them bringing the patient from Ward A to CDU; they won't allow the patient to stay there for the night... (TB unit staff, focus group)

6.4.1.2 Shunning and avoiding patients

Most HCWs, particularly, those working in non-TB units, stated that given the option, they would avoid interacting with TB patients. However, because it is exceedingly unprofessional to do so, they use various means to avoid contact with the patients. They said that sometimes when they see a TB patient approaching, they either move away or pretend to be doing something else. When it is crucial for them to interact with the patients, they pointed out that they stand at a distance or spend less time with them:

...I know some of the nurses shun the company of TB patients. I remember when I was at the TB unit, I usually move from bed to bed to enquire about the patients' health and they usually tell me that I had done very well by coming to greet them on their beds. So I got to know that some of the nurses shun the patients... (Medical ward staff, individual interview)

6.4.1.3 Segregation of patients

Segregation of TB patients at home and in the out-patients-department was advocated by most of the HCWs. Although such a policy is not in force in any health institution in the district, they mentioned that it would facilitate prompt attention to the patients by the nurse or doctor, and may encourage the patients to come for their drugs regularly. Most importantly, they pointed out that such a practice will prevent the spread of the disease to others:

...I think they (TB patients) should have their special doctor at the OPD...At the maternity unit, we usually don't know and we nurse them as ordinary patients. There was a graduate teacher who had TB; she came to deliver and because we didn't know, we didn't take any precautions. I think there should be an established unit for them... (Maternity ward staff, individual interview)

6.4.1.4 Mistrust of patients

Some of the HCWs accused TB patients of using very 'wicked' means to infect others. They pointed out that when the patients come for laboratory examination, for example, they declined to use the sputum container provided or smeared the container with sputum. Others said the patients spit around indiscriminately and start to cough as soon as you got closer to them with the intention of infecting the staff. They indicated that they know or have heard of stories of TB patients coughing or spitting in food (bread

or tea) and telephone receivers, and succeeded in infecting the attending staff:

...one of them (TB patients) coughed into the sandwich and put it down. When she (the nurse) came back, she innocently took a bite. When she raised her head, they (the patients) were all laughing. She asked the reason why and no one answered her. Then she opened the bread and saw that someone has coughed into it; she nearly died; they are very wicked... (Medical ward staff, individual interview)

6.4.1.5 Maltreatment of patients

Most of the HCWs said that they were aware of TB patients being shouted at, and sometimes maltreated by some of their colleagues. They reported various occurrences they had personally witnessed or are aware of, involving different categories of staff. Some of the reported issues were doctors or nurses shouting at patients, and asking them not to sit among the rest of the out-patients attendants:

...a defaulted client (A TB patient who did not complete his/her treatment regimen and reported back to the hospital when the disease re-occurs) was brought here with some psychiatric symptoms. The client was just coughing all over the place and refused to put the sputum into the container he was carrying. A doctor came out and shouted that we should take the patient out otherwise he is going to contaminate the whole place and we took him out... (Psychiatry ward staff, individual interview)

6.4.2 Attitudes towards TB work

6.4.2.1 Trainings and postings

Because of the fear of infection, the majority of the HCWs said they would not agree to be trained as a TB nurse or doctor. They also pointed out that they would not accept posting to the TB unit, except when it is compulsory for them to do so. They maintained that it was not necessary for a group of staff to be trained solely to care for TB patients since such a practice may expose the workers to an increased risk of infection. Instead, they advocated for periodic rotation of staff through all units, including TB units:

...most staff refuse posting to TB units because they feel that the disease is highly contagious and by going there, they will get the disease. That is why some people reject the idea of going to work at the TB unit...so they have to use a system of rotation so that every worker will go to every unit to work... (Out-patient-department staff, individual interview)

6.4.2.2 Perception of postings

There was a strong perception among some of the HCWs that posting of staff to TB units is meant to punish such individuals. They maintained that the posting is based on favouritism; if the health managers like you, then you will not be posted to the TB unit. Some said they personally know employees that 'misbehaved' and were sent there as a punishment. It was also reported that health managers post less qualified or non-performing

personnel to the TB units. They also contended that once an individual is posted to the TB unit, he/she will not be posted to other units:

...there was a girl at Ward 2 who was misbehaving and was posted there. It is about 2 years now and she is still there. If it is normal rotations as some of you are saying, then some people are kept there for too long...if you do something and they post you there, it is definitely a punishment... (Health Manager, focus group)

However, some of the HCWs pointed out that there are no criteria for selecting staff to work at the TB units of the hospitals. Such individuals maintained that the postings are part of the normal changes that the nursing administration undertakes periodically. They emphasised that any nurse could be posted there since this helps the hospitals to build expertise in that speciality. Others also thought that the administration considered previous experience of working at the TB unit and that in recent times, certain doctors and nurses have specialised in TB management and control and are therefore made to work at the TB units:

...some nurses went to Israel to be trained purposely for that and when they came back they were stationed there (TB unit). During the periodic changes, they are given supporting staff because it is a specialized area... just like theatre nursing, eye nursing and ENT (Eye, Nose and Throat) nursing... (Medical ward staff, focus group)

6.4.2.3 Special incentives

The majority of the HCWs pointed out that any high risk job, such as working at a TB unit should have special incentives attached. They posit that the incentive packages will serve as morale boost for the staff, and this may 'compensate' for the risk associated with working at the TB units. They contended that in most developed countries, high risk jobs have special incentives attached, and this was practiced in Ghana in the past. They mentioned various forms of incentive packages, such as, regular workshops, scholarship offers for further studies and provision of sugar and milk as means to motivate the staff working at the TB units. Besides, because of the possibility of development of TB in the future, the incentive package would be a 'consoling reminder' of what they got while working at the TB unit:

...those working there (TB units) should be given special incentives to boost their morale. In time past, those working at TB units were given provisions (milk, sugar, soap etc) and eggs to help build their immunity so that they would be able to fight the disease if they get infected. That is why people refuse postings to TB units; because if you know you won't get anything, why should you go to work there? ... (TB unit staff, individual interview)

6.4.3 Administrative procedures and policies

6.4.3.1 Location and state of TB units

It was pointed out that in most hospitals the TB units are usually located in isolation wards, and sometimes separated from the main hospital building.

In certain situations, means of transport to the TB unit is not available, thus compromising workers' security and safety, particularly at night. Some of the HCWs indicated that the physical structures are in a poor state:

...another thing is that the place is so depressing; ventilation too is very poor in the rooms; it is like fevers unit. If nothing is done about it, I don't think people will be willing to go there and work... I think we need to light up the place to make people to accept to go there... (Health Manager, focus group)

6.4.3.2 Tools and equipment

Most of the HCWs, particularly, those working at the TB units, indicated that tools and equipment are usually not provided. They pointed out that because the health managers give less priority to the needs of the TB programme and services, logistics they need for day-to-day running of the units are not provided, resulting in lack of basic tools and equipment:

...there is nothing to work with... they (Health Managers) preach infection control but there is nothing to prevent infection of staff involved in the management of the condition. So how do we control the infection? They should make sure that the necessary tools are there to work with...I know as a nurse I am supposed to work in any unit; if there are things to protect my self and work with I won't say I won't go to work there...(Medical ward staff, individual interview)

6.4.3.3 Supervision and support

Most of the HCWs, especially those working at the TB units, indicated that since they were posted there, it was only on a few occasions that the

health managers came around to find out how they were faring and coping with the work. They lamented that although they had to work under poor conditions, it seemed their efforts were not appreciated by their supervisors to warrant regular visits. Some of them said that they believe the managers have forgotten that they are also part of the hospital. They indicated that the very few visits made by their supervisors confirm their view that they are not recognised:

...when I was there (TB unit), anytime the matron at that time come to the place, they don't even want to come out of their car, let alone to enter the wards. Even the distance they keep when talking to you speaks for itself... So I had the impression that when you are there you don't have any relationship with the heads... (Paediatric ward staff, focus group)

6.5 Section D: Effects of TB stigma on patients

The effects TB stigma has on the patients are discussed in this section. The treatment seeking behaviour, interpretation of the initial symptoms of the disease, and when and how they decided to go to the hospital examined. It also explores how the patients received and lived with the diagnosis of TB.

6.5.1 Onset of symptoms

At the initial stages of the disease, the majority of the patients did not recognise their signs and symptoms as due to TB. According to most of

them, when the symptoms started, they thought it was due to malaria or ordinary cough. They went to the nearest drug stores to buy cough remedies and other drugs. More over, because of the non-specific nature of the symptoms, and the belief in the use of traditional medicines, some patients mentioned visiting spiritual homes, known locally as ‘*nankaba garden*’, and churches, where they were given herbal remedies, ‘holy waters’ and oils to use. In certain circumstances, they consulted health professionals residing in the community for assistance. It was only when these ‘searches’ did not result in improvement in the symptoms that they decided to go to the hospital:

...I started feeling feverish and thought it was malaria so I sent for drugs from the drug store. ...Later I started to cough...Then a time came that any time I ate, I vomited everything...Within days I grew very lean, so I decided to stop taking the drugs and go to the hospital... (Male patient, focus group)

6.5.2 Visiting the hospital

For the majority of the patients, the decision to go to the hospital was influenced by family members and close friends, most of whom had had TB in the past, and recognised the signs and symptoms as due to TB. Others indicated listening to a discussion of TB on the local radio station, and sometimes on television, during which they recognised that their symptoms were likely to be due to TB, so they took the decision to go to the hospital. When they finally decided to go to the hospital, most of them

indicated multiple visits, sometimes moving from one hospital to another and were treated for many conditions and diseases before the diagnosis of TB was finally made:

...the sickness started about four months ago...I came here (the health facility where the interview was conducted) and was given treatment but I was still coughing so I went to SDA (Seventh Day Adventists) clinic. I later went to Effia-Nkwanta hospital, where I did sputum test...and was referred to CDU (Communicable Diseases Unit) and they in turn referred me here... (Female patient, individual interview)

Some of the patients did not tell the attending physician that they have been coughing for long periods, and had taken various medications without improvement before reporting to the hospital. They rather mentioned various non-specific symptoms, concealing the more specific ones, such as, prolonged cough and sometimes haemoptysis, which could be helpful in making the diagnosis of TB:

... I thought it was malaria so when I went to the hospital I told the doctor that I am having headache and feeling feverish. He treated me for a long time before I told him that I am also coughing. He then asked me to do sputum test and chest X-ray which showed that I had TB... (Male patient, focus group)

Most patients indicated that they found the attitudes and behaviours of health professionals towards them demeaning. They described such attitudes as affecting their confidence and the way they related to others in

the community. Others pointed out that it discouraged them from reporting to the hospital:

...when I went to Accra, I met a lady doctor; the woman has no patience at all! When you cough, she will shout at you saying “gentleman, go there, go there”. The way she behaves means that when you have this disease, you should not come near her; she hates you. When it happened like that, I decided to stop going there and came here instead...there are some people who wouldn't like to be treated like that, so they would not go to the hospital just because of the way she will treat them...(Male patient, focus group)

6.5.3 Reactions to the diagnosis of TB

Most of the patients indicated expressing various forms of emotion when informed they have TB. Some of them said that they were shocked, scared, confused, and cried throughout the night because they thought they would die. Others said they were worried, and wanted to commit suicide:

...when the doctor completed the investigations and said it was TB, I went home and informed my wife; she cried a lot. So when the doctor said that, I thought of poisoning my self. Anytime I am walking to the hospital and see a train passing, I hear something telling me to throw myself under the train and be killed; just because of this disease that I have... (Male patient, individual interview)

Some of the patients also mentioned that when they were told the diagnosis, their concern was how to raise money for treatment. Those who

indicated that they knew others, who had lost their job because of TB, said their concern was the likelihood of losing their jobs. The majority of the patients, however, questioned how they got the disease:

...people said the disease comes about as a result of smoking cigarette and drinking alcohol; I stopped these things a long time ago. I do not eat from the street; I give money for my meal to be prepared at home, so I do not know how I got the disease. I thought may be it is through too much thinking... (Male patient, focus group)

The pronouncement of the diagnosis aroused spiritual awareness, especially belief in the healing power of God in some of the patients. However, other patients indicated that they doubted the diagnosis, and made the attempt to cross-check the correctness of the diagnosis:

...I was shocked and doubted the results at that time, so I tried to find out if it was not a mistake from the laboratory; I was very confused and we talked for about 15 minutes and he (the doctor) said there were a lot of people waiting outside... (Female patient, individual interview)

Notwithstanding the fact that at the time of the interviews, all the patients were receiving treatment for TB, some of them said they did not know what they were being treated for. They indicated that the doctor(s) conveyed the diagnosis to close relatives or friends so they were not aware of what the diagnosis was. Others also denied that they had TB and insisted they were receiving treatment for a chest infection but not TB:

...as I was saying, I was not told that it was TB. They said I had infection in my chest which has to be treated for two months; so that was what I told my people when I got home and that is what I tell those who ask me... (Male patient, individual interview)

6.5.4 Living with TB: an isolating disease

6.5.4.1 Isolation within the family

Those patients who managed to get to the hospital and are put on treatment had to endure a lot of emotional problems and difficulties because of the stigma attached to the disease in society. The majority of patients mentioned various forms of negative attitudes and behaviours of close and household contacts. Such attitudes usually began immediately the diagnosis became known to others. Some said they were divorced and their children taken away by their partners, whilst others said they were not allowed to send any child in the household on an errand:

...there was a boy in my house that I used to send on errands; he watches television in my room, drinks my water and does everything at my place. His mother called him and told him that he should stop coming to my place and that he should not to go when I send him because I am coughing... (Male patient, individual interview)

Most of the patients revealed that close family members usually avoided sharing household items with them. They indicated that they had to eat alone, using separate plates and bowls. Some also pointed out that they were not permitted to give their left-over food to anybody, especially children, since such an act would be interpreted as intention to infect

others. In extreme cases, items used by the patients were separated from the households', resulting in the isolation of the patient within the family:

...when I had the disease, I went to Kumasi to inform my mother but she wasn't in the house when I got there, so I went to sleep at my brother's place. The next day, when I got up and was going to take my bath, he gave me a separate sponge and towel and had removed that of his children from the bathroom... (Female patient, individual interview)

Some of the patients did mention that their close contacts and friends were very supportive. However, the trigger for such supportive attitude was the improvement in symptoms of the disease, particularly, weight gain that accompanied TB treatment:

....I was staying with my friend in a room we rented together and he ran away from me. All my friends shunned my company because of the disease; I lost a lot of weight. It was when I started treatment and began to gain some weight that they started coming back... (Male patient, focus group)

6.5.4.2 Isolation within the community

Negative attitudes toward those with TB at the societal level were also reported. The patients indicated that it was uncommon to have others sit near them or even shake their hands at public gatherings, such as, at funerals and in church. When they pass by any member of the community, they turn to look at them and laugh. They pointed out that when interacting

with members of the community, they either move away to stand at a distance or turn their heads in the opposite direction, probably to avoid being infected:

...I remember when I was diagnosed, I mentioned it to my church elders and they also informed the church members. From that day, I noticed that anytime I go to church and get closer to any of the church members, they would cover their mouth and nose, so I decided to stay away... (Male patient, focus group)

6.5.4.3 Personal isolation and self-stigmatisation

Most of the patients mentioned that the negative attitudes of others affected the way they interacted with both family and community members. Patients living with relatives said they ensured that they had very limited interaction with the family members. They had to isolate themselves, separate their eating bowls and cups from the households', sleep outside, or stay somewhere (after the daily medication) till evening before going home. Socially, some of them had to limit their interaction with friends and other relatives and lived secluded lives:

...as I said, I had no friends; I always stayed in my room as an 'American' (living on his own and avoiding interaction with other). I live in such a way that I do not disturb others and others too will not disturb me... (Male patient, individual interview)

Because of the negative societal attitudes, most of the patients indicated keeping the diagnosis secret. When it became necessary to inform others,

they did so to very close contacts and family members so as to escape being shunned by others. Some also mentioned cautioning family members not to tell others about the diagnosis:

...we gossip a lot in Ghana; any one who gets to know that you have this disease will not even greet you. So it is not good to tell others that you are suffering from this disease; no. You also need to warn your wife that if others get to know that you have this disease, all of you will be despised, so she should not let any body know of it. Because when you take your bucket to the tap to fetch water, if you are not careful, they will throw it away... (Male patient, focus group)

The disease also affected the way the patients related with others, especially during interactions with members of the community. When it became unavoidable for them to interact with others, most of the patients said they took measures to avoid infecting them:

...I ensure that I will not infect others by sitting in the direction of the wind or cover my mouth with a handkerchief when talking or coughing; I also have a container for my sputum... (Female patient, focus group)

6.5.5 Economic burden

Some of the effects of TB described by the patients were related to financial difficulties they faced. Female TB patients in particular indicated that they had to stop selling, especially food items, when they developed the disease. They pointed out that although they did so to enable them to

concentrate on treatment, if they had decided to continue selling and taking TB treatment at the same time, when the community members get to know they have TB, no one would come to buy from them:

...I was selling with my aunt in the market when I developed the disease. Few days after I started the treatment, she told me that if others got to know that I go to CDU (Communicable Diseases Unit) everyday, they would not buy her food again. So she asked me to stop coming to help with the selling... (Female patient, individual interview)

Some said that they lost job opportunities because they were weak, whilst those working had their jobs terminated or were asked to minimise the hours they work. The others pointed out that because of the long duration of treatment, they had to stop working, and in the end, had lost all their trading capital and had to sell their personal belongings to raise money for the treatment:

...I was a trader and was travelling around the country selling but because of the sickness, my business has collapsed. I also had a sound system I used to entertain myself with in the market but I had to sell it because of the sickness (female patient, focus group).

6.6 Summary and conclusion

The findings have shown that the main reason why TB is stigmatised is the fear of infection. However, elements of fear were identified in all the other causes of TB stigma. Within the community setting, TB stigma operates

through the community members, families/friends of the TB patients and opinion/community leaders and usually manifests as participatory restrictions, socio-physical distance, and rules and codes for unavoidable interactions. In the healthcare system, TB stigma operates through health personnel and health managers and may manifest in three forms: administrative procedures and policies; attitudes and behaviours towards TB patients; and attitudes towards TB work. The fear of stigmatisation made the patients ignore very obvious signs and symptoms of TB and attribute it to other non-stigmatising conditions. The majority of the patients hid the diagnosis from others and led secluded lives. In the following chapter, the theory of stigma will be used to explain the identified causes of TB stigma as well as how it manifests within the community setting and healthcare system.

Chapter 7 : Discussion

7.1 Introduction

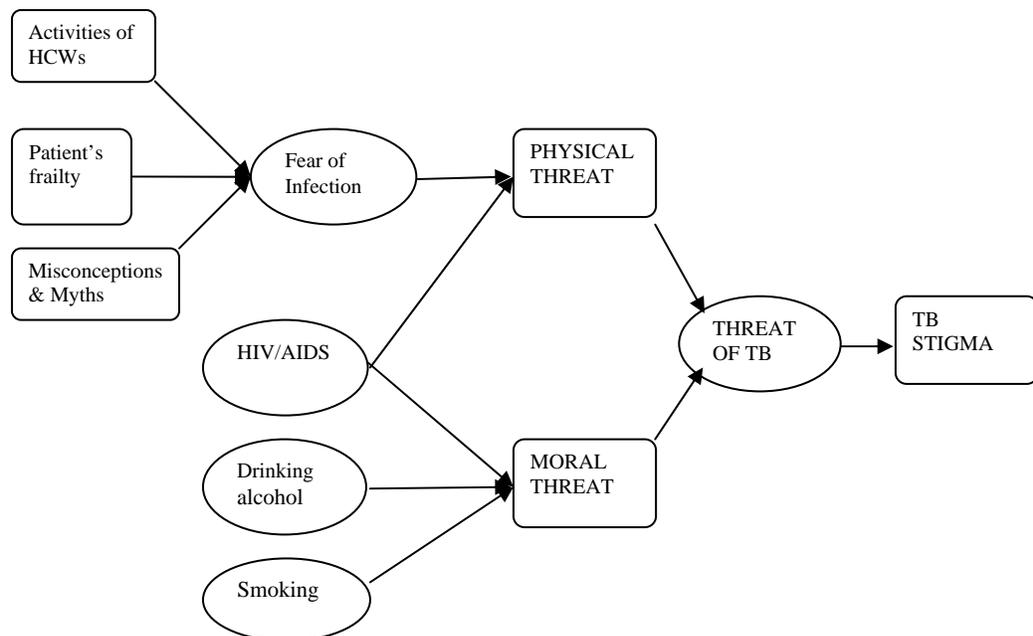
The core feature of stigma is the possession of attribute(s) that convey a devalued social identity, which is widely shared and well known among members of the culture, and becomes a basis for excluding or avoiding such person(s) (Goffman, 1963, Jones et al., 1984, Crocker et al., 1998, Dovidio et al., 2000, Link and Phelan, 2001). As Ervin Goffman argues, “when an individual who might have been received easily in ordinary social intercourse possesses a trait that can draw the attention of others and turn those he meets away from him ... such an individual possesses stigma, an undesired differentness from what we had anticipated” (Goffman, 1963, p.15). To members of this Ghanaian society, TB patients were seen to possess attribute(s) that threaten the survival of the society.

7.2 A conceptual framework of TB stigma

Based on the types and dimensions of stigma described in Chapter 3, it is apparent that TB arouses much stigmatising response from people because the patients possess attributes that pose physical and moral threats to this Ghanaian society. The evidence here has shown that the infectious nature of the disease makes it a physical health threat to others. This threat is heightened and/or endorsed by activities and practices of health professionals. The health threat the disease poses is also highlighted by the visible wasting seen among the patients and fuelled by

the misconceptions and myths surrounding the cause and spread of the disease. The moral threat is due to societal beliefs that TB is acquired by engaging in socially unacceptable lifestyles, such as, smoking and drinking alcohol. Both the physical and moral threats are further amplified by the association between TB and HIV/AIDS. A conceptual framework of TB stigma developed from the data and used to organise the discussion is presented in Figure 2.

Figure 2: A conceptual framework of TB stigma



7.3 Threat as a basis of stigma

Threat as a basis of stigmatisation has been documented in the stigma literature. As mentioned in Chapter 3, Jones and his colleagues recognised the importance of threat, which they term as “peril”, that is, the extent to which the stigmatising attribute poses a threat to others, as an important determinant of stigma (Jones et al., 1984). They pointed out that the threat ascribed to stigmatising attribute(s) is heightened in infectious diseases because the fear of contagion disrupts social groups (Jones et al., 1984). Stangor and Crandall (2000) also pointed out that the recognition of a potential threat and devising means to avoid it is a recognised basic survival strategy of all organisms, including human beings. They posit that “stigma develops out of an initial, universally held motivation to avoid danger” (Stangor and Crandall, 2000 p. 62). They emphasised that a characteristic becomes stigmatising when it is perceived, either at individual or social level, to pose a threat to the survival of the individual or the culture (Stangor and Crandall, 2000).

The view that threatening attributes play a fundamental role in the development of stigma is also supported by scholars who adopt the evolutionary perspective of stigma, which argues that there is commonality across culture in what attributes are stigmatised. Such writers point out that every social interaction poses a potential fitness cost to the individuals involved. They indicate that people are naturally equipped with the ability to identify those that may pose a danger to them. Once a threat is detected,

usually based on attributes of the individual, the result is stigma-based exclusion of such persons from the interactions (Kurzban and Leary, 2001, Park et al., 2003). Members in this Ghanaian society recognised that TB patients are a threat to society so they used stigmatisation to exclude the patients from their midst.

7.4 Tuberculosis as a physical threat

In this section, the attributes of TB that made it a physical threat and the factors that enhance the threat are examined.

7.4.1 Fear of infection

As evident from the findings, both health workers and community members demonstrated a strong desire to avoid TB patients because they are aware that association with them could result in infection. They described TB as a highly infectious disease and said that it could be transmitted through casual contacts, including touching items used by the patients. Because of the intense fear of infection, the majority of them stated that once they become aware that an individual has TB, they will not get close to interact with the person. Even social contacts and interactions such as eating from a common bowl, playing draughts games and meeting at funeral grounds are avoided.

Other authors have also observed fear of infection as a reason underlying stigmatisation of those suffering from TB (Bennstam et al., 2004, Jaramillo,

1999, Liefoghe et al., 1995, Liefoghe et al., 1997, Macq et al., 2005, Bond and Nyblade, 2006, Baral et al., 2007). Indeed, in a Congolese community, TB killed many members, disturbing the society to such an intolerable degree that its members defended themselves by keeping the patients at a distance and judging them as not being normal (Bennstam et al., 2004). Similarly, in the minds of people in this urban district in Ghana, TB is a 'death sentence' so everything possible must be done to avoid contact with those with the disease leading to stigmatising attitudes and behaviours towards them.

7.4.2 Activities and attitudes of health professional

The fear of TB is often heightened by TB control strategies used by public health authorities, such as, putting TB patients in isolation wards, sometimes on different compounds. The evidence has also shown that when health professionals wear a mask and gloves while attending to patients already on treatment it signifies fear of infection. Indeed, most of the health workers said that they were afraid of the patients, and therefore spent less time interacting with them. These practices and behaviours, unfortunately, send out messages to the community that TB is somehow different, resulting in a negative image about the disease in society. Such exclusionary practices can lead to stigmatisation of the disease and those who suffer from it (Macq et al., 2005, Westaway and Wolmarans, 1994, Liefoghe et al., 1997). Many people in the community hold this view and

said that they wanted those with TB to be treated away from the community.

The inappropriate health education messages by some health professionals also contribute to the stigmatisation of TB patients in society. As have been reported in other studies (Khan et al., 2000, Macq et al., 2005), health workers in this Ghanaian society advised the patients to use separate plates and cups when eating. In most African societies, sharing household activities, such as, cooking and eating from a common bowl is the norm. Because health professionals are supposed to have a better understanding of diseases and advised against such practices, it was accepted by the community members. Consequently, they avoided eating with the patients and separated items the patients used from that of the household. The prohibition of such cultural norms and practices because of a disease can result in further isolation of the patients in society. This may have devastating consequences which can worsen the illness experience of those affected by the disease in society.

Furthermore, although not practiced in recent times, the community members pointed out that, in the past, when people died from TB, health workers did not allow family members to take the dead body home for the due burial ceremony. In Ghanaian society, burial rites are used by members of the community, who knew the deceased person, to pay their last respects. The denial of such a socially important custom to any

member of the community because of the disease he/she died from is indeed shameful. Thus, the historical practices coupled with the continuing fear-based reactions of health professionals towards those with TB depict stigmatising behaviours.

The importance of a label assigned to any identifiable entity becomes particularly significant if it is applied by persons who hold positions of authority (Volinn, 1983). As pointed out by Goffman, by virtue of the supposed knowledge health professionals have about diseases, they are considered the 'wise' (Goffman, 1963). Since stigma is dependent on social, economic, and political power to be effective, (Link and Phelan, 2001) when health workers are seen to be treating TB with dread, it enhances the fear of the disease, and arguably re-enforces the stigma attached to the disease in society (Liefoghe et al., 1995, Macq et al., 2005). It also reinforces similar stigmatising attitudes and behaviours of community members towards those suffering from the disease, as is evidenced in the statements of the community members. Thus, the exaggerated barrier nursing practiced by health professionals portrays fear of infection and serves as an endorsement of similar attitudes and practices by community members.

7.4.3 Aesthetic features

As mentioned in Chapter 3, one important feature of stigmatising attribute that has profound effect during interactions between stigmatised and non-

stigmatised individuals is the disruptiveness or visibility of the attribute. The visible physical frailty, to use Goffman's term, 'abominations of the body'(Goffman, 1963) seen among TB patients, often make them look ugly and undesirable. During social interactions, such features draw the attention of others and also reveal the extent to which the disease poses a threat to the survival of others (Katz, 1979). Indeed, the most dreaded and stigmatising illnesses are those that are associated with dehumanising and disfiguring attributes (Sontag, 2001).

As indicated by most of the participants, they had seen family members and close friends die from TB. For some, more than two people from the same family had died from the disease. As a result, when they see the physical wasting among the TB patients, they are reminded of pain, tragedy and death as well as their own vulnerability to sickness (Dovidio et al., 2000, Jones et al., 1984). Since stigmatisation shields the stigmatiser from the anxiety that awareness of pain and death arouses (Rosenblatt et al., 1989, Jones et al., 1984), people avoided interactions with TB patients. By stigmatising the patients and attributing other negative features to them, the non-stigmatised individuals feel protected and also affirm their belief in a just world in which bad things befall only bad people. Consequently, employers have been reported to have sacked employees after the diagnosis of TB and wives/husbands refused to attend to their partners because they have TB.

Furthermore, the visible physical wasting of the patients is also seen as a threat to gene transmission and therefore survival of others. More so, because such individuals are sick and weak, and can not work effectively, they tend to use the group resources without equally contributing to the communal stock. The exclusion of the TB patients through stigmatisation ensures that members of the society protect themselves from the disease as well as the group resources. Thus, through stigmatising attitudes and behaviours that often result in exclusion of the patients from society, they are able to manage the anxiety such interactions bring up and also ensure survival of the members of the society.

7.4.4 Misconceptions and myths

When the cause of a disease is not well understood and it is treated as mystery, it tends to elicit fear from others (Sontag, 2001). Indeed, societal knowledge, understanding and beliefs about TB have been shown to be a cause of TB stigma (Bennstam et al., 2004, Rajeswari et al., 2005). As evidenced from the data, both health professionals and community members showed inadequate knowledge of TB, particularly, the cause of the disease and how it spreads. They also hold many beliefs on how those who suffered from the disease in the past were treated.

Furthermore, the belief that TB is spread when one steps with bare feet on the sputum or shares eating plates and cups with the patient can lead to shunning such individuals to avoid contact with their sputum.

Consequently, the community members stated that they expected the TB patients to follow certain 'codes of conduct'. Most of them said that TB patients should not mingle with others, should cover the mouth when coughing, and put the sputum into a container with a cover. When any of these 'rules' are broken, TB patients were perceived as having the intention to infect others and this worsens the already tense relationship existing between the patients and the community members.

The misconceptions and myths about the disease are often aggravated by the incorrect health education messages from health workers, which most often do not explain to the community members how TB is not spread. When there is uncertainty about how a disease is transmitted, the multiple interpretations of the cause and spread that ensue have the propensity to fuel stigmatisation of individuals suffering from the disease (Ogden and Nyblade, 2005).

7.5 Is fear of infection justified?

It is imperative to point out that there is a real risk of infection with TB when one spends prolonged periods with patients, especially, the smear positive ones. The risk of infection is especially documented among health workers in developed countries (Menzies et al., 1998, Meredith et al., 1996, Kilinc et al., 2002, Schwartzman et al., 1996, Seidler et al., 2005, Curran and Ahmed, 2000). Although the problem is poorly characterised in the developing world, the available literature indicates that health professionals

in resource-poor countries are also at a higher risk of acquiring TB in the course of their work (Harries et al., 1999b, Do et al., 1999, Alonso-Echanove et al., 2001, Harries et al., 2002, Pennelly and Iseman, 1999, Kayanja et al., 2005, Naidoo and Jinabhai, 2006). In Malawi, for example, it was reported that, compared to the general population, the relative risk of developing TB among health workers was 11.9 (Harries et al., 1999b). Furthermore, the advent of HIV/AIDS in sub-Saharan Africa has made the problem of nosocomial transmission of TB to health workers very crucial, since this region has the highest incidence of HIV infection, a known factor responsible for the increased number of TB cases in the region (Fennelly, 1998, Harries et al., 2005, Harries et al., 1997).

Close contacts of TB patients, particularly, smear positive ones, are also at a higher risk of infection with TB, as well as the development of clinical disease. The rates of TB infection and clinical disease among close contacts have been found to vary between 37% and 51%, and 2% and 7% respectively (Dhingra et al., 2004, Vidal et al., 1997, Teixeira et al., 2001, Morrison et al., 2008, Jackson-Sillah et al., 2007, Wang and Lin, 2000, Guwatudde et al., 2003, Kumar et al., 1984). Moreover, in TB endemic communities, a substantial transmission of infection takes place within the community, usually during social interactions, such as, drinking together (Classen et al., 1999, Lockman et al., 2001, Verver et al., 2004). Furthermore, compared to adults and HIV-negative individuals, children less than five years and HIV-infected individuals are at considerably

increased risk of developing TB when exposed to a source of the disease (Verver et al., 2004, Guwatudde et al., 2003).

Nevertheless, it is important to make a distinction between legitimate precautions to prevent the spread of TB to others and stigmatising attitudes and behaviours. Such an exercise needs to consider the subtle balance between public health risks and restrictive or exclusionary policies of TB patients based on convincing clinical and epidemiological data (Weiss and Ramakrishna, 2001). Indeed, there is sufficient proof that the spread of TB to family contacts usually occurs before the diagnosis is made (Kamat et al., 1966, Ramakrishnan et al., 1961, Andrews et al., 1960). Furthermore, with effective treatment, TB patients are no longer infectious approximately two weeks after initiation of treatment (WHO, 2003, Harries et al., 1997).

When people initially perceive that their livelihood is threatened, they exaggerate the perceptions and share them with each other until there is a collective agreement that they are threatened (Stangor and Crandall, 2000). Similarly, the evidence presented here demonstrates that this genuine fear of infection is often exaggerated. Some health professionals were reported to shout at patients already receiving treatment to cover their mouth when coughing and others stand at a distance when talking to TB patients. Family and community members avoided contact with the patients, with some actually presenting an aggressive stance against the

continuing presence of TB patients in the community. That the fear-based reactions and practices may persist even after completion of treatment, points to stigmatisation of the disease, rather than safety measures to avoid infection.

7.6 Tuberculosis as a moral threat

In this section, the attributes of TB that made it a moral threat to the society and factors that enhance this threat are discussed.

7.6.1 Deviant behaviours

Stigma has always had a moral dimension, as apparent in the meaning of the word 'stigma', which according to Goffman, is to "expose something unusual and bad about the moral status of the bearer" (Goffman, 1963 p.11). Consequently, individuals who are perceived to be a threat to societal values will be stigmatised (Stangor and Crandall, 2000). The belief in this society that adopting certain 'socially unacceptable lifestyles', such as smoking of cigarette and cannabis, drinking alcohol and having multiple sexual partners could cause TB has been reported in other settings (Macq et al., 2005, Long et al., 1999, Sengupta et al., 2006, Ngamvithayapong et al., 2000, Edginton et al., 2002). Such moral positions can make people think that individuals who develop TB have themselves to blame because they undermined social morals. This can lead to societal attitude of condemnation towards those with the disease. By using moral ideologies, the TB patient is viewed as breaking societal norms and therefore fairly

deserving of stigmatisation. Thus, in the 'mind' of the non-stigmatised individuals, the development of the disease is a 'result of' or 'punishment for' engaging in such 'social vices' and this ultimately takes away any feeling of sympathy for the patients.

7.6.2 Mistrust and judgement

The perception of a discrediting attribute in an individual often make others think that the bearer possesses other negative traits as well (Katz, 1979). During interaction between TB patients and members of the society, stereotypic conceptions of TB patients as "wicked", with intention to infect others, was activated, and this affected their behaviour towards the patients. The data showed that both health workers and community members do not trust TB patients and are very suspicious of them. They stated that certain behaviours shown by the patients, such as, keeping the diagnosis secret and giving their left-over food to people, especially children are deliberate attempts to infect others. There were also various unsubstantiated stories about successful infection of health workers by patients already on treatment, using very 'wicked' means, such as, spitting in food items eaten by the workers and coughing onto telephone receivers at the hospitals. The mistrust of TB patients by others, particularly, health workers has been reported elsewhere (Macq et al., 2005). By ascribing to the patients other negative attributes, it helped the non-stigmatised individuals to assign blame and hold the patients responsible for their

predicament. By shifting the blame to the patients they tend to have less sympathy for them.

7.7 TB as physical and moral threats

7.7.1 Association between TB and HIV/AIDS

Since its inception, infection with HIV/AIDS has been associated with already stigmatised groups - socially unaccepted forms of sexual preference and injection drug use (Crandall and Coleman, 1992). In most sub-Saharan African society, HIV/AIDS is associated with those who are sexually promiscuous, a behaviour often considered to be inconsistent with the norms of the society (Ogden and Nyblade, 2005). As such, infection with HIV/AIDS is often viewed as breaking moral rules, a central contributing factor to HIV-related stigma (Deborah, 1999, Seidel, 1993, Kopelman, 2002, Somma et al., 2008). Furthermore, although TB stigma existed long before the advent of HIV/AIDS, the link between the two diseases has changed the perception of members of communities in high HIV prevalence settings about TB, since the visible symptoms of TB make them think that TB patients are also infected with HIV/AIDS, increasing the existing TB stigma (Godfrey-Faussett and Ayles, 2003, Bond and Nyblade, 2006, Ngamvithayapong et al., 2000).

The evidence here shows that the association between the two diseases was apparent in the community discussions, as most of the community members mentioned that those who have TB are infected with HIV/AIDS

as well. Such a link was also a source of anguish to the patients, some of whom said that when they were informed of the diagnosis, they prayed that it does not become HIV/AIDS.

As mentioned in the previous section, members in this Ghanaian community believe that those who develop TB in society do so because their lifestyles undermine certain moral values. Thus, the association between TB and HIV/AIDS has added an additional dimension to the already existing TB stigma (Somma et al., 2008, Bond and Nyblade, 2006). Consequently, individuals affected by TB in the community are seen as having two diseases the community members are afraid of contracting and at the same time hold the patients responsible for acquiring. The result is increased stigmatisation of those affected with TB in society.

7.8 Consequences of TB stigma

7.8.1 Delayed health seeking

Since stigma is socially constructed, the attributes that are stigmatising are well known and shared in a culture (Goffman, 1963, Jones et al., 1984, Major and O'Brien, 2005, Dovidio et al., 2000, Link and Phelan, 2001, Crocker et al., 1998). This means that the community members may be aware of their stigmatising attitudes and behaviours towards TB patients. Moreover, when members of a society become aware that existing stereotypes about certain attributes can be applied to them, such a consciousness is often threatening (Stangor and Crandall, 2000, Steele

and Aronson, 1995). For example, in an Ecuadorian community, when patients with symptoms suggestive of TB were asked to undergo laboratory investigation for TB, just the thought of undergoing such a test was sufficient to evoke feelings of depression, loneliness and stigmatisation among them (Armijos et al., 2008). It is therefore possible that for fear of being stigmatised, community members with symptoms suggestive of TB may fail to report to the hospital.

Also, most of the patients mentioned that they knew other close contacts, friends, and community members who had had TB in the past, and might have been stigmatised. Consequently, when they develop symptoms suggestive of TB, this was disturbing enough to warrant concealment or denial. Indeed, it has been documented that because of the stigma attached to TB, patients often refuse to acknowledge the signs and symptoms of the disease, and explain it as due to non-stigmatising conditions, such as, common cold or malaria, just to reduce the contempt of others (Cambanis et al., 2005, Liefoghe et al., 1997, Long et al., 1999, Eastwood and Hill, 2004, Dick et al., 1996, Liam et al., 1999, Johansson et al., 1999, Weiss and Ramakrishna, 2001, Macq et al., 2005). Similarly, the evidence presented here has demonstrated that most of the patients attributed their symptoms to other diseases, and this made them spend extended periods in the community self-medicating. It was only when such searches did not yield any result that they reported to the hospital. This

may explain the four months delay in diagnosing TB (Lawn et al., 1998) and the very low case detection rate of 38% in Ghana (NTP-Ghana, 2004).

The exclusionary practices of public health authorities can also affect health seeking behaviours of the community members. When TB patients were isolated and treated in sanatoria in the developed world, negative effects on TB treatment seeking behaviour were noticed. Among the Natives in British Columbia, for example, TB case finding and treatment were reportedly very difficult in the 1970s because people were afraid that if they developed TB, they would be sent to die, away from family and friends, in a sanatorium (Jenkins, 1977). Such historical practices and experiences were evident in the discourse of immigrants and Aboriginal communities in Canada, and still influenced their perceptions and thoughts about modern management of the disease (Gibson et al., 2005). Similarly, in this Ghanaian society, there were a lot of historic accounts of how, in the past, those who suffered from TB were sent to isolated parts of the community, sometimes in the forest, till either they died or were cured. Such historical accounts may elicit fear among the community members, and may delay help seeking behaviour.

7.8.2 Adherence to treatment

The attitudes of others, particularly health professionals, towards individuals with TB may affect adherence to TB treatment. As Goffman emphasised, before health workers ('the wise'), the stigmatised does not

need to feel ashamed, because in spite of the failings, he/she will be seen as an ordinary person (Goffman, 1963). However, the evidence here has demonstrated that health professionals often show discriminatory attitudes and behaviours towards TB patients. This may put the patients in a difficult position since the support expected from the health professionals may not be available. Such negative attitudes affected the motivation of the patients to adhere to treatment. Indeed, some of the patients indicated that they could not withstand the stigmatising attitudes and behaviours of some of the health professionals and had to move to another health institution to be able to continue with the treatment. Although no information was available on how TB patients are managed at the hospitals they moved to, a study conducted at the Effia-Nkwanta Regional hospital in the SAEM district showed that one factor that motivated patients to complete TB treatment was the encouragement they received from health professionals (Dodor and Afenyadu, 2005). Thus, when health professionals show stigmatising attitudes and behaviours towards TB patients, this can affect their motivation to adhere to the long duration of TB treatment.

Furthermore, persons with stigma learn and incorporate the stand-point of non-stigmatised individuals in society and accept the general belief of being stigmatised persons (Goffman, 1963). As documented in other studies (Khan et al., 2000, Baral et al., 2007, Macq et al., 2005, Bennstam et al., 2004, Long et al., 2001, Liefoghe et al., 1997, Atre et al., 2004, Hansel et al., 2004, Rajeswari et al., 2005, Zhang et al., 2007, Somma et

al., 2008, Armijos et al., 2008), TB patients in this Ghanaian society demonstrated the awareness of the shame associated with having TB. Most of them expressed fear of stigma when they were told of the diagnosis for the first time. Some found the diagnosis difficult to accept or rejected it, whilst others asked that the diagnosis be kept secret or hid it from others. Some of the patients mentioned that they had wanted to commit suicide when they were informed about the diagnosis.

Consequently, most of the patients isolated themselves and avoided interaction with others. Some of them used different names when they came to the hospital or did not want any one to see them coming into contact with the TB clinic (Dodor and Afenyadu, 2005). Others described living secluded lives just to avoid being stigmatised. This demonstrated their understanding of the commonly held view about TB in society, and this clearly constituted a major source of anguish to them. In other words, the patients demonstrated the shame of possessing the stigmatising attribute (felt stigma) through their reactions and responses to the disease. However, there is also sufficient evidence in the data to indicate actual experience of discrimination because of possessing the negative attribute in question-enacted stigma (Scambler, 1984).

The patients also stated that they had to rely on social support, such as, financial help, provision of food and prayers from family and friends as means of coping with the disease. Others had to borrow money to be able

to cope with the economic burden. However, the majority said that, for fear of infection, people did not get close to offer any support. The data showed that the community members continued to avoid the patients even after completion of treatment, and often failed to provide any form of social support. In most African society, the availability of social support conveys social identity and feeling of belongingness. Therefore, the absence of this may lead to a variety of stressors which may have negative consequences for the psychological health of the TB patients. Since non-adherence to treatment could be used as a strategy to relieve patients from the pain of stigmatisation (Meulemans et al., 2002), such societal attitudes and behaviours can lead to default from treatment (Ngamvithayapong et al., 2000, Dodor and Afenyadu, 2005, Long et al., 2001, Johansson et al., 1999, Jakubowiak et al., 2007).

7.8.3 Poor prognosis

Mortality from TB is a key performance indicator and is also likely to be a significant factor affecting the credibility of the TB control programme in the community. Since most of the patients indicated that they reported to the hospital very late, usually in a very bad state, the late initiation of treatment is less likely to improve the prognosis of the disease. Such delays in reporting to the hospital and the subsequent late initiation of treatment may account for the high mortality documented among TB patients in some African countries (Dodor, 2004, Barker and Millard, 1998, Olle-Goig, 1999).

The increased mortality from TB may invariably heighten the fear of the disease, and result in stigmatisation of the patients in society.

7.9 Limitations of this study

The limitations of this study are discussed under two broad areas: effects of the researchers on the research process and methodological issues.

7.9.1 Effects of the researcher on the research process

It is important to discuss the effect the researchers may have had on the research process. First, as was mentioned in Chapter 1, I was working as a medical doctor at a TB clinic during the research period. Two of the RAs were also working as nurses with the TB control programme in the SAEM district. This may have helped in gaining access to some settings. However, it was also possible that if the respondents treated the research team members primarily as 'experts' on TB, instead of researchers, they may have assumed that we had more knowledge about the issue under investigation and may have fail to explain certain issues during the interview process.

To help the participants speak their mind, the data collection sessions were started with an explanation of the purpose of the study, and the importance of their views in understanding TB stigma was emphasised. The fact that there were no right or wrong answers and that each participant was at liberty to express his or her views was emphasised. This approach helped

to assure the participants of the importance of their view in understanding the topic and this encouraged them to speak their mind.

7.9.2 Methodological issues

The recruitment of the participants was done through various 'gate keepers' within the healthcare system and in the communities. As such, no information was available on the number of people contacted and how many refused to participate in the study. It is also possible that the gate keepers invited their friends or individuals they believed had a deeper understanding of the topic. Such 'selection bias' may influence the findings. However, because TB is a common disease most individuals within the various settings may have had similar understanding of the disease and could equally speak to the issue being investigated.

As mentioned in Chapter 5, potential disadvantages of the focus group method are the possibilities of peer pressure and embarrassment which can make the participants keep quiet or fail to share their experiences (Darlington and Scott, 2002). No peer pressure or inhibition was noticed. Instead of just accepting the dominant views, the group interaction provided the opportunity for participants with dissenting views and opinions to explain their position. No unwillingness to discuss personal experience was witnessed. Rather, the informal setting provided the opportunity for the participants to speak freely and readily shared their experiences when appropriate. Moreover, the hypothetical nature of the questions also made

it non-threatening and allowed the study participants to freely talk about those they knew or heard of, usually family members and close friends, who had ever had TB.

Also, although only individuals who had never had TB were invited for the community data collection, it was noticed during the focus groups that three participants in three communities had had TB in past. They kept it secret and revealed it to the researchers at the end of the sessions. In such potentially threatening situations, the hypothetical nature of the questions had permitted them to contribute to the discussions without other participants recognising that they ever had TB.

The patients and community data were collected in the local language and later transcribed and translated verbatim into the English language for analysis. Although some researchers argue for forward-backward-forward translation, that is, English-Twi-English, so as to improve the correctness of the translation, this was not done because of logistics and funding constrains. Moreover, the linguistic differences between spoken English and Twi made it difficult to find exact translation for certain words. However, because the research team members are familiar with the culture, speak and write both English and Twi languages, it was possible to preserve the meaning of statements and words during the translation.

Furthermore, for purposes of clarity and readability, limited editing of the texts were done. These processes can introduce the possibility of losing

meaning and context of some of the data. However, because of the familiarity with the local language, issues associated with the local TB control programme, and the fact that all the interviews were recorded on audio tapes and notes taken, any discrepancies in translation were crossed-checked. This was done by listening to the tapes many times and cross-checking with the notes to ensure that the original meaning and integrity of the accounts were preserved.

The association between HIV/AIDS and TB was evident in the community and patient's discussion of TB. However, this was not clear from the health workers' data. Since the health workers are part of the community and may share the same beliefs on certain issues, their attitudes and behaviours could be rooted in the fear of getting HIV/AIDS as well. This needs clarification during future research projects.

7.10 Summary and conclusion

The findings have shown that TB is stigmatised because the disease poses physical and moral threats to society. The basis of the physical threat is the exaggeration of the contagious nature of the disease. This threat is heightened by the negative attitudes and practices of health professionals, which often endorse similar attitudes and behaviours of the community members. The aesthetic features of the patients, especially the coughing up of blood and the extreme weight loss interfere with social interactions and enhance the fear of the disease. Societal knowledge and

beliefs about the disease, especially the different interpretations of the cause(s) and spread also fuelled the threat the disease poses to others and made people adopt stigmatising attitudes and behaviours towards TB patients.

TB is also perceived as a moral threat largely because of the belief that one can develop the disease by adopting certain socially unacceptable lifestyles, such as, smoking cigarette and cannabis, drinking alcohol and using hard drugs. Such ideologies allow people to view the development of TB as a sign that moral codes have broken which demand sanctioning through stigmatisation. The increased awareness about the association between HIV/AIDS and TB has also increased the already existing stigma attached to TB. The concluding chapter examines interventions that can help reduce the stigma attached to TB.

Chapter 8 : Policy Recommendations and conclusion

8.1 Introduction

Having established in the previous chapter that TB is stigmatised because the disease poses physical and moral threats to this Ghanaian society, this concluding chapter examines interventions that could help to minimise the stigma attached to TB in society. The chapter ends by discussing alternative approaches and questions raised for future research.

8.2 Recommendations

8.2.1 Improve attitudes of health workers

Health professionals occupy respected positions in their communities so their attitudes to TB can influence the way society perceives the disease. This was apparent in the many instances where stigmatising behaviours of community members were mirrored in those of the health professionals. Thus, when attitudes of health professionals are improved this may help to reduce the stigma attached to the disease in society. The following approaches may help to improve the attitudes of healthcare workers towards those suffering from TB.

8.2.1.1 Protect health workers

The long duration of TB treatment, and the limited resources available to health workers in resource poor countries make the provision of TB

services very demanding. Moreover, the advent of HIV/AIDS has also dramatically increased the number of TB cases in sub-Saharan Africa, and led to the need to increase the number of staff caring for TB patients (Harries et al., 2005). Compared to other countries in sub-Saharan Africa, TB/HIV co-infection in Ghana is lower, reported to be 14.3% (Owusu-Dabo et al., 2006). Nonetheless, adequate provision of physical resources, tools and equipment to facilitate prompt diagnosis of TB is urgently called for, because the available evidence indicates that health professionals are at higher risk of infection when there is a delay in making a diagnosis (Harries et al., 2002, Harries et al., 1997). The NTP should ensure that algorithms on how TB suspects should be investigated are provided and posted at vantage points so as to be easily visible to all health workers. Equipments and reagents should also be provided on time and in sufficient quantities to all laboratories in the district to facilitate early diagnosis. When adequate resources are provided, it will decrease the exposure of health workers to the disease, and help to minimise their fear of infection. The resulting sense of security may help to improve their attitudes and behaviours towards the patients.

8.2.1.2 Reward and motivate health workers

As evident in the data, health workers drew attention to the 'risk' attached to working with TB patients and demanded that incentives be given to those working at TB units. Although there is no documented evidence to show that rewarding and motivating health staff involved in TB control may

help improve their attitudes towards the patients, such a recommendation may not be out of place since studies examining the effects the provision of incentives have on case finding are inconclusive. Whilst some reported that performance-based incentives have a potential to contribute to increasing TB case detection and cure rates (Beith et al., 2007), others did not find any effect (Yao et al., 2008). With support from the Global Fund for TB, the NTP has started providing an 'enablers' package to TB patients and health workers in pilot districts in the country. The package involves identification of individuals, either in the community or the healthcare system to support TB patients during treatment. Such individuals are responsible for collection of the patient's drugs from the hospital and ensuring that the drugs are taken regularly and in correct doses. The cost of transport to collect drugs for the patient is reimbursed by the TB control programme. Moreover, the patients are also provided with food supplements, such as, sugar, Milo, and milk and their transport cost to the hospital reimbursed. The TB control programme also makes available funds to healthcare workers involved in managing the disease to enable them meet regularly to review their progress and plan for the future. Although this has not yet been thoroughly evaluated, there are indications that it has drastically improved defaulter rates in those districts (NTP-Ghana, 2004).

It is also important to note that financial incentives alone may not be adequate. While most of the health workers indicated that financial reward

is essential for their work satisfaction, it is vital to consider results from other settings that show that non-financial interventions may be more effective means to improve worker motivation (Franco et al., 2004). Training and professional development, for example, are important non-financial motivation determinants, as they help to provide health professionals with the requirements of their job, and also enable them to take on more demanding duties and positions (Mathauer and Imhoff, 2006). This is particularly relevant in Ghana since the attitudes and behaviours of the health workers demonstrate inadequate knowledge of TB and its management, which often resulted in exaggeration of the risk of infection and subsequent stigmatisation of TB patients.

Regular and frequent supervision is also another form of non-financial incentive that can contribute considerably to health workers' self-efficacy, and improve motivation (Mathauer and Imhoff, 2006). As reported in this study, some of the health workers providing TB services disapprove of the low frequency and irregularity of supervision, and indicated feeling neglected by their managers. It is also clear from the data that health professionals appreciate small benefits, such as, provision of free sugar, milk and tea, particularly, to those working at TB units, as a strong motivating factor. If the health managers put TB on their list of priority diseases, and want to motivate their workers, these items could be provided from locally generated funds.

8.2.2 Integrate TB control into the healthcare system

The findings also call for complete integration of TB services into the general health care system. Separating TB services and siting TB wards and units at isolated places, sometimes far away from the general hospital may reinforce the community's fear of the disease and thus promote stigmatisation (Liefoghe et al., 1995, Macq et al., 2005). This is because when any disease is treated as unique and special, its attributes easily become conspicuous to others and may increase the tendency of the disease to be singled out for stigmatisation, more especially if it is misunderstood and has so much myth surrounding it like TB. Efforts should therefore be made to integrate TB services into the health care system so as to avoid TB being seen as different from other diseases.

Integration of TB services can be achieved by 'attaching' it to other non-stigmatised diseases. For example, in Pakistan, when reproductive health services for women was attached to other programs, it led to a reduction of the stigma attached to its use and resulted in increased uptake of the services (WHO, 2003). Similarly, existing community health programs, such as, Community Health Planning and Services (CHPS) can be utilised in TB case finding, treatment supervision and monitoring. TB services can also be integrated into other on-going community health programs in the district, for example, Roll Back Malaria and other community nutrition programs. When members of the community are encouraged to view both

diseases as the same, it has the tendency of reducing the fear of the disease and over time may result in reduction in the stigma attached to TB.

8.2.3 Information, Education & Communication campaign

The inadequate knowledge of TB demonstrated by both health workers and community members can be improved through intensification of health education on the disease. The campaign needs be three-pronged: targeted at the patients, community members and health workers.

When TB patients are educated on the disease, the derived knowledge may be of help in the course of treatment. It can help them to accept their condition, provide them with the confidence needed to stand-up to stigmatising behaviours from others and decrease self-stigmatisation (Rafferty, 2005). Education of patients would also help to improve early recognition of symptoms and subsequent reporting to the hospital for early diagnosis and initiation of treatment, which invariably would improve the prognosis of the disease.

The community campaign should be custom-made to suit the community's needs and understanding of the disease, taking into account local culture and belief systems (Rafferty, 2005). Individual members of the community with deeper understanding of local beliefs and issues should be trained to spear-head the exercise (Rafferty, 2005). When community volunteers are trained to understand what TB is, and to communicate it to the community

in their own language, this may help reduce the myth and misconceptions surrounding TB and hence reduce the stigma attached to the disease (Rafferty, 2005). It is also important to target community leaders during the health education exercises. This is because such individuals have much power within the community setting and their attitudes and behaviours towards the disease may affect the experience of stigma among the general population (Weiss and Ramakrishna, 2001).

Health workers should also be “re-educated” to update their knowledge of the disease. Such an exercise should target those working at units of the hospital where TB patients are most likely to be attended to, for example, out-patient department staff. Regular re-fresher courses, workshops and seminars should also be organised for the general health workers to help update and improve their understanding of the disease. The NTP should also ensure that information on TB services is widely circulated, not just to those working within the TB control programme. Information should be made available to staff working in all units of the hospital since such guidelines and documents serve as important guide when they are dealing with TB suspects and patients.

During the IE&C campaign, progress and successes of tuberculosis control programme should be highlighted. This has the potential of altering the perception of risk ascribed to the disease. For example, the fact that with effective drugs treatment taken in correct doses, patients are no longer

infectious a few days after starting treatment should be emphasised. Meanwhile, community discussions on TB should be encouraged since such open debate about the disease will encourage those suffering from symptoms suggestive of TB to recognise it and report to the hospital. It may also lead to reduction in the stigma attached to TB in the community, since TB patients may not be seen as deviating from any social norms that may single them out for stigmatisation.

8.2.4 Change the image of TB using the media

The media has the potential to shape ideas and perceptions about all aspects of life including views on diseases. However, the potential of the media has not been adequately tapped by the health services in Ghana probably because of viewing the media as a hindrance to public health. When health professionals fail to provide correct information on TB, this results in sensational TB stories, which often perpetuate misconceptions about the disease, exaggerate the risk of infection and promote the stigma attached to the disease (Migliori et al., 2007). Such media depiction of the disease can shape cultural meanings attached to the disease, with damaging consequences for those affected by TB in society (Lawrence et al., 2008). It is therefore important for health professionals to take advantage of TB stories published in the media and use the opportunity to clarify issues on TB so as to deepen societal understanding of the disease (Migliori et al., 2007). When the media is well informed on TB, and encouraged and equipped to 'send' out appropriate messages and

information about TB to the communities, it may generate open discussions on the disease and this may lead to improvement in the community's understanding of the disease.

Public health professionals should also be trained in communicating health statistics on TB to the media and to avoid the use of such figures in a way that may create unnecessary fear and tension among the public since this may re-enforce the existing stigma attached to TB in society.

8.2.5 Empower TB patients

Individuals with a particular stigma often seek the company of those with similar attributes among whom their stigma may be less of a bother and also to complete their socialisation (Goffman, 1963, Crandall, 2000). Such individuals, to use Goffman's term "the own", provide a supporting shoulder for each other and offer the avenue to voice out any concerns and issues that the stigmatised may have. Thus, TB patients should be encouraged to come together to form groups for self help and socialisation. For example, in Ethiopia, when TB patients were encouraged to form "TB clubs", adherence to treatment as well as attitudes and practices of community members towards the disease were reported to have improved (Demissie et al., 2003). Similarly, in Nicaragua, when TB clubs formation was implemented together with improved relationship between health workers and TB patients this resulted in considerable improvement in internalised stigma among TB patients (Macq et al., 2008). Similar strategies can be

implemented for TB patients in Ghana. Patients from the same or neighbouring communities should be encouraged to come together to form social groups since this may help provide support and avenue for socialisation.

8.3 Alternative approaches

In line with the limitations of the study pointed out in the previous chapter, had I adopted a different approach to this research, what would I have done differently? The first thing I would have done differently would be to focus more on depth rather than breadth! From hindsight, I realised that I collected too much data and I may have sacrificed depth for breadth. Probing for clearer and deeper responses from fewer participants would have been a wiser option. For example, further probing to understand whether the stigma attached to TB “ends” when the patient is cured and what the community members would do if the TB patient did not meet the behavioural expectations would have been helpful and provided a deeper understanding of the dynamics of interactions between TB patients and the community members.

Also, I would have included family members and friends of TB patients among the study participants. These individuals are very close to the patients, and their attitudes and behaviours may affect the illness experience. Moreover, because stigma is “contagious” and spreads to social contacts, their view may help to build a holistic picture of TB stigma,

especially, the dynamics of how TB stigma spreads from the stigmatised individual to affect other social contacts and the way such secondary targets respond to it. Nonetheless, there were many instances during the interviews when some participants talked freely about relatives and close friends who had TB and how they related to them during the period of the illness. Such discussions provided anecdotal evidence, although limited, that may help to put in place interventions to mobilise their support for the patients.

Community leaders are also very influential in the community and their attitudes to TB may affect the community's perception of the disease, and the experience of TB stigma by the patients. Such persons can also be mobilised to spear-head any community interventions that may be put in place to reduce TB stigma in society. Their inclusion in the study would have helped to elucidate their influence on the attitudes and behaviours of members in society.

Furthermore, because one of the aims of the study was to understand how stigma affect treatment adherence, inclusion of patients who had defaulted from treatment would have helped to clarify the mechanisms through which TB stigma operate to affect adherence to the treatment regimen.

Finally, observation could have been used as an additional method to enhance the comprehensiveness of the findings. For example, observing TB patients while going through the healthcare system could have

provided additional information on how healthcare workers interact with the patients as well as their attitudes and behaviours towards them. The findings could then be used to enhance results from the other data collection methods.

8.4 Questions raised and future works

A number of possible future works have been identified to build on or extend this research.

8.4.1 Quantification of TB stigma

A quantitative evaluation of TB stigma is worth undertaking. Such a project could use the qualitative findings in this study to develop scales and instruments for quantitative assessment of TB stigma. This may help to identify issues that are more representative and therefore more relevant so that appropriate interventions can be implemented to reduce TB stigma. For example, although it has been generally accepted that TB stigma can affect health seeking behaviour and adherence to treatment, the dynamics are not well understood. A quantitative research may help to elucidate and delineate the relevant parameters that may need specific interventions to address them.

8.4.2 Perceptions about postings to TB unit

There was a strong perception among health workers that postings of workers to TB units are meant to punish the individual! Although I have

worked for more than five years as the TB referral clinician and control coordinator in the district, and have personally been told by a former health manager that a staff was posted there because of misbehaviour, such strong perceptions need to be investigated further. This is because such feelings and perceptions can breed resentment for TB work and make staff refuse postings to the TB units. Furthermore, such perceptions can be demotivating for those who accept posting to TB units, since they may think that they were posted there because they did something wrong or are disliked by the health managers.

8.4.3 Development of guidelines for the prevention of TB transmission to health workers

This study has shown that the main reason healthcare workers stigmatise TB patients is the fear of getting infected. This fear is often exaggerated in many circumstances, and has exposed deficiencies in their knowledge of the disease. It also highlights unavailability of uniform guidelines on how healthcare workers can handle individuals suffering from infectious diseases. There is therefore the need to develop a national guideline to prevent the transmission of TB to health workers. Such an exercise will help to alleviate the fear of TB among health workers. Moreover, when there is a uniform guideline for health workers to rely on when dealing with infectious diseases such as TB, it may help improve their attitude towards those affected in society.

8.4.4 Perspectives of secondary targets of stigma

Apart from health staff working in the TB control programme, secondary targets of TB stigma, such as, family members and friends of the patients, were not separated from the other community participants. As mentioned in the limitations of the study, the role of such secondary targets of stigma needed to be examined since their attitudes and behaviours can influence the experience of stigma. When their role is understood, appropriate interventions can be put in place so as to mobilise their support for TB patients.

8.4.5 Gender differences in the experience of stigma

The social participatory restrictions imposed on those with TB, such as, prohibition of sharing eating plates and bowls, the disqualification of TB patients as marriage partners and the prohibition of TB patients from selling, may lead to disruptions of the life of the individuals affected by the disease, particularly women. This is because in Ghanaian societies, women are generally responsible for the upkeep of the family. They attend to domestic chores, cook and take care of the children and spouses. Consequently, the exclusion of TB patients from social functions may be more pronounced in women than men. This study did not examine the differences in the experience of stigma among males and females, but it has been reported in other settings that women experience TB stigma more than men (Meulemans et al., 2002, Long et al., 2001,

Ngamvithayapong et al., 2000, Eastwood and Hill, 2004, Hoa et al., 2004, Johansson and Winkvist, 2002, Somma et al., 2008). Although the role that stigma plays in the differences between the notification of TB among women and men has been inconsistent (Hudelson, 1996, Balasubramanian et al., 2004, Long et al., 2001, Bennstam et al., 2004, Johansson and Winkvist, 2002), could this be a contributing factor to the fewer cases of TB reported in women in Ghana?

8.5 Concluding remarks

This study used individual interview and focus group with TB patients, healthcare workers and community members to explore the causes, manifestations and consequences of the stigma attached to TB in an urban district in Ghana. The findings showed that TB poses physical and moral threats to members in this Ghanaian society. This stereotypic conception of the disease as a threat conveys a devalued social identity about the patients, and underlies the beliefs, thoughts, and actions of the whole society when interacting with the patients. It also links and fuels societal attitudes and behaviours and also explains how the whole society responds to TB patients. The threat of TB makes the patients to be devalued, rejected, blamed and excluded from social participation (Weiss et al., 2006).

The fear of stigmatisation makes individuals with very obvious signs and symptoms to attribute it to non-stigmatised diseases or hide the diagnosis

from others. Those put on treatment may end up defaulting from treatment because of lack of support. For an infectious disease such as TB, prompt diagnosis and initiation of treatment is the best way to minimise the spread of the disease (WHO, 2003). The TB control programme should therefore put in place interventions to reduce the stigma attached to TB in society.

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APPENDICES

Appendix 1

GUIDE FOR COMMUNITY INTERVIEWS

Q: Do you know of any one who ever suffered from TB in this community?

What happened to him?

Q: Do you think TB is a shameful disease and why?

Q: What group of people normally get TB in this community?

Q: What would you say to a TB patient marrying you or your family member?

Q: What would you say to the consideration or selection of a TB patient to represent this community at any function?

Q: How do you expect TB patient to behave in the community?

Q: What would you do if you have TB?

Q: What kinds of problems do you think TB patients pose to the society?

Q: How do you feel around TB patient? E.g. sitting closely in church or car?

Q: What is your concern about a TB patient selling in the community?

Q: Do you think TB patients should be allowed to stay at home and report to hospital daily for treatment or be confined till they recover?

Q: Should TB patients maintain their place of work i.e. to continue going to work till they are cured?

GUIDE FOR PATIENTS

Q: I want you to tell me all that you did since your sickness started till you ended up at the hospital.

Q: What difficulties or problems did you encounter when you were seeking help?

Q: Who posed problems to you before and after starting treatment?

Q: Do you think TB is a shameful disease and why?

Q: How did you feel or what went through your mind when you were told you have TB?

Q: Were you able to tell others that you have TB e.g. family members, friends, employers and community members?

Q: Who was the first person you informed or talked to and what was the person's reaction and comments?

Q: What will make you agree to willingly tell others that you have TB?

Q: How do people relate with you as a TB patient and how does it affect you?

Q: How has the fact that you have TB affected the way you relate with people?

Q: Can you tell me of any episode of discrimination against you or loss of benefits/privileges because you have TB?

Q: Can you tell me how you were able to cope/manage as a TB patient?

GUIDE FOR HEALTH STAFF GROUP

Q: What do you think the administration (nursing/medical) base their decision on when deciding who to post to work at TB units?

Q: What do you think is the reason(s) for health staff's refusal to work at TB units?

Q: What would you do if you are posted to/asked to work at a TB unit and what will make you willingly accept posting there?

Q: What would be your reaction if you are asked to be trained in the management of TB i.e. being a TB nurse/chest physician?

Q: Should health staff working at TB units be given special incentives? Why?

Q: Do you think TB is a shameful disease and why?

Q: What would you say to a TB patient marrying you or any member of your family?

Q: Should TB patients, including health staff, who develop TB, be allowed to go work whilst on treatment?

Q: Should a patient diagnosed as having TB openly inform others; wife/husband/children etc about the diagnosis?

Q: Can you recollect any episode at your hospital that you feel was mal-treatment of TB patients or unpleasant behaviour from a TB patient?

Q: What would you do if you have TB? Will you willingly tell your colleagues if you have TB?

Q: What would you say to the observation that TB patients mix up with other patients at the OPD/wards when they visit the hospital?

Q: How do you feel around TB patients, e.g. taking his blood sample, explaining some issues, administering drugs?

Q: Have you nursed/seen a suspected TB patient before? What effect did the diagnosis of TB have on your further interaction with the patient?

Q: What kinds of risk do you think TB patients pose to the society?

Q: What is your concern about TB patients selling in the community?

Q: What effects can the way we relate with TB patients have on them?

Appendix 2

Copies of invitation letter

In case of reply the number
And date should be quoted



EFFIA-NKWANTA REG. HOSP.
P. O. BOX 229
SEKONDI
25TH JANUARY 2005

My Ref. No ENRH/PF/001

Your Ref. No.....

Dear Colleague,

INVITATION TO PARTICIPATE IN FOCUS GROUP DISCUSSION

A research team from the Communicable Diseases Unit of Effia-Nkwanta Regional Hospital is organizing a focus group discussion for health workers as part of efforts to understand how stigmatization and risk perception of TB affect treatment seeking and compliance. You have been identified to participate in the discussions.

The details of the meeting are as follows:

Venue: Conference Room- ENRH
Time: 12 pm prompt
Date: Monday, 31st January 2005

Thanks for your participation in advance.

NB: Item 13 will be provided* .

Yours truly,

DR. EMMANUEL ATSU DODOR
(Principal Investigator)

* Refreshment will be provided

In case of reply the number
And date should be quoted



EFFIA-NKWANTA REG. HOSP.
P. O. BOX 229
SEKONDI
24TH FEBRUARY 2005

My Ref. No ENRH/PF/001

Your Ref. No.....

Dear,

INVITATION TO PARTICIPATE IN FOCUS GROUP DISCUSSION

A research team from the Communicable Diseases Unit of Effia-Nkwanta Regional Hospital is organizing a focus group discussion for selected members of your community as part of efforts to understand how stigmatization and risk perception of TB affect treatment seeking and compliance. You have been identified to participate in the discussions.

The details of the meeting are as follows:

Venue: Community centre
Time: 12 pm prompt
Date: Wednesday, 2nd March 2005

Thanks for your participation in advance.

NB: Item 13 will be provided* .

Yours truly,

DR. EMMANUEL ATSU DODOR
(Principal Investigator)

* Refreshment will be provided