UNIVERSITY OF SOUTHERN DENMARK

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DEDICATION

I dedicate this thesis to my mother, my father, my wife and my son.

Without their patience, understanding,

support, and most of all love,

the completion of this work

would not have been possible.

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ABSTRACT

Background: In Sudan an estimated annual risk of tuberculosis (TB) infection is 1.8%, which gives an incidence of 90/100,000 smear positive cases, placing Sudan among the high prevalence countries for TB in the Eastern Mediterranean Region. Certain local practices and beliefs such as illness representations of the illness character and shame related to it may delay diagnosis hence increasing the spread of the disease in the community. Stigma contributes to the suffering from illness in various ways, and it may delay presentation and treatment leading to prolonged transmission of infectious diseases, drug resistance or complications that increase treatment costs for this treatable health problem. Studying illness perceptions in relation to TB can bring information, which helps, in improving the cure rates amongst tuberculosis patients, especially in improving the present low adherence to the administered therapy. It is extremely important that a holistic view of treatment is taken in view of the complex psychosocial characteristics of the disease. TB affects all the predicted fields of quality of life, such as general health perception, corporal sense, psychological health, mental peace and functionality of physical and social roles. The first part of this study was conducted in Khartoum state to assess the tuberculosis control programme and to identify both the challenges and needs of the programme (research question No1). The second part of the study was conducted in Gezira state Sudan, to study determinants of the low case finding and high default rate of TB patients, despite the implementation of Directly Observed Treatment Short course (DOTS) to control TB. This part of the study dealt with three psychosocial issues: awareness about TB disease (research question No2), social stigma related to TB (research question No3) and illness perceptions as well as quality of life (research question No4). Further, a literature review on TB stigma worldwide (research question No5) was done.

Methods: For the research question No1, a descriptive retrospective study design was used to evaluate the TB control programme in Khartoum. The study population was TB control departments at the levels of the

state (n = 1), localities (n = 7), health areas (n =19) and health facilities (n =42). Records review and group interviews were used to collect the required data. For the research questions No2 & No3 a case-control study design was used to determine TB awareness and stigma among TB patients and controls. In research question No4 a descriptive cross-sectional study design was used to determine TB illness perceptions and quality of life among TB patients in Gezira. Literature review method was used for research question No5 to find out a worldwide experience in TB stigma.

New smear positive TB patients registered in 2010 (n=425), and controls who attended the same health facility for other reasons (n=850) formed the study population. Awareness and stigma were measured by using a modified standard WHO TB Knowledge, Attitudes and Practice (KAP) instrument. The illness perceptions were measured by using Brief Illness Perceptions Questionnaire (BIPQ). Health Related Quality of Life (HRQoL) was assessed by means of the 12-item short form Health Survey questionnaire (FS-12). The literature review of TB stigma based on the studies published in English between January 1990 and October 2010 included publications (n=40) identified by searching the PubMed database, WHO and CDC publications, Social Science citation index, Arts and Humanities and Social Science Data base.

Results: The study found that the TB control programme in Khartoum State achieved a 77.2% case detection rate of the targeted smear-positive cases; 73.5% treatment success rate; case fatality rate of 2.2%; treatment failure rate of 2.2%, and default rate of 14.1%. There was no system to detect the prevalence of MDR-TB (multi-drug resistant TB) or HIV (human immunodeficiency virus) among the TB cases. The programme was not well implemented at locality or health area levels. In Gezira there was no significant difference between TB cases and their controls in TB awareness. About two thirds of TB cases and their controls had good TB awareness. Gender had an effect on awareness among the controls but not among the TB cases. Age, level of education, type of residence and type of occupation were significantly associated with the level of TB awareness while marital status had no effect. Males, highly educated persons, those

being either employers or employees had very good awareness and so did those living in towns. TB stigma did not differ between the TB cases and their controls: a mild degree of stigma was found in both groups. Moreover, the higher degree of stigma among both groups was significantly associated with higher age, lower level of education, rural type of residence area, non-working and poor TB awareness while gender had no association with the degree of stigma in either group. TB patients saw TB having minor consequences, being not so well controlled by treatment, and TB lasting long; they also associated several symptoms with TB. Furthermore, around half of TB patients had fair physical quality of life, while about 10% had poor mental quality of life. Concern about illness was associated with poor physical quality of life while coherence, meaning understanding of the illness, was associated with poor mental quality of life.

Most of the published studies reviewed showed that poor TB knowledge was the major cause of TB stigmatization, which was supported with the findings in this study. Association between gender of the patient and stigma varied from one study to another. Stigma has serious consequences on health seeking behaviour and adherence to TB treatment.

Conclusion: The tuberculosis control programme in Khartoum State is centralized; it is not updated and it does not achieve the targeted goals. TB cases and their controls in Gezira state, Sudan, had good level of awareness about TB; this awareness needs to be maintained to facilitate future prevention and control of the disease. Media and healthcare workers as the most important sources of TB information, their health education resources and role need to be strengthened. Although the TB stigma among the Gezira population was found to be of mild degree, it can affect TB patients' adherence to treatment. Empowering both TB patients and communities by increasing their knowledge through proper education programmes will effectively contribute to the effort of controlling TB in the state. The illness perceptions of the TB patients might influence their adherence to treatment. The poor quality of life of the TB patients and its impact on different areas of life such as daily activities and work, calls for programmes to strengthen TB

information, education and counselling. The perception of TB as a stigmatizing disease reviewed seemed to differ according to the cultural context. More studies are needed to clarify the relationship between TB stigma and ethnicity, religious orientation, DOTS, stigma in relation to HIV / AIDS and TB multidrug resistance.

Key words: Tuberculosis control programme, case-control, awareness, stigma, socio-demographic, illness perception, quality of life, Sudan.

LIST OF ORIGINAL PAPERS

1. Ahmed Suleiman MM, Sodemann M, Aro AR. Evaluation of tuberculosis control programme in Khartoum State for the year 2006. Scandinavian Journal of Public Health 2009;37(1):101-8.

2. Ahmed Suleiman MM, Sahal N, Sodemann M, Elsony A, Aro AR. Tuberculosis awareness among Gezira population, a case – control study. (under revision).

3. Ahmed Suleiman MM, Sahal N, Sodemann M, Elsony A, Aro AR. Tuberculosis stigma in Gezira, Sudan, a case–control study. International Journal of Tuberculosis and Lung Disease 2013;17(3):388-393.

4. Ahmed Suleiman MM, Sahal N, Sodemann M, Elsony A, Aro AR. Illness perception and quality of life among tuberculosis patients in Gezira, Sudan. (Submitted).

5. Ahmed Suleiman MM, Sahal N, Sodemann M, Aro AR. Tuberculosis stigma and discrimination worldwide: literature review. East African Public Health Journal (accepted for publication 24th July 2012).

The published papers are included in this thesis with the permission of the publishers.

ACRONYMS AND ABBREVIATIONS

AFB: Acid-fast bacilli

AIDS: Acquired immunodeficiency syndrome

BCG: Bacille Calmette-Guérin

CDC: Centre for Diseases Control

CXR: Chest X-ray

DOT: Directly observed treatment

E: Ethamputol

EPI: Expanded programme of immunization

EPTB: Extra pulmonary tuberculosis

FDC: Fixed-dose combination

H: Isoniazid

HIV: Human immunodeficiency virus

IUATLD: International Union against Tuberculosis and Lung Disease

MDR-TB: Multidrug-resistant TB (resistance to at least rifampicin and isoniazid)

NTP: National tuberculosis programme

PHC: Primary health care

PTB: Pulmonary tuberculosis

R: Rifampicin

S: Streptomycin

SMX: Sulfamethoxazole

STB: Stop TB Department

T: Thioacetazone

TB: Tuberculosis

TB/HIV: HIV-related TB

UNAIDS: Joint United Nations Programme on HIV/AIDS

WHO: World Health Organization

Z: Pyrazinamide

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1. INTRODUCTION

Tuberculosis (TB) is among the top ten causes of global mortality (1, 2). It is estimated that approximately one-third of the world's population is infected with tuberculosis bacillus, and each year eight million people develop tuberculosis disease which annually kills 1.8 million worldwide (3, 4). Approximately 80% of TB cases are found in 23 countries; the highest incidence rates are found in Africa and South-East Asia (3, 4). The TB situation has worsened over the past two decades in Africa owing to the HIV/AIDS epidemic and in Eastern Europe in association with multidrug resistance, following deterioration of the health infrastructure (4, 5).

TB is caused by Mycobacterium tuberculosis (M. tuberculosis), a microorganism whose principal reservoir is humans. M. tuberculosis is spread by patients with pulmonary tuberculosis, especially those with positive sputum smears (6, 7). Of those becoming infected, 10–12% will develop tuberculosis disease after a period ranging from weeks to decades (8, 9, and 10). The risk of disease declines steeply with time after infection. Disease may also occur after re-infection (9, 11).

TB carries high public health importance as someone in the world becomes newly infected with TB bacilli every second (3). TB has high morbidity and mortality rates despite its status as a treatable disease. Tuberculosis is almost always curable if patients are given sufficient uninterrupted therapy. Despite the treatability of this infection, tuberculosis has proven to be impossible to eliminate, and the number of drug-resistant cases has increased (3). Most experts acknowledge the central role of patient adherence in these problems, and its importance in efforts to control the disease (19). Ensuring the regular intake of drugs to achieve a cure is as important as making the diagnosis of tuberculosis (20). For these reasons, in addition to the expensive nature of the drugs used in the treatment, it is important to launch special programmes for the control of tuberculosis.When evaluating TB control programmes the agreed criteria for the success as stated by the WHO are a case detection rate of smear positive TB cases of 70% and an achievement of treatment

success in 85% of the detected cases. These guidelines represent the levels, which produce a significant epidemiological impact as demonstrated by field experience in high incidence countries (12).

In Sudan, an estimated annual risk of TB is 1.8%, which gives an incidence of 90/100,000 smear positive cases, and puts Sudan among the high prevalence countries for TB in the Eastern Mediterranean region (13). Also, the Khartoum state (population of 5 752.425 in the year 2005) has the annual risk of 1.8 % of TB. In 2005, the programme was able to detect 2981 new smear positive cases (82% from the target) and achieve the cure rate of 43% from the detected cases. The case fatality rate was 3.2%, which relatively increased compared with previous two years (2003: 2.6%; 2004: 2.3%) (14). This may be due to increases in the incidence of HIV, emergence of multi-drug resistance TB, or increase in default rate.

With HIV infection and multidrug resistance, the WHO has declared tuberculosis to be a global emergency (13). In response, WHO has adopted a new strategy and framework for effective TB control, namely DOTS (Directly Observed Treatment with Short course chemotherapy) (16). DOTS strategy was launched in 1991 and was considered the most effective measure in combating TB in developing nations (17). In Sudan tuberculosis is a major public health problem and in response the national tuberculosis -programme (NTP) was launched with a mandate of reducing the incidence of tuberculosis by diagnosis and effectively treating as many tuberculosis patients as possible until it is no longer a public health problem (18).

In 1993, the Ministry of Health in Khartoum state established tuberculosis control programme with the following core components for conducting overall planning and policy: identifying smear positive cases, management of active and suspected cases, providing laboratory and diagnosis services, providing training for health professionals, and tuberculosis data collection and analysis and supervision. The TB services are delivered in primary health services along with all other routine health services (15).The programme provides care through the DOTS strategy consisting of passive case-finding, assurance of regular drug supplies, and short-course chemotherapy for smear-positive patients who attend for direct observation, monitoring of case detection and treatment outcome as recommended by the WHO. Since its establishment,

the programme has never been adequately assessed. With an undetailed review of the reports of the previous years, it can be seen that there is a decline in the case detection rate from 112% in the year 2001 to 83% in the year 2005 (14).

The role of human behavior in health and illness has been increasingly recognized. Health is no longer considered simply as a biomedical problem; rather, it is influenced by social, cultural, physiological, economic and political factors that determine the behavior of the people concerned (21). In social and behavioral sciences, several models have been developed to explain and enhance health behaviors and sustained behavioral changes, also in different cultural contexts (22, 23). KAP surveys in TB can identify knowledge gaps, cultural beliefs, or behavioral patterns that may facilitate understanding and action, as well as pose problems or create barriers for TB control efforts. They can identify factors influencing behaviour that are not known and, reasons for the attitudes. KAP surveys can also assess communication processes and sources that are a key to define effective activities and messages in TB prevention and control. These surveys may be used to identify needs, problems and barriers in programme delivery as well as solutions for improving quality and accessibility of services. The data collected enable programme managers to set TB programme priorities, to estimate resources required for various activities, to select the most effective communication channels and messages, to establish baseline levels and measure change that results from interventions. For advocacy KAP data provide national TB programme managers and their staff with the fundamental information needed to make strategic decisions (24).

Health seeking behavior and the perceived knowledge on causes of TB among community members is very critical and may reduce or increase the transmission of the disease. Certain local practices, beliefs such as illness representations of the illness character and shame related to it, and failure to recognize symptoms early may delay diagnosis hence increasing the spread of the disease in the community (25). Adherence to treatment is also partly dependent on social factors such as e.g. financial insecurity and in general on lay perspectives (26, 25). The TB programme in Gezira state has conducted no assessment of the population

knowledge, attitude, and practice towards tuberculosis.

Based on the literature (25) and overview of different documents, it is known that poorer socio-economic conditions, lack of awareness of TB prevention and symptoms are risk factors for TB infections. In addition, psychosocial issues such as lack of knowledge, low risk perception and illness perceptions such as social and cultural stigma as well as poor access to treatment facilities, are related to poorer TB-related behaviors and poorer adherence to TB treatment (26).

Case detection rate in Gezira state was (in year 2007) 39.7% (26), which was far below the global target of 70%. Sudan overall, has (in 2007) a low TB case detection rate of 30% (27). Low detection rate may in part be due to the psychosocial issues mentioned above, which hinder patients' access to care and cause increased default rates among those who start treatment. Gezira state is one of the high TB burden states, and further, there is high default rate (12.8% in the year 2010).

Stigma has important impact for health policy and clinical practice. It contributes to the suffering from illness in various ways, and it may delay presentation and treatment leading to prolonged transmission of infectious diseases, drug resistance or complications that increase treatment costs for a treatable health problem (28).

Despite the existence of an effective cure for TB, incidence rates in high burden countries suggest barriers to effective diagnosis, treatment and cure. Evidence suggests that socio-cultural factors and TB-related stigma may inhibit patients from seeking care or maintaining a full course of treatment, increasing morbidity and mortality from TB and aggravating its spread within communities. TB patients may encounter isolation and rejection, fear of, or actual job loss (29; 30), and segregation at home (31). Interruption of the treatment consequently results in treatment failure, death, and drug resistance. Most experts acknowledge the central role of patient adherence in these problems and its importance in efforts to control the disease (32). Ensuring the regular intake of drugs to achieve a cure is as important as making

the diagnosis of tuberculosis (33).

Illness perceptions are increasingly being shown to be related to important outcomes in a number of illnesses. There is also evidence that patients attending for medical investigations, who have already developed negative illness perceptions of their condition, are less reassured by findings showing no pathology (34). Studying illness perceptions in relation to TB can bring information, which helps, in improving the cure rates amongst tuberculosis patients, especially in improving the present low adherence to the administered therapy. It is extremely important that a holistic view of treatment is taken in view of the complex psycho-social characteristics of the disease.

TB affects all the predicted fields of quality of life, such as general health perceptions, corporal sense, psychological health, mental peace and functionality of physical and social roles (35). Active tuberculosis can have drug side effects, social isolation and stigma from relatives, family members and friends, as well as causing various symptoms such as hemoptysis, chest pain, fever, profuse sweating, weight loss and fatigue; all these affect the quality of life (35).

This study has a potential to improve and help the Sudanese TB control programme in two most populated states Khartoum and Gezira, to achieve its targeted global goals of 70% smear positive case detection rate, and 85% treatment success rate.

To address these issues, the first part of the thesis was conducted in Khartoum state to assess the tuberculosis control programme and to identify both the challenges and needs of the programme. The second part of the study was conducted in Gezira state Sudan, to study determinants of the low case finding and high default rate of TB patients, despite the implementation of Directly Observed Treatment Short course (DOTS) to control TB. This part of the study was interested in three psychosocial issues: awareness about TB disease, social stigma related to TB and illness perceptions as well as quality of life. In addition to empirical study a literature review shed light on the TB stigma worldwide.

2. LITERATURE REVIEW

Tuberculosis (TB) persists as a global public health problem of a serious magnitude requiring urgent attention. Current global efforts to control TB have three distinct but overlapping dimensions: humanitarian, public health and economic. Alleviating illness, suffering and death of individuals caused by TB, is a major humanitarian concern and calls for a patient-centered approach to TB control. The public health dimension concerns proper diagnosis and treatment of TB patients to decrease disease transmission within communities. This necessitates development of well-organized TB control programmes. TB is responsible for considerable direct and indirect costs to individuals and society. The economic dimension of TB control relates to reduction of these costs, alleviation of poverty and promotion of development (36).

Tuberculosis (TB) is the number one single infectious disease killer, taking nearly three million lives per year. So great is the concern about TB that in 1993 the WHO declared TB a "global emergency" (36).

The following list shows the magnitude of the TB problem (36):

- Someone becomes newly infected with TB every second;
- TB creates more orphans than any other infectious disease;
- TB is the leading cause of death among HIV-positive individuals;
- 7-8 million people become infected with TB every year;
- One third of the world's population is infected with TB, and 5-10 percent of these people will develop the disease;
- TB accounts for more than 1/4 of all preventable adult deaths in the developing world;
- There are an estimated 400,000 new cases of multi drug resistance tuberculosis around the world every year (37).

TB is a communicable, systemic disease caused by the Tubercle Bacillus (Mycobacterium Tuberculosis) (38). Almost every organ in the body can be affected, but involvement of the lungs (Pulmonary TB)

accounts for more than 80% of TB cases. Infection by mycobacterium bovis through ingestion of unpasteurized cow's milk is less common. Most infections are caused by inhalation of droplet nuclei containing virulent human strains of the tubercle bacillus (16). There also other types of atypical Mycobacterium; such as Mycobacterium marinum (M. marinum) which is found in salt and fresh water. M. marinum infection occurs following skin trauma in fresh or salt water and usually presents as a localized granuloma or sporotrichotic lymphangitis (39). There is also Mycobacterium avium-intracellulare, a pulmonary pathogen that affects individuals with immune compromise secondary to AIDS, hairy cell leukemia, and immunosuppressive chemotherapy (40).

Tuberculosis is not transmitted by fomites, such as dishes and other articles used by the patient. Those who become infected with TB will not necessarily develop the disease. The immune system "walls off" the TB bacilli, which can lie dormant for years. When someone's immune system is weakened, chances of developing TB increase. On average, 10% of the infected individuals develop the disease during their lifetime (16).

The major factors that determine the risk of becoming exposed to tubercle bacilli include the number of incident infectious cases in the community, the duration of their infectiousness, and the number and nature of interactions between a case and a susceptible contact per unit of time of infectiousness (16). The disease is usually chronic with varying clinical manifestations (38).

Extra-pulmonary TB can involve sites such as bones, glands, the genito-urinary system, the nervous system (tuberculosis meningitis), intestine or almost any other part of the body. The time from the receipt of infection to development of positive tuberculin test, defined as a sterile liquid preparation made from the growth products or extracts of a tubercle bacillus culture and injected into the skin as a test for tuberculosis (41), ranges from three to 6 weeks. Development of the disease depends upon the following: the closeness of contact, sputum positivity of source case (dose of infection) and host-parasite relationship. Thus, the incubation period may be weeks, months or years (16).

The most important symptoms of TB in adults (over 15years of age) are as follows: productive cough persisting for three weeks, hemoptysis, and significant weight loss. Patients with TB may also have other symptoms (which are more common, but less suggestive) such as chest pain, breathlessness, fever\night sweats, fatigue and loss of appetite (16).

Tuberculosis epidemiology

More than 90% of global TB cases and deaths occur in the developing world, where 75% of cases are in the most economically productive age group (15-54 years). Consequently, an adult with TB loses on average three to four months of work time. This results in the annual loss of 20-30% in household income and, if the patient dies of TB, an average of 15 years of lost income (42, 43).

Co-infection with the human immunodeficiency virus (HIV) significantly increases the risk of developing TB (44). Countries with a high prevalence of HIV, particularly those in sub-Saharan Africa, have witnessed a profound increase in the number of TB cases, with reported incidence rates increasing two or threefold in the 1990s (1). At the same time, multi-drug resistance, which is caused by poorly managed TB treatment, is a growing problem of serious concern in many countries around the world (45). Now a strain of Extremely Drug Resistant Tuberculosis (XDR-TB) has broken out in rural South Africa, with mortality reaching nearly 100 percent in patients with HIV (46).

Based on surveillance and survey data, WHO estimates that 9.27 million new cases of TB occurred in 2007 (139 per 100 000 population), compared with 9.24 million new cases (140 per 100 000 population) in 2006. Of these 9.27 million new cases, an estimated 44% or 4.1 million (61 per 100 000 population) were new smear positive cases. India, China, Indonesia, Nigeria and South Africa rank the first to fifth in terms of the total number of incident cases. Asia (the South-East Asia and Western Pacific regions) accounts for 55% of global cases and the African Region for 31%; the other three regions (the Americas, European and Eastern

Mediterranean regions) account for small fractions of global cases. Among the 15 countries with the highest estimated TB incidence rates, 13 are in Africa, a phenomenon linked to high rates of HIV (47).

Tuberculosis in Sudan

Sudan's National Tuberculosis Programme (NTP) was established in 1974 based upon a system of specialist 'Chest Units' situated in hospitals (15). The Sudan-NTP adopted DOTS strategy and managed to achieve about 100% DOTS service coverage in the year 2003. Although management of tuberculosis was well established in the modern health system for a long-time, accurate national registry was missing. Establishment of NTP provided a reliable registry and served in reflecting the magnitude of TB in Sudan.

The NTP launched a decentralization policy to integrate TB services into the Primary Health Care (PHC) facilities, aiming to increase accessibility to health care, strengthening PHC services and secure better treatment outcome (48). This decentralization is expected to minimize time lag between diagnosis and treatment initiation and provide better opportunities for women to services. Strategies used to reduce barriers preventing women from seeking care focus on women's heavy workload as well as lack of mobility, independence and access to cash (49). In her article about effects of decentralization on tuberculosis services, El-Sony concluded that decentralization was associated with changes in the profile of patients accessing services (48). This observation was particularly obvious among women, who changed their choice of service from referral hospital to the PHC facilities. Bringing services closer to where patients live enhances their access to the services and thus their adherence to treatment (48).

Despite decentralization of TB services, there remains a problem of increasing detection rates. While the NTP in Sudan is approaching achievement of 80% treatment success rate of TB smear positive detected cases, the case detection rates are still lagging behind at a rate of less than 60% of estimated cases, with the highest case notification of 26000 cases in the year 1999 (50). According to a 1986 survey done in Sudan,

the prevalence of TB was 180 per 100,000 population and 50% were cases with positive sputum (51).

Table 2.1: TB case notifications in Sudan in the year 2011

New cases	(%)	Retreatment cases	(%)
Smear-positive	7 266 (39)	**Relapse**	712 (41)
Smear-negative	5 294 (28)	**Treatment after failure**	145 (8)
Smear-unknown / not done	1 452 (8)	**Treatment after default**	733 (42)
Extra-pulmonary	4 624 (25)	**Other**	159 (9)
Other	0 (0)		
Total new	**18 636**	**Total retreatment**	**1 749**
Other (history unknown)	0		
Total new and relapse	**19 348**	**Total cases notified**	**20 385**

Source: www.emro.who.int/STB/pdf/CountryProfile-sud-11.pdf

Tuberculosis in Khartoum and Gezira state

There are three different levels of organizing TB services in Khartoum and Gezira states: the federal level is responsible for the large specialized teaching hospitals; the TB programme of Khartoum state is responsible for the TB services in the other general hospitals and health centers; and the Sudan Council of Churches (SCC) is responsible of TB services in the five displacement camps. In both states the teaching hospitals formerly were the main health facilities for case detection, but with introduction of decentralization, the NTP focused in evacuating these hospitals and integrating TB cases into the PHC facilities aiming for better application of DOTS strategy. By the end of the year 2002, Khartoum and Gezira state declared achieving DOTS all over the states, i.e. each 100,000 population is covered with a diagnostic and management facility for tuberculosis (TBMU) (52).

Annually, Khartoum state notifies one third of the total documented cases in Sudan. This high notification is explained by the population density in the state, which accounts for almost one-fifth of the total

population of Sudan. The case notification in Khartoum reached its peak during the year 1999, when it had 8749 documented cases. The mean case finding in this state is about 8000 cases/year. The smear positive cases accounted for 58% of all notified cases during the period between 1997 and 2002. In each quarter of a year there are around 1100 smear-positive cases being notified in Khartoum state (52).

Case detection rate in Gezira state was (in year 2007) 39.7% (26), which was far below the global target of 70%. Sudan overall, has (in 2007) a low TB case detection rate of 30% (27). Low detection rate may in part be due to the psychosocial issues mentioned above, which hinder patients' access to care and cause increased default rates among those who start treatment. Gezira state is one of the high TB burden states, and further, there is high default rate (12.8% in the year 2010).

Risk factors for TB

Anyone of any age, race or nationality can contract TB, but certain factors increase risk of the disease. These factors include:

- Close contact with someone who has infectious TB (53);
- Age: Older adults are at greater risk of TB (53);
- Substance abuse: Long-term drug or alcohol use weakens immune system and makes you more vulnerable to TB (53);
- Malnutrition may account for a greater population attributable risk of TB than HIV infection. Malnutrition profoundly affects cell-mediated immunity (CMI), and CMI is the principle host defense against TB (54);
- Living or working in a residential care facility: People who live or work in prisons, immigration centers or nursing homes are all at risk of TB. That is because the risk of the disease 0is higher anywhere there is overcrowding and poor ventilation (53);
- Living in a refugee camp or shelter: People are weakened by poor nutrition and ill health and living in crowded conditions (53);

- Health care work: Regular contact with people who are ill increases chances of exposure to TB bacteria (53);
- International travel: As people migrate and travel widely, they may expose others or be exposed to TB bacteria (53);
- Lowered immunity: Having a disease that suppresses immunity, such as HIV/AIDS, diabetes or the lung disease silicosis, and receiving treatment with corticosteroids, arthritis medications or chemotherapy drugs, can damage body's ability to protect itself (55);
- Smoking and the consumption of traditional beer may both be associated with an increased risk for TB through increased iron content in broncho-alveolar macrophages leading to reduced host defense towards intracellular micro-organisms (56);
- Poverty may be itself related to a number of the above risk factors. This list is by no means exhaustive as new risk factors are added on a continuous basis (57).

Tuberculosis control

The aim of interventions in tuberculosis control or elimination strategies is to reduce or eliminate the adverse impact of epidemiological risk factors that promote the progression from one-step to the next in the path genetically based model (58).

There are four principal interventions (59):

1. **Treatment** of tuberculosis reduces the risk of death from tuberculosis; it aims at restoring health and curing patients, and it reduces the risk of transmission of tubercle bacilli in the community;

2. **Prophylactic** treatment aims at preventing infection with *Mycobacterium tuberculosis* from occurring primarily for children who are household contacts of TB patients;

3. **Vaccination** with Bacille Calmette-Guérin (BCG) before acquisition of infection with *M. tuberculosis*, aims at priming the immune system so that the risk of progression from sub-clinical, latent tuberculosis infection to clinically overt tuberculosis, is reduced should such infection be acquired;

4. **Preventive** chemotherapy is treatment of sub-clinical, latent *Mycobacterium tuberculosis* populations in the human host, given to reduce the risk of progression to clinically overt tuberculosis. It has been demonstrated in numerous prospective clinical trials that preventive chemotherapy with isoniazid for one-year duration is efficacious in reducing the risk of tuberculosis among persons with latent infection (60).

Tuberculosis case detection

Infectious pulmonary tuberculosis is often not detected until a late stage, even though the patient may have attended health facilities during the initial stages of the disease. Physicians frequently do not suspect tuberculosis or do not request smear examination in patients with cough, particularly if those patients present with non-respiratory ailments. It is estimated that as many as 5–10% of adults attending outpatient health facilities in developing countries may have a persistent cough of more than 2–3 weeks' duration (1, 61). The proportion of smear-positive pulmonary tuberculosis among these individuals depends on the prevalence of tuberculosis in the community. Systematic identification of adults with persistent cough among outpatients in general health facilities can detect a large proportion of sources of tuberculosis infection (62). This reduces treatment delay and identifies infectious patients who are a risk to the community and to other patients and staff at the health facility. Successful treatment of these patients has a rapid effect on tuberculosis prevalence, mortality (63), and transmission (1).

Sputum microscopy is the most efficient way of identifying sources of tuberculosis infection. This method

is used to diagnose tuberculosis in persons with suspected pulmonary disease and to identify sources of infection among persons presenting with cough who attend health facilities for any reason. Sputum microscopy is also used to monitor the progress of infectious patients during treatment, including confirmation of cure (64).

Case detection in outpatients by microscopic examination of sputum can significantly increase the number of sources of infection diagnosed. The number of outpatients investigated, the number of smears for diagnosis, and the numbers of sources detected are indicators of the case-detection activity. In Peru, for instance, 210 905 smear examinations were carried out in 1990, leading to the identification of 24 023 cases of smear-positive pulmonary tuberculosis. In 1993, 602 000 smears from 332 000 persons were examined and 35 646 cases were identified. By 1999 Peru was examining approximately 5% of the adult population for tuberculosis by smear microscopy every year and the number of smear-positive cases had decreased to 24 511 despite an increase in the number of smear examinations to 1 938 201 in 1 085 749 persons (63). The proportion of positive smears is an indirect indicator of the impact of the programme in reducing the prevalence of tuberculosis in the community. The rate of smear positivity in persons with respiratory symptoms in Peru was 18.7% in 1990, 14.3% in 1991, 8.5% in 1993, and 2.7% in 1999. Similarly, in Chile the smear positivity rate fell from more than 10% to less than 2% in two decades (1).

Sputum smear microscopy has a fundamental role in monitoring the response to treatment of infectious cases of pulmonary tuberculosis. Smear examination should be performed at the end of the initial phase of treatment; if smears are still positive, the intensive phase should be extended for an additional month. Smears should be examined during and at the end of the continuation phase to confirm cure. The conversion rate at 2–3 months (defined as the proportion of initially smear-positive patients with negative smears out of the total who started treatment) is a good operational indicator. It shows the capacity of the programme to maintain patients on treatment, obtain smear samples, and eliminate sources of infection, and it is an early surrogate of the treatment outcome indicator (65).

Delays in case detection, diagnosis and treatment of TB, result in severe disease and a higher mortality. Delay also leads to an increased period of infectivity in the community. A study done in Ethiopia showed that health providers' and health systems' delays represent the major portion of the total delay. The major factors associated with the patients' delay were related to lower access to medical providers and prior attendance to non-formal health providers. In contrast, the major factors associated with the health systems' delay were prior attendance to the health posts/clinic and private medical providers. Therefore, considering the high magnitude of pre-treatment delay, it is imperative to access a simple and rapid diagnostic test for TB that can be used at the lowest health care facility level (66). Many studies have shown that health system delays are longer than patient delays (67).

The use of BCG vaccination is not considered of great epidemiological impact on TB transmission. In fact, the protective efficacy of BCG varies between 0% and 80%. This variability is influenced by differences in the prevalence of infection with environmental mycobacterium (68) and differences between BCG strains (69). The most important benefit of BCG is that it may give protection up to 80% against disseminated tuberculosis, including tuberculosis meningitis in childhood (69). Recent studies have suggested that BCG immunization may have a nonspecific beneficial effect on infant survival. The effect seems most pronounced among girls. These findings may have implications for future vaccine trials and policy (70).
BCG vaccine is one of the preventive strategies to control TB. There are different policies in different countries according to the TB burden. The currently implemented policies worldwide include (71):

- **BCG** only at birth – this is currently recommended by the WHO Expanded Programme of Immunization (EPI) and the WHO Global Tuberculosis Programme, and is the policy in most of the world, particularly in developing countries;

- **BCG** once in childhood – this policy has been in use in the UK for many years, along with selective vaccination of tuberculin-negative adolescents;

- **Repeated/booster BCG** – in Eastern Europe BCG is recommended up to five times in some countries (the criteria for re-vaccination differ between countries);

- **No routine BCG** – this has always been a policy in the US and the Netherlands, but a number of other countries have also been moving to this in recent years. BCG is still recommended in high-risk groups. Implementation of these policies varies across countries, based on regional differences in TB, differences in health systems, and local history.In Sudan, where there is a high burden of tuberculosis, the recommended strategy is to give BCG only at birth as part of an expanded programme of immunization (EPI); the BCG coverage under EPI programme for the 90 % of children under 5 years of age in Khartoum state in the year 2005 was 90.7% (72).

Tuberculosis treatment

The aims of TB treatment regimens are to: cure the patient, prevent death from active disease or its late effects, prevent the emergence and spread of drug-resistant organisms, minimize relapse, and protect the community from continued transmission of infection. All treatment regimens have two phases – an initial intensive phase and a continuation phase (73, 74).

Initial intensive phase

The initial intensive phase of treatment is designed to kill actively growing and semi dormant bacilli. This means a shorter duration of infectiousness, usually with rapid smear conversion (80–90%), after two to three months of treatment (73). The initial phase of rifampicin-containing regimens should always be directly observed in order to ensure compliance. That phase usually involves between three and five drugs. If initial resistance rates are high, use of a three-drug regimen carries the risk of selecting drug-resistant mutants, especially in patients with high bacillary loads, i.e. with smear positive pulmonary tuberculosis.

Use of a four-drug regimen reduces the risk both of developing drug resistance and treatment failures and of relapses. If a patient defaults on treatment after the initial intensive phase, relapse is less likely (73).

Table 2.2: Standard tuberculosis treatment regimens

TB diagnostic Category	TB cases	Regimen (daily or 3 times weekly) *	
		Intensive phase	Continuation phase
III	New smear – negative pulmonary TB (other than in category I) Less severe forms of EPTB	2HRZ+	4HR or 6HE
I	New smear – positive pulmonary TB New smear – negative pulmonary TB With extensive parenchymal involvement Severe forms of EPTB other than TB meningitis – see below Severe concomitant HIV disease	2HRZE	4HR or 6HE+ +
I	TB meningitis	2RHZS§	4RH
II	Previously treated smear – positive pulmonary TB: relapse treatment after interruption treatment failure	2HRZES / 1HRZE	5HRE
IV	Chronic and MDR-TB	Specially designed standardized or individualized regimens	

*****Direct observation of drug administration is recommended during the initial phase of treatment and whenever the continuation phase contains R.

\+ In comparison with the treatment regimen for patient in diagnostic category I, E may be omitted during the initial phase of treatment for patient with none cavity, smear negative pulmonary TB who are known to be HIV negative, patients known to be infected with fully drug- susceptible bacilli, and young children with primary TB

++ This regimen (2HRZE / 6HE) may be associated with a higher rate of treatment failure and relapse compared with the 6- month regimen with R in the continuation phase

§ In comparison with treatment regimen for patient in diagnostic category I, S replaces E in the treatment of TB meningitis

Source: WHO. Guidance for National Tuberculosis Programmes on the management of tuberculosis in children.INT J TUBERC LUNG DIS 10(11):1205–1211. 2006
http://whqlibdoc.who.int/hq/2006/WHO_HTM_TB_2006.371_eng.pdf

TB control through the DOTS strategy

DOTS is the internationally recommended strategy to ensure cure of tuberculosis. It is based on five key

principles that are common to disease control strategies, relying on early diagnosis and cure of infectious cases to stop spread of tuberculosis (75).

Definitions of DOTS

The recommended strategy for TB control comprises (76):

1. Government commitment to ensuring sustained, comprehensive TB control activities;
2. Case detection by sputum smear microscopy among symptomatic patients self-reporting to health services;
3. Standardized short-course chemotherapy using regimens of six to eight months, for at least all confirmed smear positive cases. Good case management includes directly observed therapy (DOT) during the intensive phase for all new sputum positive cases, the continuation phase of rifampicin-containing regimens and the whole re-treatment regimen.
4. A regular, uninterrupted supply of all essential anti-TB drugs;
5. A standardized recording and reporting system that allows assessment of case-finding and treatment results for each patient and of the TB control programme performance overall.

Adherence to tuberculosis treatment

It is well known that the early detection of smear positive tuberculosis cases and prompt treatment are corner stones in controlling the spread of the disease, since interruption of the treatment consequently results in treatment failure, death, and drug resistance. The patient who is infected with multi-drug resistance transmits drug resistant mycobacterium tuberculosis strain to others. This requires treatment with the second line, which is very expensive. To avoid this problem, it is very important to ensure high compliance and adherence to tuberculosis treatment.

Tuberculosis is almost always curable if patients are given sufficient uninterrupted therapy. Despite the treatability of this infection, tuberculosis has proven to be more difficult – sometimes even impossible to eliminate, and the number of drug-resistant cases has increased. Most experts acknowledge the central role of patient adherence in these problems, and its importance in efforts to control the disease (77). Ensuring the regular intake of drugs to achieve a cure is as important as making the diagnosis of tuberculosis (77).

The consequences of inadequate and incomplete TB treatment are serious:

1. Prolonged illness and disability for the patient;
2. Infectiousness of the patient causing continued transmission to the community;
3. Development of drug-resistant tuberculosis;
4. Possibility of death.

In one study, for example, non-adherent patients took longer than adherent patients to convert to negative culture results (254 versus 64 days); they were more likely to acquire drug resistance (relative risk 5.6); they and required longer treatment regimens (560 versus 324 days) (79).

Patient non-adherence has been identified as the most serious remaining problem in tuberculosis control (80) and a major obstacle to the elimination of the disease (81). In the midst of renewed efforts at TB control in 1993, 17.5 % t of patients failed to complete therapy within a 12-month period nationwide (82). In some areas, the rate of non-adherence was nearly 50 %. For example, a study of 184 patients in New York City diagnosed with tuberculosis in April 1991 (before strengthening of the control programme) found that 88 patients (48 %) were non-adherent to therapy. The goal is to get this failure rate below 10 % (79). Treatment adherence is a major challenge in tuberculosis. This is because disease treatment and prevention require the use of medications for a long period. Also, the use of multiple medication regimens is complicated, some of the drugs have unpleasant side effects, and rising problems of TB complicated with HIV -all negatively affecting the adherence of the patient to the treatment.

Tuberculosis knowledge attitude and practice (KAP)

The role of human behaviour in health and illness has been increasingly recognized. Health is no longer considered simply as a biomedical problem; rather, it is influenced by social, cultural, physiological, economic and political factors that determine the behaviour of the people concerned (83). In social and behavioural sciences several models have been developed to explain and enhance health behaviours and sustained behavioural changes, also in different cultural contexts (84, 85). Knowledge, attitudes, and practice (KAP) surveys in TB can identify knowledge gaps, cultural beliefs, or behavioural patterns that may facilitate understanding and action, as well as pose problems or create barriers for TB control efforts. They can identify factors influencing behaviour that are not known and reasons for the attitudes. KAP surveys can also assess communication processes and sources that are a key to define effective activities and messages in TB prevention and control. KAP surveys may be used to identify needs, problems and barriers in programme delivery as well as solutions for improving quality and accessibility of services. The data collected enable programme managers to set TB programme priorities, to estimate resources required for various activities, to select the most effective communication channels and messages, to establish baseline levels and measure change that results from interventions. For advocacy KAP data provide national TB programme managers and their staff with the fundamental information needed to make strategic decisions (86).

Health seeking behaviour and the perceived knowledge on causes of TB among community members is very critical and may reduce or increase the transmission of the disease. Certain local practices, beliefs such as illness representations of the illness character and shame related to it, and failure to recognize symptoms early, may delay diagnosis hence increasing the spread of the disease in the community (87, 88). Adherence to treatment is also partly dependant on social factors such as e.g. financial insecurity and in general on lay perspectives (27, 88).

The impact of stigma and discrimination on TB care and control

Many authors (89-95) describe the effects of stigma and discrimination associated with TB. The principal effects in developing countries are social isolation of patients, both outside the family, where the person may be avoided by friends and acquaintances, and inside the family, where the patient may be forced to eat and sleep separately (96,97). Patients often isolate themselves to avoid infecting others and to avoid uncomfortable situations such as being shunned or becoming the subject of gossip. Being either a patient or an ex-patient is likely to affect employment and employment prospects. Unmarried women with TB often find it difficult to get married due to discrimination by prospective husbands and in-laws, while married women may find that they are divorced because they have TB or if a history of TB is subsequently revealed. Stigma and consequent discrimination have a double impact on TB control. First, concerns about being identified as a person with TB make it more difficult for people with a cough of long duration who suspect they may have TB to seek care, because of the public nature of the TB diagnostic process. By delaying seeking care, these people may develop more serious symptoms, meaning they will be more difficult to treat; and as they remain infectious for longer, they are more likely to transmit the disease to others. Second, concerns about stigma and discrimination for TB make it more difficult for patients to continue with care, because their fears of being identified as being, or having been infected with TB hinder their access to services on a daily basis. Again, this can lead to serious symptoms and increased transmission (98).

Causes of stigma and discrimination associated with TB

There are few published papers that attempt to determine the causes (rather than the existence or effects) of stigma and discrimination associated with TB. One study has addressed social stigma associated with TB in Nicaragua (99).This study described two pairs of contradictory influences of stigma and discrimination: (a) feelings of affection and supportive attitudes towards people affected by TB, countered by the fear of

transmission of TB; and (b) sympathy for people affected by TB considered to be unlucky, contrasted with mistrust of people affected by TB considered to have brought the disease upon themselves. This leads to self-stigmatization and discrimination. Issues of power and knowledge further mediate the situation. Another study deals with a very specific group of potential discriminators: nurse instructors in various (unspecified) countries (100).The main findings were that the main causes were fear of contracting the disease (58%), association with poverty (40%) and lack of knowledge (34%). The percentages quoted come from a self-selected sample of respondents, and are therefore not representative of any specific population group, so care must be taken in interpreting these results. Other studies not focusing specifically on stigma and discrimination identify the following determinants of stigma and discrimination associated with TB: unfounded beliefs about transmission (101,102); health staff attitudes (103); and associations with other potential sources of discrimination (104).

Theoretical framework of illness perception

When patients are diagnosed with an illness, they generally develop an organized pattern of beliefs about their condition. These views are the key determinants of behaviour directed at managing illness. It is a dynamic process, which changes in response to shifts in patients' perceptions and ideas about their illness. These illness perceptions or cognitive representations directly influence the individuals' emotional response to the illness and their coping behaviour such as adherence to treatment. Despite their importance, patients' views of their illness or symptoms are rarely sought in medical interviews, and patients tend not to bring up their illness beliefs to the doctors (105).

Patients build mental models

When faced with a new health threat such as a new symptom or diagnosis, individuals will actively build cognitive models of this threat, and this mental representation will determine how they respond (106). These models are based on their own medical knowledge or from personal experience of others such as family members with similar symptoms or diagnoses. The patient's model of his or her illness will guide the patient to reduce the danger of the symptoms or illness and simultaneously to guide coping strategies designed to reduce the emotional response to the threat. Researchers have noticed that there is often symmetry between bodily symptoms and illness labels (107). When patients have symptoms there is a pressure for them to find a label or explanation for their ill-health. Conversely, when patients are given a diagnosis it generally generates a search for symptoms they see as relevant to their label – even when the illness may be asymptomatic. Patients' knowledge of medical concepts and the body is often rudimentary which can limit the accuracy and complexity of the models they build (107).

Components of illness perceptions

There is a consistent pattern to the way in which individuals make mental models of their illness. Previous studies found five main interrelated components that make patients' views of their illness (105):

1. Identity of their illness;
2. Causal beliefs;
3. Timeline beliefs;
4. Beliefs about control or cure;
5. Consequences.

The fascinating aspect of illness perceptions is how patients with the same illness or injury can have widely different perceptions of their condition; further, these perceptions can lead the same patients down very different illness trajectories (105).

Assessing illness perceptions

In the clinical setting patients are rarely asked about their view of their illness but are usually happy to discuss their ideas if the invitation is welcoming and they do not feel they are being 'tested' on their knowledge. A possible opening question would be 'Many patients develop their own ideas about their illness and I would be interested in discussing these with you'. This can be followed up with specific questions such as 'What do you think may have caused this condition?' and 'What are the main consequences of this illness for you?' Clinicians seeking a more formal assessment of a patient's illness perceptions can use the Illness Perception Questionnaire (108), which has different versions available depending on the purpose of the assessment. For most clinical applications the brief version of the scale will provide a rapid picture of the patients' view of their illness (109).

Illness perceptions and clinical outcomes

Illness perceptions are increasingly being shown to be related to important outcomes in a number of illnesses. There is also evidence that patients attending for medical investigations who have already developed negative illness perceptions of their condition are less reassured by findings showing no pathology (110). A number of studies have shown that when patients hold generally negative illness perceptions about their illness (e.g. a large number of symptoms associated with the condition, more severe consequences, and longer timeline beliefs), these perceptions are associated with increased future disability and a slower recovery, independent of the initial medical severity of the condition (111).

Quality of life

The World Health Organization (WHO) defined quality of life (QOL) as the ability of individuals to perceive their position in life within the cultural, contextual and the value systems in which they live,

being in accordance with their goals, expectations, standards and concerns (112). Health-related quality of life (HRQoL) is a multi-dimensional concept that associates the physical, emotional, and social components of an individual with his/her medical conditions or treatment (113). HRQoL is used to distinguish health effects from other factors influencing a subject's perceptions (such as environmental factors or job satisfaction) (114).

There are no published studies on HRQoL among TB patients from Sudan. A study from India showed that the HRQoL among both active and inactive tuberculosis cases was deformed; the quality of life was affected by demographic and socio-cultural characteristics, depression, daily sleep period, treatment period and accompanying diseases (35).

TB affects all the predicted fields of quality of life, such as general health perception, corporal sense, psychological health, mental peace and functionality of physical and social roles (35). Active tuberculosis can have drug side effects, social isolation and stigma from relatives, family members and friends, as well as causing various symptoms such as hemoptysis, chest pain fever, profuse sweating, weight loss and fatigue; all affecting the quality of life (35).

3. AIMS OF THE STUDY

This study sets out to evaluate TB control programme in Khartoum state, Sudan for the year 2006 and to study, prevalence of stigma, population awareness and illness perceptions in Gezira state, Sudan.

The specific research questions of the study were as follows:

Research question No. 1: To what extent the TB control programme in Khartoum state achieves its global targeted goals of 70% smear positive case detection rate, and 85% treatment success rate? (Paper No. 1).

Research question No. 2: What is the level of TB patients' and general population's awareness of TB in Gezira state? (Paper No. 2).

Research question No. 3: What is the prevalence of stigma among TB patients and population in Gezira state? (Paper No. 3).

Research question No. 4: What is the level of illness perceptions and quality of life among TB patients n Gezira state? (Paper No. 4).

Research question No. 5: What are the differences in perceiving TB stigma worldwide? (Paper No. 5).

4. MATERIALS AND METHODS

The study was conducted in two most populated states with highest TB burden in Sudan: evaluation of TB control programme was conducted in Khartoum state while a population study was conducted in Gezira state.

First part of the study: Evaluation of TB control programme in Khartoum state (Paper No. 1)

Setting and design of the study

Khartoum state has an area of 28,000 km2 and population of about 5,752,425. It is located between longitude 15.1-16.3N and latitude 31.4- 34.2E. (figure 4.1) Khartoum is divided into seven localities (districts) and 19 health areas. Its health facilities include 43 hospitals, 147 health centers, 185 NGO centers, 235 dispensaries, 365 primary health care units (PHC) (14).

The structure of the health care system in Khartoum state is based on the primary health care and the health area concept, which is conceived as a decentralized health care system able to integrate at district level. The existing vertical programmes, including preventive, curative and health promotion activities, has been fully developed but is not yet universally applied (14).

Figure 4.1: Khartoum state– Sudan map

A descriptive study design was used to evaluate tuberculosis control programme in Khartoum state, Sudan. This design is practical, fairly quick, easy to perform, low cost, and it provides wealth of data that can be of great use in further analytical studies.

The study population

Tuberculosis control departments at the levels of the Khartoum State e (n=1), localities (n=7), health areas (n=19) and health facilities (n=42) were the study population of the assessment the TB control programmes.

Sampling

For the assessment of the programme at central and health, facility levels, no sampling procedures or techniques were used because all tuberculosis control units were studied.

Measures, data gathering and analysis

The achievement of the global target goal of tuberculosis control programme in Khartoum state was measured based on the World Health Organization (WHO) indicators, which were routinely reported programme outcome, diagnosis, case management, drug supply, reporting and recording, supervision, and human resources (115).

For evaluating TB control programme in Khartoum state, the fieldwork took place in Khartoum, Sudan, in the period from April to June 2007; the records review at the central level was done by the researcher and at the health facilities level by three medical doctors trained in the research data gathering tools. Focus group discussions were carried out by the researcher and a trained medical doctor as moderator; the participation rate in the four focus group discussions was 100%. The data from records review were collected by using a data collection sheet, which was developed based on the standard WHO indicators; the focus group discussion data were collected using tape recording and notes taking. The data obtained from these sources were of good quality (data were complete, disaggregated by age and sex and place of residence and accessible for the time of evaluation). The qualitative focus group data were analyzed using contents analysis based on themes arising from the data. After each focus group discussion, the recorded tapes used were transcribed, and focus group discussion notes were summarized; both were used to formulate initial analysis and the data were coded by using different color highlighters according to the relevance of different issues of the discussion. Further quotes are used as examples of the participants' input.

Table 4.1:Process of data gathering for evaluation of TB control programme in Khartoum state, Sudan.

Data Gathering methods	Description	Measurement
Review of medical records	The following records found at the various levels were reviewed: at the state level: monthly and quarterly plan reports and statistical reports for the year 2006. At health facility level: patient registers, copies of monthly and quarterly statistical, pharmacy and laboratory reports for January− December 2006	The global targeted goal for tuberculosis control programme in Khartoum state was measured based on the World Health Organization (WHO) indicators, which are routinely reported programme outcomes indicators, diagnosis indicators, case management indicators, drug supply indicators, reporting and recording indicators, supervision indicators, and human resources indicators
Focus groups	Four focus group discussions were conducted in three different large areas of Khartoum state, namely Khartoum, Omdurman and Khartoum North and at the central level of the tuberculosis control programme. Groups of 8-10 tuberculosis control programme personnel at locality health area and health facility levels participated. The selection of these persons (n=29) was based on the representativeness of both urban and rural localities, health areas, and health facilities. The fourth focus group discussion was held on the central level of tuberculosis control programme and the participants were the whole staff at this level (n= 8).	A four-item interview guide :a) **technical issues (**TB patient management (diagnosis, treatment, and follow-up in form of guidelines and methods), TB control programme reporting system (methods, frequency, distribution, feedback), TB control programme supervision (methods, frequency, feedback, benefits), TB control programme meetings (frequency, feedback, benefits); b) **human recourses** (staff (adequacy, training, motivation, and relations)**;** **c) logistics** (drug supply (availability, quality, methods of distribution, and storage), laboratory supply (availability, quality, methods of distribution, and storage), registration and reporting materials (availability, quality, and methods of distribution), programme materials and guidelines (availability, simplicity, and quality); d) **TB programme financing** (TB control programme budget at all levels (adequacy, continuity, and availability of the recommended time)

Second part of study: population study in Gezira (Papers Nos. 3-4)

Setting and design of the study

Gezira state lies between the Blue Nile and the White Nile in the east-central region of Sudan (figure 4.1). It has an area of 27,549 km² and population of 2,796,330.

The structure of the health care system in Gezira State is based on the primary health care and the health area concept, which is conceived as a decentralized health care system able to integrate at district level.

A case-control study design was used to determine the awareness, prevalence of stigma, and descriptive cross-sectional study design was used to determine illness perception and quality of life among Gezira state population.

The study population

New smear positive TB patients registered in 2010 (n=425) and controls who attended the same health facility for other reasons (n=850) formed the study population for measuring TB awareness and stigma and TB cases (n=425) for measuring TB illness perception and quality of life.

Sampling

All new smear positive TB cases diagnosed in the TB microscopic units in Gezira state in the period from January to June 2010 were the cases, and for each case two controls were chosen from other people attending the health care facility for any other purpose. The sample size was calculated for cases from the equation n=z2 pq /d2 Where; n =sample size z=level of confidence=1.96, p=0.5, q=1-p=0.5 ,d=desired margin of error=0.05.

Thus the sample size was :(1.96) (1.96) (0.5) (0.5)/ (0.05)2 = 384 patients; 10% of the calculated sample size was added to guard non-response. Thus, the sample sizes were 425 patients and 850 controls.

The sample size was divided between the units according to the number of registered patients from January to December 2010. In addition, the two controls for each patient were selected randomly from other people attending to the heath facility for any other purpose which match the cases in the age. Other patients attending the health facility were used since there is no civil registry from which controls could be drawn. These control patients were selected randomly from the health facility clinic registry book during the same time period as the patients were selected.

A written consent was taken from the respondents. Objectives, process and expected outcome of the research were explained to the participants and their right to withdraw from the study at any time was explained without any place for unwanted consequences for their current care. Absolute confidentiality of the information gathered was followed before, during and after finishing the study.

Measures, data gathering and analysis

The tuberculosis, awareness and TB stigma were measured using a standard modified WHO TB KAP instrument; illness perceptions were measured by the short form modified Illness Perception Questionnaire (IPQ-R) (25, 134 & 144) while quality of life was measured by Health Survey Scoring Demonstration SF12 (107, 116). The interview instrument was tested in a pilot study in Gezira state.

For the population study measuring TB awareness, stigma, illness perception and quality of life, the field work took place in Gezira state, Sudan, in the period from December 2010 to December 2011. The data were collected by 25 trained health workers.

The analysis of the quantitative data was done using Statistical Package for Social Sciences (SPSS) version 19.0 programme. To calculate the frequency values descriptive statistics was used; percentages were used to express the values for qualitative variables. Chi Square test was used to compare between groups for descriptive data. P values of less than 0.05 were considered statistically significant. Multinomial logistic

regression was conducted to predict multivariate relation of socio-demographic characteristics and TB awareness and TB stigma. Also multinomial logistic regression was conducted to predict multivariate relation of TB illness perceptions and quality of life among TB patients.

The assessment of the level of TB awareness among the TB cases and their controls was based on the summation of the Likert scale response (nine points) of the correct answers for the questions which measured the awareness on the TB: having enough information about TB, types of TB, methods of transmission, TB symptoms and signs, methods of TB prevention, TB treatment, TB vaccination, people at risk for TB, cost of TB treatment and diagnosis. Cronbach's alpha was calculated for the TB awareness scale showing the reliability of 0.73 for the 20 items included in the scale. Later, awareness for all TB cases and their controls was categorized into four levels: very poor, poor, good and very good awareness.

TB stigma was measured using a standard modified WHO TB KAP instrument (13).The interview instrument was tested in a pilot study. The field work took place in Gezira state, Sudan, in the period from December 2010 to December 2011.The TB stigma was evaluated using the following indicators: family history of TB, lack of access to treatment units due to distance, feeling shame, service quality and cooperation of the health staff, delay in seeking medical advice and feeling after knowing the diagnosis, compliance to treatment, impact on patient's social relationships and work performance, feeling guilty about infecting others, feeling of loneliness, stress, depression and community disapproval of TB. Stigma was stratified into four degrees: no stigma, mild degree of stigma, moderate degree of stigma and severe degree of stigma.

The control group was asked to imagine that they had TB when answering the stigma questions. Likert scale was used and stigma was calculated based on the summation of the Likert scale responses. Cronbach's alpha calculated for the scale was 0.87 for the 17 items included in the stigma scale.

The Brief Illness Perceptions Questionnaire (BIPQ) (134), which has been found feasible and sensitive enough for population studies (134), was used to measure illness perceptions. Translation to Arabic

language and back translation was conducted. BIPQ contains the following nine items, each measuring the previously established illness perception dimensions: identity, consequences, timeline, personal control, treatment control, concern, understanding, emotional representations, and the 9th item about the causes of TB. The scale was a five-point Likert scale, with higher scores indicating stronger endorsement of that item: High **identity** score indicates that the participants experienced more symptoms; high **consequences** score means that the participants saw their illness having major consequences; the high **timeline score** means that the participants thought that their illness will last for a long time; high **personal control** score means that the participants perceived having good control of their illness; high **treatment control** score means that the participants thought the treatment being extremely helpful in managing their illness; high **coherence** score means that the participants understood their illness; high **emotional representation score** means that the participants' illness affected their emotions extremely; and high illness **concern score** means that the participants were highly concerned about their illness. The TB cause item responses can be grouped into categories such as stress, lifestyle, heredity etc. determined by the particular illness studied. Categorical analysis can then be performed either on just the top listed causes or all three listed causes. In the questionnaire, the items for TB patients were formulated as follows: e.g. ***how much control do you feel you have over your TB disease?***

Health Related Quality of Life (HRQoL) was assessed by means of the 12-item short form Health Survey questionnaire (FS-12) (116), translation to Arabic language and back translation was conducted. The SF-12 is a generic measure of health status, encompassing 12 questions covering eight dimensions of health significantly affected by medical condition: physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health. This eight-scale profile was summarized into two components (116): physical component summary (PCS) (including limitation in self-care, physical, social, role activities, severe bodily pain and frequent tiredness) and mental component summary (MCS) (including the presence of psychological distress, the limitation in usual social and role activities due to emotional problem).Cronbach's alpha was calculated for the physical and mental components scale

showing the reliability of 0.89 for the 8 items and 0.88 for the 4 items included in the scales respectively. Later, both physical and mental components for TB cases were categorized into three levels: poor, fair and good.

Literature review part: TB stigma a world wide experience (Paper No. 5)

A literature review method was used to assess tuberculosis (TB) stigma and discrimination worldwide.

To assess the world wide experiences of TB stigma, the publications found on TB stigma that were published in English between January 1990 and October 2010 were reviewed. The publications were identified by searching the PubMed database, WHO publication, and CDC publication, Social Science citation index, Arts and Humanities and Social Science database. Several term combinations were used of the word “stigma”, “tuberculosis”, “barriers”, “perception”, “cause”, “impact”, “treatment” “knowledge”, “attitude”, “adherence”, “compliance”, “gender” and “practice”. No ethical clearance was needed as this is a review with secondary data.

Forty two studies were identified. First, the titles and abstracts were screened by the first two authors, and if relevant, the whole papers were read through. Two review studies were excluded: one from Nicaragua, a review on methodological approaches for assessing TB stigma (117) and another considered other stigmatizing diseases such as HIV/AIDS, mental illness, leprosy and epilepsy in general and was not specific to TB (112). Additional reports were identified by manually reviewing the references of the studies found (snowball approach).

5. RESULTS

Research question No. 1: Achievement of the TB control programme in Khartoum state (1)

The central level of the tuberculosis control programme and 42 tuberculosis microscopic units (TBMUs) in Khartoum state were covered in the study.

Tuberculosis case detection

The TB smear positive detection rate in Khartoum state was 2,900 cases (77.2% of the 70% (n=3,756) recommended standard). In Khartoum state 92.9% of the health care facilities traced positive TB patients' contacts. The focus group expressed that the case detection rate was still below the acceptable rate. This may be due to either most of the population in the state not being aware of the programme, shown by the following quote: "*There is no health education programme and this may lead to a decrease in the number of cases discovered* "; alternatively, the disease burden may have changed in the state and there might be a reduction of TB prevalence since the last TB prevalence survey was conducted in 1986.

Tuberculosis treatment outcomes

The treatment success rate of the detected cases in Khartoum was 73.5% *[**Numerator**:* Number of new smear-positive pulmonary TB cases registered in a specified period that were cured plus the number that completed treatment. ***Denominator**:* Total number of new smear-positive pulmonary TB cases registered in the same period ((1897+ 1790) / 5020) X 100)] (Table 1). The prevalence of MDR-TB and HIV among TB cases is a very important issue, but unfortunately, no system existed for MDR-TB and HIV sero-prevalence for the TB cases surveillance in Khartoum. The case fatality rate was 2.2 %; and the treatment failure was 2.2%. The programme in Khartoum state had default rate of 14.1% and transfer-out rate of 8.1%. Further, 6.3% of the cases were classified as re-treatment TB cases in Khartoum state.

In the focus group discussion it was mentioned that the absence of the private health care sector share in the TB control programme activities in the state (although it deals with small numbers of patients) might have a negative impact on the case detection and treatment outcome, as stated by a focus group participant: “Most *of the private medical specialists prescribe TB treatment differently from the standard protocol. Also there was no follow-up system by the private medical specialties for TB patients, so some of these patients may interrupt their treatment”*. The discussion revealed that the low treatment success rate in the state might be due to the DOTS programme in Khartoum state. DOTS had one of its components (DOT (directly observed treatment) not well implemented; this meant that there was no direct daily observation of patient treatment. The focus group participants brought this up as follows *"there are no real DOTS in most hospitals and health centers*" *and “this is due to many technical, social and economic factors”*. Also "*most of the patients have no economic possibilities to come daily to the health facility to have drugs under direct supervision; so the health professionals give the treatment for one or two weeks; some of the treatment centers are located far away from the patient’s residence; and another factor is the stigma of TB as a disease*".

TB case holding

In Khartoum state only 81% of the health care professionals’ traced *defaulters’* cases; 30% of the health facilities had no transportation methods to trace high percentage (14.1%) of defaulters recorded in the year 2006. Also according to the focus group discussion the programme had problems in tracing TB defaulters. This was both due to incomplete patients’ addresses and due to staff-related difficulties such as culturally ‘unsuitable’ health professionals to trace TB treatment defaulters: “professionals *who trace defaulters and contacts are old people or females who cannot ride the bicycle, which is the transportation method for defaulter tracing"*.

Tuberculosis diagnosis indicators

The laboratory network exists in Khartoum state. Almost 95% of the health facilities had available laboratory equipment and material to conduct TB investigation; 88.1% of the TB microscopic units had the workload of at least two slides per day. The proportion of all smear negative cases properly diagnosed in Khartoum state was 99.2%, while 90.1% of all detected smear-positive cases were registered for treatment; and 97.5% of the health care facilities in Khartoum state in 2006 kept of all smear positive slides; and 10% of randomly selected smear negative slides for the quality assurance.

The socio-demographic characteristics of the population study

The study included 425 TB cases and 850 controls: among the TB cases the proportion of men was slightly higher than among the controls. Marital status distribution was similar as half of the cases and half of the controls were married and one third of both were singles. There was a statistically significant difference in the level of education between the groups (Table 5.1); 20% of the cases had no education and seven percent had university education whereas the respective percentages among the controls were 10 and 20. The cases lived more often in the rural area than the controls. Further, the cases were less often employees than the controls; somewhat less than half of both groups were without work. (see table 5.1. following page)

Table 5.1: The socio-demographic characteristics of TB cases (n=425) and their controls (n=850) in Gezira state, Sudan

Variable	TB cases (n = 425)		Controls (n = 850)		Significance
	Frequency	%	Frequency	%	P-value
Age group					
Less than 30 years	158	37.2	329	38.7	0.69
31 – 50 years	194	45.6	390	45.9	
More than 50 years	73	17.2	131	15.4	
Gender					
Male	262	61.6	480	58.2	0.04
Female	163	38.4	370	41.8	
Marital status					
Married	235	55.3	442	53.1	0.15
Single	148	34.8	292	34.5	
Others	42	9.9	116	12.4	
Education level					
No school	148	34.8	152	17.9	< 0.001
Middle level of education	155	36.5	242	28.5	
High level of education	122	21.1	455	53.6	
Type of residency					
Town	151	35.5	392	46.1	< 0.001
Village	242	56.9	429	50.5	
Others	32	7.5	29	3.4	
Occupation					
Non-worker	199	46.8	364	42.8	< 0.001
Employee	21	4.9	143	16.8	
Labourer	98	23.1	157	18.5	
Employer	107	25.2	186	21.9	

There was no significant difference in the family size between the cases and controls. About half of both groups had families of four to seven members, which is typically the size of modern Sudanese families. The number of rooms per house was two for half of the TB cases while a half of the controls had three to four rooms; the controls significantly different from the TB cases in having a house consisting of more than four rooms. Only six per cent of the TB cases and five per cent of their controls had no home.

Both the cases and controls primarily (89%) sought health care in governmental health facilities. Very few of both TB cases and their controls sought health care either from traditional healers or in private sector. The TB cases had significantly more often than the controls ($p<0.05$) attended health care facilities in the past year although only 18% of them attended health facilities due to their TB disease. A quarter of the TB

cases and 13% of their controls had a family member who had TB; less than 20% of both TB cases and their controls had neighbour who had TB; and about 10% of both TB cases and their controls had a friend who had TB.

Half of the TB cases sought for help two or three times in a health facility during the last year while one fifth of them never sought for any help during the last year and very few of them went to a health facility more than five times. Half of the controls did not seek any health care during the last year.

Research question No 2: Level of awareness related to TB among Gezira population (Paper No. 2)

Almost everyone in both groups of TB patients and their controls had heard about TB. On the other hand, the groups differed significantly in the sources of their TB knowledge: the controls mentioned media more often and the cases mentioned family slightly more often. One third of both the cases and their controls had got knowledge about TB from health care workers.

Only about 30% of both the cases and controls stated that they had enough information about TB. The cases and controls were not much different in how well they understood the TB information that they received from different sources. TB was viewed as a common disease in Sudan by almost half of both the TB cases and their controls. TB was mentioned to be very serious by around one third of both TB cases and their controls. The cases more often than controls answered that they did not know how common and how serious TB was. Regarding the knowledge of the clinical presentation i.e. symptoms of TB, most of the TB cases and their controls knew some of TB symptoms while 1/3 of both cases and controls knew all TB symptoms. Seventy percent of both TB cases and their controls knew the methods of TB transmission (Table 5.2). The methods of TB prevention were known by about two thirds of both TB cases and their controls. Eighty percent of both TB cases and their controls mentioned that anyone can get TB while 10% of both thought that TB was a disease of poor people only.

Table 5.2: TB awareness among TB cases (n=425) and their controls (n=850) in Gezira state

Items	TB cases Frequency	%	Controls Frequency	%	Significance P-value
Information about TB was understandable					
Yes fully	85	20.0	144	18.0	< 0.001
Yes partially	84	19.8	322	37.9	
No	266	41.1	384	45.2	
Total	425	100.0	850	100.0	
Reasons for not understanding TB information					
Information difficult	46	17,3	70	18.2	0.04
Information too much	38	14.3	100	26	
Information incomplete	63	23.7	189	49.2	
Other	119	44.7	25	0.6	
Total	266	100.0	730	100.0	
How serious a disease is TB					
Very serious	134	31.5	251	29.5	< 0.001
Somewhat serious	170	40	351	41.3	
Not very serious	50	11.8	167	19.6	
I have no idea	71	16.7	81	9.5	
Total	425	100.0	850	100.0	
How serious a problemis TB in Sudan					
Very serious	128	30.1	220	25.9	< 0.001
Somewhat serious	147	34.6	303	35.6	
Not very serious	59	13.9	178	20.9	
I have no idea	91	21.4	149	17.5	
Total	425	100.0	850	100.0	
People at risk					
Knowledge of all people at risk	331	77.9		74.0	0.02
Knowledge of some people at risk	39	9.2	105	12.4	
No knowledge of people at risk	55	13.9	116	13.6	
Total	425	100.0	850	100.0	
Availability of vaccination against TB					
Yes	135	31.8	408	48	< 0.001
No	49	11.5	66	7.8	
I have no idea	241	56.7	376	44.2	
Total	425	100.0	850	100.0	
TB vaccination is protective					
Yes	110	81.5	360	88.2	< 0.001
No	25	18.5	34	8.3	
I have no idea	0	0	10	3.5	
Cost of TB diagnosis in Sudan					
Knowledge of TB diagnosis cost	373	87.6	612	72	< 0.001
No knowledge of TB diagnosis cost	52	12.4	238	28	
Total	425	100.0	850	100.0	
Cost of TB treatment in Sudan					
Knowledge of TB treatment cost	367	86.4	616	72.5	< 0.001
No knowledge of TB treatment cost	58	13.6	234	27.5	
Total	425	100.0	850	100.0	

Nearly 90% of both TB cases and their controls considered TB as a treatable disease; 80% of both groups knew that TB was treated by specific drugs given by governmental health facilities (Table 5.3). The TB treatment and diagnosis was known to be free of charge by about 90% of TB cases and 80% of their controls; a quarter of both mentioned that TB treatment is for six months while the others gave a range from one month till lifelong. Some of both TB cases and their controls considered the duration of TB treatment as long or short without knowing exactly the period. Regarding TB vaccination, only one third of TB cases and half of their controls knew about availability of vaccination against TB. More than two thirds of those who knew about TB vaccination thought that vaccine would prevent TB occurrence.

About two thirds of both TB cases and their controls had good TB awareness; around 20 % of had very good awareness and about 11% of both had poor awareness; 1% of both groups had very poor TB awareness (Table 5.3). On the other hand, there was no significant difference between TB cases and their controls in their overall level of their awareness about TB.

Table 5.3: The level of TB awareness among TB patients (n= 425) and their controls (n= 850) in Gezira state

Level of TB awareness	TB cases(n= 425)		Controls (n=850)		Significance
	Frequency	%	Frequency	%	P-value
Very poor awareness	5	1.2	8	0.9	
Poor awareness	48	11.3	124	14,6	0.81
Good awareness	279	65.6	576	67.8	
Very good awareness	93	21.9	142	16,7	
Total	425	100.0	850	100.0	

In the univariate analysis of the association between socio-demographic characteristics and TB awareness separately among cases and controls (Table 5.4), it was found that gender had an effect on the awareness among the controls but not among the TB cases; men having better awareness. Younger

age, higher level of education, living in town settings and being an employer or employee, were significantly associated with the higher level of TB awareness among both the TB cases and their controls while marital status had no effect (Table 5.4).

In the multinomial logistic regression analysis, to avoid unexpected singularity, the very poor and poor categories of the awareness level were merged (only 13 participants had very poor TB awareness); the crude odds ratios for the socio-demographic characteristics associated with TB awareness showed that high education level and being married were associated with very good awareness among the TB cases; younger age, living in town settings, high education level and being employer, were associated with very good awareness among the controls. High education level, being married and being employer were associated with good awareness among the TB cases while among the controls, high education was associated with good awareness (Table 5.5). Gender was found to have no effect on the level of awareness among either the TB cases or controls. Marital status had no effect on the awareness among the controls.

Table 5.4: Univariate analysis of the relation of TB awareness and socio-demographic characteristics among TB cases (n= 425) and their controls (n= 850) in Gezira state, Sudan

Items	TB cases (n= 425)					Controls (n=850)				
	Very poor awareness	**Poor awareness**	**Good awareness**	**Very good awareness**	**Significance P-value**	**Very poor awareness**	**Poor awareness**	**Good awareness**	**Very good awareness**	**Significance P-value**
Age	**Frequency**	**Frequency**	**Frequency**	**Frequency**		**Frequency**	**Frequency**	**Frequency**	**Frequency**	
Less than 30 years	1	15	111	31	0.02	5	46	215	63	0.02
31 – 50 years	4	25	130	35		2	69	266	53	
More than 50 years	0	8	38	27		1	9	95	26	
Gender										
Male	4	26	175	57	0.57	6	54	339	81	0.01
Female	1	22	104	36		2	70	237	61	
Marital status										
Married	3	26	159	47	0.17	6	66	304	66	0.53
Single	2	21	94	31		2	41	198	51	
Divorced or widow	0	1	26	15		0	17	74	25	
Education level										
No school	1	15	81	51	<0.001	0	7	105	40	<0.001
Middle level of education	4	26	175	39		4	82	335	81	
High level of education	0	7	23	3		4	35	136	21	
Type of residence										
Towns	3	22	101	25	<0.001	7	73	264	48	<0.001
Villages	0	21	166	55		1	49	294	85	
Others	2	5	12	13		0	2	18	9	
Occupation										
Non-worker	1	10	8	2	<0.001	3	38	91	11	<0.001
Employee	2	15	64	17		2	27	115	13	
Labourer	2	15	136	46		3	46	240	75	
Employer	0	8	71	28		0	13	130	43	

Table 5.5: Multinomial logistic regression analysis of the association between the level of TB awareness and socio-demographic characteristics among TB cases (n =425) and their controls (n = 850) in Gezira state, Sudan

Level of TB awareness (a)		Reference	TB cases (n =425)				Controls (n =850)			
			P value	Odds ratio	95% Confidence Interval		P value	Odds ratio	95% Confidence Interval	
					Lower Bound	Upper Bound			Lower Bound	Upper Bound
Poor awareness; reference very good awareness*										
Age	Less than 30 years	More than 50 years	0.06	0.17	0.03	1.08	0.05	2.76	1.02	7.45
	31 – 50 years	More than 50 years	0.70	0.81	0.27	2.34	0.40	1.47	0.60	3.57
Gender	Male	Female	0.81	0.88	0.31	2.68	0.23	1.46	0.79	2.73
Marital status	Married	Divorce and widow	0.03	0.21	0.05	0.82	0.22	0.62	0.29	1.34
	Single	Divorce and widow	0.17	0.30	0.06	1.64	0.51	0.75	0.31	1.79
Education level	No school	High education level	0.02	6.16	1.43	25.75	0.00	3.63	1.53	8.64
	Middle education level	High education level	0.19	2.89	0.60	13.97	0.04	2.12	1.02	4.41
	Town	Camps	0.77	0.82	0.22	3.18	0.01	0.21	0.06	0.72
Residence	Village	Camps	0.05	0.27	0.07	0.99	0.18	0.43	0.13	1.47
	Non-worker	Employer	0.43	0.38	0.04	5.08	0.13	0.42	0.14	1.28
Occupation	Employee	Employer	0.06	0.17	0.03	0.74	0.03	0.35	0.14	0.88
	Laborer	Employer	0.70	0.81	0.27	1.70	0.98	1.01	0.45	2.24
Good awareness; reference very good awareness										
Age	Less than 30 years	More than 50 years	0.38	1.47	0.62	3.47	0.71	1.13	0.61	2.09
	31 – 50 years	More than 50 years	1.00	1.00	0.47	2.10	0.93	0.97	0.56	1.69
Gender	Male	Female	0.77	1.09	0.62	1.93	0.08	1.38	0.96	1.99
Marital status	Married	Divorce and widow	0.06	0.33	0.11	1.03	0.18	1.42	0.85	2.37
	Single	Divorce and widow	0.03	0.25	0.07	0.86	0.28	1.38	0.77	2.47
Education level	No school	High education level	0.78	1.10	0.56	2.15	0.65	1.14	0.64	2.03
	Middle education level	High education level	0.03	2.09	1.10	3.99	0.03	1.63	1.05	2.51
Residence	Town	Camps	0.08	2.35	0.90	6.09	0.44	0.66	0.22	1.92
	Village	Camps	0.12	2.05	0.82	5.11	0.55	1.39	0.47	4.10
	Non-worker	Employer	0.05	0.33	0.11	0.98	0.05	0.57	0.32	1.01
Occupation	Employee	Employer	0.24	0.66	0.33	1.32	0.07	0.60	0.35	1.03
	Laborer	Employer	0.83	0.93	0.45	1.89	0.58	0.86	0.51	1.45

Research question No 3: Prevalence of stigma among TB patients and their controls in Gezira state (Paper No. 3)

The reactions of the TB cases when they got the diagnosis and that of their controls when imagining that they had TB were rather similar: one third of both had fear, and one third of both felt sad. Half of the TB cases had talked and half of their controls would talk about their illness to health care workers, 20% of both had told (or would tell) their spouse or other family member.

The first things done by both the diagnosed TB cases and their controls imagining that they had the disease, were: 80% sought or would seek help in a health facility; two thirds sought (would seek) health care when the symptoms and signs of the disease lasted (would last) for longer time, that is more than 3 weeks (Table 5.6).

Table 5.6: Reactions towards TB among TB cases (n=425) and their controls (n=850) in Gezira state

Items	TB cases Frequency	%	Controls Frequency	%	Significance P-value
Talk about your illness to					
Health care worker	190	44.7	442	52	0.14
Family member	203	47.8	363	42.7	
Friend	20	4.7	26	3.1	
No one	12	2.8	19	2.2	
Total	425	100.0	850	100.0	
First thing to do when having TB					
Seek health care	329	77.4	732	86.1	0.12
Self -treatment	19	16.1	31	3.6	
Wait and see	8	1.9	7	0.8	
Other	69	1.6	80	9.4	
Total	425	100.0	850	100.0	

Half of the TB cases as well as of their controls seemed to accept the TB patients in the community while less than five per cent of both saw that the community in Gezira state isolates patients with TB. The TB cases and controls did not differ in feeling shame of having TB, since more than half of both informed that they did\would not hide their TB disease and about two thirds of both said they did not/ would not isolate themselves as the result of the TB disease.

Half of both TB cases and their controls felt that social relations suffer from TB and two thirds of both groups felt that TB affects work while only one third of both mentioned that TB affects marital life. On the other hand, half of both TB cases and their controls mentioned that TB affects family responsibilities as well as the chance of marriage in Gezira state.

Less than half of both TB cases and their controls in Gezira state reported no experience of TB stigma. Almost half of those in both groups with some experience of TB reported mild degree of stigma; around five per cent of both reported moderate degree of stigma; none reported severe degree of stigma (Table 5.7).

Table 5.7: The degree of TB stigma among TB patients (n=425) and their controls (n=850) in Gezira state

Items	TB cases Frequency	%	Controls Frequency	%	Significance P-value
Degree of TB stigma					
No stigma	193	45.5	376	44.2	0.65
Mild	205	48.2	408	48	
Moderate	27	6.4	66	7.8	
Severe	0	0	0	0	
Total	425	100.0	850	100.0	

In the analysis of the association betweensocio-demographic characteristics and TB stigma separately among the cases and controls, it was found that middle age, lower level of education, rural type of residence and being labourer had significant association with the degree of stigma among both TB cases and their controls while gender had no association (Table 5.8). The lower level of TB awareness was significantly associated with the higher degree of TB stigma in both groups.

Table 5.8: Univariate analysis of the relation of TB stigma among and socio-demographic characteristics TB cases (n= 425) and their controls (n= 850) in Gezira state, Sudan

Items	TB cases (n= 425)				Controls (n=850)			
	No stigma (n = 193) Frequency	Mild stigma (n = 205) Frequency	Moderate stigma (n = 27) Frequency	Significance P-value	No stigma (n = 376) Frequency	Mild stigma (n = 408) Frequency	Moderate stigma (n = 66) Frequency	Significance P-value
Age								
Less than 30 years	83	72	3	0.001	135	174	20	0.02
31 – 50 years	80	101	13		169	186	35	
More than 50 years	30	32	11		72	48g	11	
Gender								
Male	111	133	18	0.27	196	243	41	0.07
Female	82	72	9		180	165	25	
Marital status								
Married	104	117	14	0.01	193	224	45	<0.001
Single	73	70	5		138	144	10	
Other	16	18	8		65	40	11	
Education level								
No school	73	59	16	<0.001	80	57	15	<0.001
Middle level of education	97	137	10		191	276	35	
High level of education	23	9	1		104	35	16	
Type of residence area								
Town	85	56	10	0.02	224	147	21	<0.001
Village	95	132	15		134	251	44	
Other	13	17	2		18	10	1	
Occupation								
Non-worker	10	10	1	0.03	68	63	12	0.01
Employee	39	52	7		55	85	17	
Labourer	144	143	19		153	260	37	
Level of TB awareness								
Poor awareness	18	7	6	0.001	48	25	9	<0.001
Good awareness	139	143	13		217	293	37	
Very good awareness	36	55	8		111	90	20	

The multinomial logistic regression analysis of the association between the socio-demographic characteristics and TB stigma showed that low educational level and being divorced or widow were significantly associated with stigma. Being single was associated with moderate degree of stigma while basic education level and being single were associated with mild degree of stigma (Table 5.9).

Table 5.9: Multinomial logistic regression analysis of the degree of TB stigma and socio-demographic characteristics among TB cases (n=425) and their controls (n= 850) in Gezira state, Sudan

Degree of TB stigma		Reference	P value	Odds ratio	95% Confidence Interval	
					Lower Bound	Upper Bound
No stigma; reference moderate degree stigma						
Age	Less than 30 years	More than 50 years	0.61	1.23	0.56	2.69
	31 – 50 years	More than 50 years	0.95	1.02	0.54	1.95
Gender	Male	Female	0.52	0.84	0.49	1.44
Marital status	Married	Divorce and widow	0.24	1.46	0.78	2.73
	Single	Divorce and widow	0.00	3.66	1.58	8.48
Education level	No school	High education level	0.45	1.39	0.59	3.24
	Middle education level	High education level	0.21	1.57	0.77	3.20
Residence	Town	Camps	0.91	1.08	0.30	3.92
	Village	Camps	0.16	0.40	0.11	1.41
Occupation	Non-worker	Employer	0.50	1.35	0.56	3.24
	Employee	Employer	0.65	0.86	0.44	1.67
	Laborer	Employer	0.10	1.80	0.80	3.58
TB awareness	Poor awareness	Very good awareness	0.62	0.84	0.42	1.67
	Good awareness	Very good awareness	0.23	1.36	0.82	2.24
Mild stigma; reference moderate degree stigma						
Age	Less than 30 years	More than 50 years	0.43	1.37	0.63	2.99
	31 – 50 years	More than 50 years	0.78	1.10	0.58	2.09
Gender	Male	Female	0.51	0.83	0.48	1.44
Marital status	Married	Divorce and widow	0.05	1.88	0.99	3.56
	Single	Divorce and widow	0.00	4.08	1.76	9.49
Education level	No school	High education level	0.75	1.15	0.49	2.70
	Middleeducation level	High education level	0.01	2.47	1.21	5.05
Residence	Town	Camps	0.42	0.59	0.16	2.15
	Village	Camps	0.33	0.54	0.15	1.90
Occupation	Non-worker	Employer	0.93	0.96	0.40	2.28
	Employee	Employer	0.34	0.73	0.39	1.39
	laborer	Employer	0.80	1.09	0.55	2.15
TB awareness	Poor awareness	Very good awareness	0.02	0.41	0.20	0.86
	Good awareness	Very good awareness	0.04	1.68	1.02	2.77

Research question No. 4: The level of illness perceptions and quality of life among TB patients in Gezira state (Paper No. 4).

Illness perceptions

The TB patients perceived that TB lasted long (**timeline)**; they indicated several symptoms to TB (**identity);** they saw TB being not well controlled by treatment (**treatment control)** but they saw minor consequences from TB (**consequences);** they thought that they understood their illness well (**coherence**); they were neither very much concerned about their illness (**concern**) nor emotionally disturbed by their illness **(emotional response**) **(**Table 5.10). The patients mentioned that the most common causes of TB were: poor nutrition, poverty and contact with TB patients.

Table 5.10: Mean scores (5 point Likert scale) on the B-IPQ dimensions among TB patients (n= 425) in Gezira state, Sudan

	TB patients(n = 425)	
B-IPQ dimensions	**Mean**	**SD**
Consequences	2.77	3.455
Timeline	4.22	1.360
Personal control	3.74	1.810
Treatment control	1.83	2.099
Identity	4.51	0.919
Concern	3.76	1.626
Coherence	3.15	1.776
Emotional response	3.12	1.938

Health Related Quality of Life

Two thirds of the TB patients rated their health between good and fair while less than 10 % rated their health as poor. Near to a half of the patients mentioned that their health affected their activities a lot (Table 5.11). About two thirds of the TB patients said that their health affected their work and activities; half of the patients felt depressed and reported that their work performance was affected by this

depression (Table 5.11). Feeling pain had moderate effect on their activities among two thirds of the TB patients.

The TB patients felt calm and peaceful most of the time (Table 5.12). Sometimes they felt that they had enough energy and around two thirds felt downhearted very few times. Further, half of the TB patients mentioned that their health problems had minor effect on their social relations (Table 5.11).

Table 5.11: Health Related Quality of Life (SF-12) among TB patients (n= 425) in Gezira state, Sudan.

Quality of life items	TB patients	
	Frequency	%
1.Health status		
Excellent	45	11.0
Very good	37	9.0
Good	143	34.9
Fair	136	33.2
Poor	49	12.0
2**.Limited activities**		
Limited a lot	165	41.9
Limited a little	197	50.0
Not limited at all	32	8.1
3. Moving for a long distance		
Limited a lot	206	50.5%
Limited a Little	179	43.9%
Not limited at all	23	5.6%
4.Work or other regular activities affected by physical health		
Yes	316	74.4%
No	109	25.6%
5.Activities limited in the kind of work or other activities		
Yes	329	77.4%
No	96	22.6%
6.Activities affected by feeling depressed		
Yes	195	45.9%
No	230	54.1%
7.Work or other activities affected by emotional problems		
Yes	195	45.9%
No	230	54.1%
8.Pain interfere with your normal work		
Not at all	57	14.0%
A Little bit	51	12.5%
Moderately	144	35.4%
Quite a bit	109	26.8%
Extremely	46	11.3%

Contd Table 5.11: Health Related Quality of Life (SF-12) among TB patients (n= 425) in Gezira state, Sudan.

Quality of life items	TB patients	
	Frequency	%
9.Felt calm and peaceful		
All of the time	65	16.0
Most of the time	137	33.8
A good bit of the time	68	16.8
Some of the time	73	18.0
A Little of the time	41	10.1
None of the time	21	5.2
10. Having a lot of energy		
All of the time	17	4.2
Most of the time	94	23.2
A good bit of the time	47	11.6
Some of the time	151	37.3
A Little of the time	74	18.3
None of the time	22	5.4
11.Felt downhearted		
All of the time	20	5.0
Most of the time	23	5.7
A good bit of the time	22	5.4
Some of the time	66	16.3
A Little of the time	159	39.4
None of the time	114	28.2
12.Physical health or emotional problems interfered with social activities		
All of the time	20	5.0
Most of the time	30	7.4
A good bit of the time	33	8.2
Some of the time	102	25.2
A Little of the time	117	29.0
None of the time	102	25.2

About half of the TB patients had fair physical quality of life while only around 15% had poor physical quality of life; about 10% had poor mental quality of life while around 40% had either good or fair mental quality of life (Table 5.12).

Table 5.12: Quality of life components (SF-12) among TB patients in Gezira state, Sudan

Quality of life components	TB cases (n =425)	
Physical component		
	Frequency	**%**
Poor	76	17.9
Fair	238	56
Good	111	26.1
	TB cases (n = 405)	
Mental component	**Frequency**	**Percent %**
Poor	53	13.1
Fair	170	42.0
Good	182	44.9

In the multinomial logistic regression analysis for the association between the socio-demographic characteristics and the two quality of life components (physical and mental), the crude odds ratios showed that only TB patients who had lower education level had poor physical and mental quality of life (Table 5.13 and 5.14). Being younger, single and with low education level were associated with fair physical quality of life while low education and living in village setting were associated with fair mental quality of life (Table5.13 and 5.14).

Table 5.13: Multinomial logistic regression analysis of the association between the physical component of quality of life and socio-demographic characteristics among TB patients (n= 425) in Gezira state, Sudan

Degree of physical quality of life		Reference	P value	Odds ratio	95% Confidence Interval	
					Lower Bound	Upper Bound
Poor physical quality of life; reference good physical quality of life						
Age	Less than 30 years	More than 50 years	0.60	0.74	0.25	2.21
	31 – 50 years	More than 50 years	0.58	0.77	0.30	1.95
Gender	Male	Female	0.58	0.81	0.38	1.73
Marital status	Married	Divorced and widow	0.22	1.88	0.68	5.14
	Single	Divorced and widow	0.41	1.65	0.50	5.48
Education level	No school	High education level	0.10	2.21	0.87	5.67
	Middle education level	High education level	0.01	3.25	1.37	7.70
Residence	Town	Camps	0.29	1.94	0.56	6.69
	Village	Camps	0.18	2.24	0.69	7.22
Occupation	Non-worker	Employer	0.36	0.36	0.04	3.15
	Employee	Employer	0.16	0.26	0.04	1.67
	Laborer	Employer	0.33	0.40	0.07	2.53
Fair physical quality of life; reference good physical quality of life						
Age	Less than 30 years	More than 50 years	0.00	4.38	1.86	10.33
	31 – 50 years	More than 50 years	0.00	4.85	1.81	12.97
Gender	Male	Female	0.16	1.65	0.83	3.28
Marital status	Married	Divorced and widow	0.11	1.70	0.89	3.23
	Single	Divorced and widow	0.02	3.03	1.18	7.76
Education level	No school	High education level	0.02	3.01	1.22	7.43
	Middle education level	High education level	0.13	0.24	0.04	1.51
Residence	Town	Camps	0.20	0.34	0.07	1.74
	Village	Camps	0.72	0.74	0.15	3.75
Occupation	Non-worker	Employer	0.10	0.26	0.05	1.32
	Employee	Employer	0.00	4.38	1.86	10.33
	Laborer	Employer	0.00	4.85	1.81	12.97

Table 5.14: Multinomial logistic regression analysis of the association between the mental component of quality and socio-demographic characteristics of life among TB patients (n= 425) in Gezira state, Sudan

Degree of mental quality of life		Reference	P value	Odds ratio	95% Confidence Interval	
					Lower Bound	Upper Bound
Poor mental quality of life; reference good mental quality of life						
Age	Less than 30 years	More than 50 years	0.58	1.38	0.45	4.21
	31 – 50 years	More than 50 years	0.51	0.73	0.28	1.88
Gender	Male	Female	0.18	1.71	0.78	3.74
Marital status	Married	Divorced and widow	0.47	1.57	0.46	5.38
	Single	Divorced and widow	0.85	0.87	0.20	3.78
Education level	No school	High education level	0.10	2.27	0.84	6.12
	Middle level education	High education level	0.03	2.81	1.10	7.17
Residence	Town	Camps	0.21	2.45	0.60	9.98
	Village	Camps	0.08	3.28	0.86	12.52
Occupation	Non-worker	Employer	0.05	0.20	0.04	0.99
	Employee	Employer	0.57	0.65	0.15	2.82
	laborer	Employer	0.04	0.19	0.04	0.95
Fair mental quality of life; reference good mental quality of life						
Age	Less than 30 years	More than 50 years	0.82	0.91	0.40	2.06
	31 – 50 years	More than 50 years	0.87	0.94	0.48	1.87
Gender	Male	Female	0.34	1.31	0.75	2.30
Marital status	Married	Divorced and widow	0.69	0.85	0.38	1.92
	Single	Divorced and widow	0.36	0.64	0.25	1.66
Education level	No school	High education level	0.97	1.01	0.53	1.95
	Middle level education	High education level	0.03	1.93	1.06	3.52
Residence	Town	Camps	0.18	2.09	0.71	6.11
	Village	Camps	0.00	5.61	1.98	15.88
Occupation	Non-worker	Employer	0.93	1.06	0.29	3.90
	Employee	Employer	0.83	1.15	0.32	4.16
	laborer	Employer	0.73	1.26	0.34	4.67

In the multinomial logistic regression analysis for the association between the two quality of life components (physical and mental) and the eight dimensions of illness perceptions (identity, consequences, timeline, personal control, treatment control, concern, understanding and emotional presentations) the crude odds ratios showed that TB patients who had high concern about their illness (concern), had poor physical quality of life while TB patients who understood their illness poorly

(coherence) had fair physical quality of life (Table 5.15). The opposite was found for mental quality of life as those TB patients who understood their illness poorly (coherence) had poor mental quality of life while thoseTB patients who had high concern about their illness (concern) had fair mental quality of life (Table 5.16).

Table 5.15: Multinomial logistic regression analysis: physical component of quality of life and TB illness perceptions among TB patients (n= 425) in Gezira state, Sudan.

Level of physical components		Physical component of quality of life			
				95% Confidence Interval	
	B-IPQ dimensions	P value	Odds ratio	Lower Bound	Upper Bound
Poor physical component*	Consequences	0.87	0.99	0.82	1.19
	Timeline	0.95	0.99	0.75	1.31
	Personal control	0.05	1.33	1.00	1.77
	Treatment control	0.18	1.15	0.94	1.41
	Identity	0.29	1.29	0.80	2.09
	Concern	0.00	1.68	1.18	2.41
	Coherence	0.36	1.13	0.87	1.45
	Emotional response	0.10	0.82	0.65	1.04
Fair physical component*	Consequences	0.80	1.01	0.92	1.11
	Timeline	0.08	1.21	0.98	1.49
	Personal control	0.35	0.92	0.77	1.10
	Treatment control	0.87	1.01	0.88	1.16
	Identity	0.16	1.21	0.93	1.57
	Concern	0.90	1.01	0.85	1.20
	Coherence	0.00	1.32	1.11	1.58
	Emotional response	**0.05**	**0.85**	**0.73**	**1.00**

Table 5.16: Multinomial logistic regression analysis: mental component of quality of life and TB illness perceptions among TB patients (n=405) in Gezira state, Sudan.

Mental component of quality of life		P value	Odds ratio	95% Confidence Interval	
				Lower Bound	Upper Bound
Poor mental component *	Consequences	0.43	0.90	0.70	1.16
	Timeline	0.11	0.80	0.62	1.05
	Personal control	<.001	0.66	0.53	0.82
	Treatment control	0.11	1.19	0.96	1.47
	Identity	0.83	1.05	0.67	1.64
	Concern	0.09	1.30	0.97	1.74
	Coherence	0.04	1.29	1.02	1.64
	Emotional response	0.17	0.84	0.65	1.08
Fair mental component*	Consequences	0.78	0.99	0.91	1.07
	Timeline	0.84	0.98	0.79	1.22
	Personal control	0.60	0.95	0.80	1.14
	Treatment control	0.34	1.07	0.93	1.22
	Identity	0.94	1.01	0.76	1.34
	Concern	<.001	1.51	1.25	1.82
	Coherence	0.35	1.09	0.91	1.29
	Emotional response	0.39	0.94	0.81	1.09

Research question No. 5: Tuberculosis stigma and discrimination worldwide (Paper No. 5)

The forty studies included came from the following countries: eight from the North America, three from South America, three from Europe, 12 from Asia, 13 from Africa and one was a multi-continent study. Most (n=33) of the studies were qualitative, either focus group or individual interview studies, three were quantitative survey studies using validated measurement scales while the rest used ad hoc items. Stigma related to TB was studied from the viewpoints of the groups of TB patients, community members and health care staff.

TB stigma among TB patients

Most studies addressed the issue of stigma perception among TB patients (83.3%). Lack or poor knowledge of tuberculosis as a disease, its transmission, management and the belief in the extreme contagiousness of TB were the leading causes to TB social stigma. This was found in the studies originating from countries such as USA (118, 119), Ecuador (120), Ethiopia (121), Kosovo (122), Mexico (123) and India (124).

The results concerning the association between the gender of the patient and TB stigma were inconclusive. Women had higher stigma than men in a study from Gambia (125); the reverse situation was found in the study from Vietnam (126). On the other hand, the studies from Bangladesh (127) and India (128) found no gender differences in perceiving TB stigma.

Having personal history of tuberculosis seemed to decrease the level of the stigma in comparison to no previous history as described by the studies from USA (119) and Ghana (129) .

In Ghana a study found that the causes of TB stigma among TB patients were: fear of infection, physical frailty, association with HIV/ AIDS, perceived causes and spread of TB, societal beliefs and practices about TB, public health practice and discourse. Fear of infection was identified as the main cause of TB stigma, with an element of fear recognized in all the other nine causes (listed above), named the 'moderating elements' (129).

A very important issue was addressed by a study from Uganda (130), which found that the Community-Based Directly Observed Therapy (CB-DOT) for tuberculosis was not a leading factor to increase the perception of TB stigma as was previously thought (130).

Incorrect beliefs may increase or decrease stigma perception level, which was demonstrated by the studies from Indonesia (131), Peru (135) and USA (132). The study from Indonesia (133) showed that the stigmatization of TB was associated with beliefs that TB is caused by Balinese magic or spirits; the

association of TB with being unclean; and beliefs that TB is an inherited disease. A study from USA showed that false beliefs regarding transmission and treatment of TB were common and there was a misconception that TB is transmitted similarly to infectious diseases such as HIV/AIDS which resulted in higher level of stigma towards TB (143). A surprising finding was done in a study from Peru (135), which found the TB stigma being very low due to the incorrect beliefs of TB being a nutritional disease. In that study TB was not associated with the fear of airborne transmission (135).

Associating TB infections with other chronic infectious diseases might increase the stigma level. Especially in the areas where TB and HIV are endemic (136-138), stigma of TB may be enhanced by its association with AIDS. E.g. in Malawi, TB related stigma was associated with sexual contact, and with the stigma of HIV/AIDS (139).

TB stigma and health care staff

Health care staff attitudes might induce a positive or negative impact on TB stigma. A study from Ghana (140) mentioned that health professionals enhanced the fear of the disease by the following five inter-related ways in the communities: isolation and exclusionary practices; behaviour of health professionals towards patients with TB; public health discourse; food safety and hygiene practices, and prohibition of full burial rites to those who died from TB. Also another study from Ghana found that health care staff's own fear of TB, blaming and shaming TB patients were leading causes to induce stigma among TB patients (129). On the other hand, in a study from Ethiopia the perceptions about sin and punishment from God as causes of TB were equally confirmed by both health care professionals and patients (129).

TB stigma among community members

TB was perceived as ‘a difficult disease’ because it disrupts patients’ social life, leading to social isolation and stigmatization not just for the patient, but for the family too - this was found in a study from Kenya (118).

A belief in the extreme contagiousness of TB seemed to lead to social stigma and isolation among communities as it was mentioned by a study from USA (118 &141). According to a study from Ghana (141) general socioeconomic factors and the forms of the health seeking behaviour affected the perception of TB stigma in the community.

Similarly to the results about gender and stigma among the TB patients, results concerning TB stigma perceptions in community members were inconclusive: a study from India reported gender differences where the stigma of TB was more visible in women than in men (142), while a study from Congo (143) found no gender differences in perceiving TB stigma.

Religion may play an important role in the TB stigma among the communities; it was found that Buddhists seemed to stigmatize TB patients while Muslims seemed to support TB patients in their communities. However, this is the only study on the theme and thus remains suggestive (144).

6. DISCUSSION

Based on the WHO indicators for monitoring and evaluating TB control programmes, which was used to assess the TB control programme in Khartoum state, the main findings can be summarized as follows: the TB control programme in Khartoum state achieved 57.3% case detection rate of all TB forms, and 77.2% of the smear postive cases. The programme achieved 73.5% treatment success rate, and it had death rate of 2.2%, treatment failure rate of 2.2%, and default rate of 14.1%. There was no system to detect the prevalence of MDR-TB (Multi Drug Resistant TB) and HIV (Human Immunodeficiency Virus) among the TB cases; 90.1% of all detected smear positive cases were registered for treatment in the year 2006. Defaulters tracing system was not activated. The programme was not well implemented at either locality or health area level. Drugs and laboratory supply systems were functioning well.

There was no significant difference between the TB cases and their controls in TB awareness. About two thirds of the TB cases and their controls had good TB awareness. Gender had an effect on awareness among the controls but not among the TB cases. Age, level of education, type of residence and type of occupation were significantly associated with the level of TB awareness whereas marital status had no effect. Younger males, highly educated persons, being employers or employeeshad very good awareness and so did those living in towns.

TB stigma did not differ between the TB cases and their controls; a mild degree stigma was found in both groups. Moreover, the higher degree of stigma among both groups was significantly associated with higher age, lower level of education, rural type of residence area, non-working and poor TB awareness whereas gender had no association with the degree of stigma in either group.

The TB cases saw TB having minor consequences, TB being not well controlled by treatment and lasting long; they also associated several symptoms with TB. Furthermore, TB cases had poor physical

and mental quality of life. Identity, consequences, personal control and emotional representations were associated with poor physical quality of life while concern about illness was associated with poor mental quality of life.

Most of the studies reviewed showed that poor TB knowledge was the major cause of TB stigmatization. Association between gender of the patient and stigma varied from one study to another. Stigma had serious consequences on health seeking behaviour and adherence to TB treatment. The perception of TB as a stigmatizing disease seemed to differ according to cultural context.

Evaluation of TB control programme in Khartoum State

Case detection

For smear positive cases, the programme in Khartoum state did not achieve the 70% detection rate recommended by the WHO. This means that the programme does not ensure a positive epidemiological impact, i.e. decreasing incidence of TB disease (116). The situation of the case detection in Khartoum was better than that in Ethiopia where it was 45% (145). On the other hand, there are countries in the East Mediterranean Region, which achieved a 70% case detection rate (146). Most probably, the cause of the low detection rate in Khartoum state is that the annual TB risk for infection is calculated based on the incidence of new cases of smear-positive TB in the year 1986, and since that the annual risk estimates have never been updated. Thus the present cutoff point for the number of cases expected to be discovered every year may not be true – this is an urgent future research issue. Another important issue, expressed by the focus group discussion, is that health care providers in the private sector are not fully involved in the tuberculosis care. There are some patients treated in this sector without any proper recording and reporting system, which may result in the underestimation of the detected cases.

In addition, as expressed by the focus group discussion, there is no health education programme for tuberculosis in the state and this may lead to the decrease in the number of cases discovered as patients may not seek treatment or may come very late. Finally, the disease stigma may play a role in this low case detection rate as some cases may not seek health care. This was brought up as an important reason also in the focus group discussion of this study. Previously, the TB-related stigma has been shown to be a problem among TB patients attending the TB microscopic units in Khartoum state where 87.8% of the patients experienced high degree of stigma (147).

Tuberculosis treatment success

The TB programme in Khartoum state achieved treatment success rate lower than 85% recommended by the WHO. This situation is similar to the situation in Congo (148). The Khartoum and Congo rates are low compared to Ethiopia where the programme achieved the treatment success rate of 85% due to the decentralization of DOTS (145). The low treatment success rate is mainly due to a high proportion of cases that interrupt treatment, die, transfer between treatment units without a record of the final treatment outcome or are not evaluated at all (149). The interruption of the treatment is an important problem in Khartoum state, which is indicated by the high default rate of 14.1%. High HIV prevalence and MDR-TB are known to have the greatest negative impact on successful outcome of the TB treatment (148,150). Unfortunately, there is no system for MDR-TB and HIV sero-prevalence in the TB case surveillance in the Khartoum state. MDR-TB and HIV problems may be present in the state and cause the problem of low treatment success rate as has been shown in Congo and South Africa (148, 150).

Tuberculosis treatment failure

The TB programme in Khartoum state has a treatment failure of a little more than 2%, which is within the level of the WHO criteria (1.5 to 3 percent) (116). There is a need for a case management review to determine if these failures could have been prevented and/or if programme interventions are warranted. Since the currently recommended treatment regimens are 98 percent effective, no programme should achieve 0 percent of treatment failure (116). This failure rate is low if compared to South Africa (10%) where most failures were due to the extremely drug-resistant TB (150). The Khartoum rate is high compared to the rate of Mehsana district, India (0.73%). The Indian success is due to the directly observed treatment, short course observed strictly (151).

The treatment failure may be due to inappropriate treatment regimens or underlying primary resistance, but as 90% of the health care professionals prescribed treatment according to the WHO standard guidelines, and almost all TB detected cases in Khartoum state in the year 2006 were treated with correct regimen, inappropriate use of the regimens is unlikely. This leads to think that drug resistance may be the major cause, but as the programme has no system to look for primary resistance, it is difficult to find that out. Interruption of TB treatment is also considered as one of the most important causes of treatment failure in Khartoum state, where it was 14.1%.

Tuberculosis treatment defaulters

The TB programme in Khartoum state had a default rate of 14.1% which is very high compared with the standard (2% -3 %.). This default rate is as high as the rate in Lusaka, urban Zambia and Kampala Kisenyi suburb of Uganda (152, 153).

As expressed by the focus group discussion, an absence of patient counseling at the start of the treatment, stigma related to TB, and economical situation, are the basic causes for a relatively high defaulting rate in the state. Many studies have demonstrated that stigma deters people from seeking care

and diagnosis (154,) which seemed to be the case also in the population study in Gezira state. A well-documented literature has shown why and how TB has been highly stigmatized throughout history (154). Whilst the stigma of TB as “a disease of the poor” persists, more recently, HIV/AIDS stigma affects TB patients, particularly in communities where HIV/AIDS is prevalent, as shown in studies in Ethiopia, Pakistan, and Thailand (154).

It is well-known that sticking to the DOTS strategy prevents treatment interruption. But as expressed by the focus group discussion, there was no real implementation of DOTS in the Khartoum state in the component of DOT. DOT has many advantages over self-administered therapy as it ensures that the patient completes an adequate regimen, it lets the health care worker monitor the patient regularly for side effects and response to therapy, it helps the health care worker solve problems that might interrupt treatment, and by ensuring that the patient takes every dose of medicine, and it helps the patient become noninfectious sooner. But DOT does have disadvantages such as being time consuming, labor intensive, it can be insulting to some patients, it can imply that the patient is incapable or irresponsible, and can be perceived as demeaning or punitive (153). In addition to these disadvantages in Khartoum state, the poor economic status of the patients as well as stigma probably hinder patients from attending on the daily bases to receive anti TB drugs. The system in the state is not sticking to daily DOTS.

The TB programme in Khartoum state faces problems in defaulter tracing as expressed by the focus group discussion due to incomplete patient addresses. On the other hand, difficulties of defaulter tracing were related to the issues such as the appointed personnel for this job, who were female or old in age. In Khartoum this means that it was not customary for them to use the bicycle - the main transportation method for defaulter tracing at the health facility level.

Tuberculosis awareness among Gezira population

Awareness is a very important parameter to be assessed in order to provide baseline data to assist the decision makers to plan for and deliver of an effective TB control programme. The present study revealed some important reflections on TB awareness among Sudanese population.

When assessing the degree of TB awareness, the majority of both TB cases and their controls had good awareness. Good awareness level can probably be explained by high prevalence of TB in Sudan, which may increase searching for knowledge about the different aspects of the disease in order to avoid it. Another explanation might be an active TB control programme in Sudan, which uses the effective DOTS for TB treatment. This might improve TB patients' and their relatives' knowledge about the disease through the regular educational and /or counselling sessions; also other methods might have similar effects such as TB World Day Celebration and education/health promotion messages. Further, the diagnosis of TB cases motivates them to further search for information. In spite of the rather good awareness level, less than one third of both cases and controls reported having enough information of TB, indicating that there is also a perceived need for more information.

In this study gender had a significant role in TB related awareness among the controls but not among the TB cases. This could be due to both of male and female TB cases sharing similar level of education as was found in Khartoum State (126). This finding among controls is similar to the findings reported in literature, e.g. from China, where women were less likely than men to get information about TB and share it with others on their own initiatives (155).

Our findings support the educational level effect on the level of TB awareness among TB cases and their controls; the level of TB awareness increased when the educational level increased.In Gezira state, persons, who had educational level at high secondary school level or higher, were likely to have very good awareness among both TB cases and their controls. This was similar to what was found in Khartoum state (155). As the controls were more highly educated than the TB cases, in the Sudanese

setting media was their choice as a source of their TB information while the TB cases had more often their information from healthcare workers. TB patients' awareness very likely came as a result of having the disease.

We found that people who lived in towns among the controls were more likely to have very good TB awareness than people who lived in rural areas. This can be explained by better accessibility to different sources of TB information in town settings such as media as well as better education level than in the rural areas. However, among the TB cases the place of living did not have effect on their TB awareness. These findings among controls are similar to what was found in Pakistan where health seeking behavior was better in the urban areas (156).

In this study, among the controls, being an employer was related to very good awareness about TB compared to non-workers; however, among the cases occupational status did not make a difference in TB awareness. This result is in line with what was found in Khartoum state (153) as well as in West Africa (157).

The level of the TB awareness is known to have positive impact on the prevention of TB (27). Having more knowledge about methods of TB transmission and about ways of preventing the disease, helps in decreasing the TB risk (158). However, this study found no significant difference in TB awareness among TB cases and their controls in Gezira state. This similarity in the TB awareness can be justified by the fact that the TB cases probably acquired this knowledge after they were diagnosed to have TB and received health education and/or counselling as a part of TB management using DOTS strategy. The role of health education to raise the knowledge of TB is highly appreciated in initiatives to fight against TB (65)**.** A good level of TB awareness found among the TB cases and their controls can function as a baseline for further TB awareness rising among the Gezira population. Health education and health promotion as continuous processes can maintain and further elevate the level of awareness (158) and thus also motivate the patients to seek the treatment and adhere to it. High level of TB

awareness in the presence of low case detection and high default rates suggests other barriers that prevent patients to access health care. This calls for further research.

TB stigma among TB cases and their controls in Gezira state

This study showed that the overall TB stigma did not differ between the TB cases and their controls in Gezira state; a mild degree of stigma was found in both groups. Moreover, the higher degree of stigma among both TB cases and their controls was significantly associated with higher age, lower level of education, rural type of residence area, non-working and poor TB awareness while gender had no association with degree of stigma in either group.

The overall mild degree of stigma among TB cases and controls might be explained by TB being relatively common disease in Sudan (147). Further plausible explanations are the unique socio-cultural nature of Sudanese community with its close social ties becoming even closer in hard times such as illness, but also the supportive nature of Islamic religion, as suggested by a study from Thailand (159).

The results concerning the middle age group among both TB patients and controls having the highest degree of stigma - even if that also was on a moderate degree - might be a result of social activity of this age group and their frequent contacts with the community. This might help when tailoring health education and health promotion activities.

In this study gender was not associated with TB-related stigma. This differs from what has been reported in the literature, as women have usually been found to be more affected than men. This may be due to cultural factors and situation of women in societies, e.g. in Bangladesh higher mean index values for stigma have been reported for women than men (160). This finding might reflect the recent improvement of the cultural and social situation of women in the Sudanese society as women became more empowered.

Our findings concerning lower degree of stigma among those with higher education (especially among the controls) are in line with a study from Pretoria (161) in which better educated had better knowledge about TB as treatable disease.

Both among the TB cases and their controls the association between TB awareness and TB stigma showed decreasing degree of stigma with increasing awareness; this might be due to accepting the disease as a curable condition. Lack or poor knowledge about tuberculosis as a disease, its transmission, management, and the belief in the extreme contagiousness of TB, were the leading causes to TB social stigma in studies originating from countries such as USA (118, 119), Ecuador (120), Ethiopia (121) and England (162).The English study showed that knowledge about the signs and symptoms was lower among non-white patients than among white patients who were more knowledgeable and less stigmatized.

Stigma impaired the quality of life through concerns about disclosure, and it affected work, education, marriage, and family life, as was found in the literature review. Social consequences due to TB stigma seem to differ between studies and countries. In a study from England patients did not feel threatened by their illness as they believed that the disease was not infectious to their family or friends; they looked forward to a complete recovery after treatment; they also considered TB to be acceptable by family and friends (162). On the other hand, the studies from Pretoria (161) and Cali, Colombia (163) did not support this fact as was found in the review Paper No V. Disease-related stigma may cause problems in family relationships and friendships, increase inequities between those who are affected and who are not; it can also lead to participation restriction, loss of job, and to economic dependency, which may affect entire families (164).

The finding that people who lived in rural areas among both TB cases and controls were more likely to have more stigma than those who lived in towns is in line with a study in Ethiopia (165) and could be a

consequence of low awareness and lower education about TB among rural people as suggested in Paper No 3.

TB illness perceptions and quality of life among TB patients in Gezira state

Illness perceptions are the organized cognitive representations or beliefs that patients have about their illness. These perceptions have been found to be important determinants of behaviour and have been associated with a number of important outcomes such as treatment adherence and functional recovery (104, 106).

The results of this study among TB patients in Gezira, Sudan, showed that TB patients perceived often their illness to be of long duration, having several symptoms and TB treatment being not so effective. These perceptions might mean that TB patients have low treatment adherence. Further, the emotional reactions to TB as well as limitations in their social activities might be barriers to seek treatment and adhere to treatment. Adherence is a challenge for the TB control programme in Sudan, as the early case detection, prompt treatment and case holding, are the golden strategies in controlling TB (166). Having symptoms of TB such as chronic productive cough, hemoptysis, weight loss, and perceiving the nature of TB to be an infectious disease in some patients, might initiate the feeling of guilt of infecting others and aggravating the sense of stigma. The latter is considered as a barrier for seeking and maintaining treatment (164).

It is known that socio-demographic factors are associated with illness perceptions (166, 174). Thus it is important to tailor and deliver the appropriate TB interventions both for prevention and cure so that socio-demographic characteristics are taken into account. This indicates that more care is needed in terms of counseling and health education of TB patients in order to decrease the psychological impact of TB.

In this study the overall quality of life among TB patients was found to be relatively poor. The association of illness perceptions with decreased quality of life has been found in a number of other illnesses (e.g. diabetes and renal disease) (167-172). Illness perceptions of patients have been shown to significantly influence both psychosocial and physical well-being and thus affect the quality of life of the patient (22). This study found that TB patients who were highly concerned about their illness seemed to have fair mental quality of life. This is opposite to which was found in a study from Pakistan (173).

Based on the literature, depression and anxiety are very high in patients with tuberculosis. Psychiatric complications such as anxiety and depression can severely impact quality of life of TB patients (175). In our study about half of the TB cases felt depressed, which is on the same level as in Pakistan (173); this might be due to the perception of the nature of TB as chronic disease, severity of the symptoms and social stigma associated with the diseases (152&164). Feeling of depression might affect the adherence to TB treatment, which results in high default rate; default rate has been shown to be high in Sudan (152) and can thus bring failure to control TB. This finding is supported by a study from India (29).

TB patients had poor levels of social and physical activities dimensions of health related quality of life, which might reflects their performance at work and generally in life and could lead with other factors to stigma and poor adherence to treatment (175).

Tuberculosis stigma and discrimination worldwide by a review

The studies reviewed provided descriptive information on the perceptions of TB stigma and its impact from the perspectives of TB patients, community members and health care staff in different parts of the world, including both developed and developing countries. The studies also suggested ways to alleviate or manage this stigma.

Most of the studies in both developed and developing countries showed that poor knowledge of both the community members and TB patients about the disease and its transmission was the major cause of TB stigmatization (118-124). On the other hand, incorrect beliefs (119) about nutrition as a determinant for TB may also protect from stigma instead of it being infectious. We know from the illness perceptions and health psychology literature that even if basic cognitive structures of the illness representations remain the same across cultures, the specific contents of the representations may vary (176, 177).

Generally in the studies reviewed there are many factors that may play a role in the perception of the stigma: lack of knowledge about TB transmission, diagnosis and treatment; gender in certain contexts; feeling guilty about infecting others or being afraid of getting TB; as well as attitudes towards TB patients. Our findings differed from these studies in that in Gezira state gender had no effect on the level of either experienced or perceived TB stigma.

No coherent picture emerged from the studies reviewed about gender-based features of TB stigma. Occurrence and nature of stigma might reflect different gender roles in different cultures. More culturally sensitive studies are needed in this area.

Stigma against TB patients can occur in many settings: on the family level, in workplaces, within the community and most seriously at the level of healthcare facilities where health care providers such as nurses (112) and other health professionals (140,142) can induce stigma by their negative attitudes towards TB when performing diagnosis and treatment of the patients in isolating manner. This increases the feeling of the stigma for both patients and their relatives. Moreover, this may enhance fear of the disease in the community, which again might worsen the stigma among TB patients (142).

According to the health psychology literature, negative illness perceptions (e.g. a large number of symptoms associated with the condition, more severe consequences, and longer time-line beliefs) can have serious impact on patients' well-being, including psychological well-being; on behaviour, e.g. interpreting early warning signs, seeking diagnosis, care, and adherence (178, 179); but also on

functional recovery and in general on outcomes independent of the initial medical severity of the condition (108 - 113).

TB stigma can have psychological effects on the patients by increasing stress, anxiety, depression, feeling of loneliness or discrimination (93,180); it can also shatter infected person's identity and self-confidence, significantly decreasing their ability to manage the disease successfully. Stigma can have medical effects such as increased disease disabilities, decrease motivation to seek medical advice or continue treatment and may lead to poor prognosis (28&181).

The social stigma imposed by TB infection resulting in incapability to work can lead to an economic crisis for both the patient and their family members (103). In some areas of the world this stigma is a more temporary taint – that fades away once a person is cured – but in other areas of the world, TB gives a more permanent stigma that can even affect marriage prospects and relationships (96).

Stigma has serious consequences on TB control in two ways: firstly, as the result of fear and stigma, TB patients may delay to seek care (130&212). This may lead to increase of risk of complications, and TB will become more difficult to treat; the TB patient may become a source of infection for longer time affecting large groups of the population and the end result will be increasing incidence of the disease in the community. Secondly, TB stigma might negatively affect the adherence and compliance of the TB patient to the treatment (92). Poor adherence to the treatment of the disease can lead to a large number of defaulters, which results in prolongation of the duration of the TB transmission to a larger section of the community. Further, a more serious outcome can be a multi-drug resistance problem due to partial access to the TB treatment.

Locally tailored community interventions towards certain groups such as adolescents, using special non-traditional information and health education means such as drama might be efficient (182, 183).

Further, communication of medical information of TB might help in managing the TB related stigma (184). Health education and social marketing directed toward increasing TB knowledge and changing

perceptions and attitudes could ultimately contribute to improve early diagnosis, treatment adherence, prevention, and decreased TB stigma (184).

Social support as a facilitator and stigma as a barrier are diametrically opposed concepts (185). So broad, culturally specific, patient, family, and community level education programmes against TB related stigma might help in managing TB stigma. Thus formulation of a social support programme to TB patients might be another important strategy to treat TB related stigma. It should create a supportive emotional environment for TB patients.

Another option in managing of TB related stigma is mainly based on the empowerment of both TB patients (186, 187) and the communities by increasing their knowledge through proper education programmes as well as proper education of the health care providers who take care of TB patients. Training workshops in TB control have been shown effective for promotion of knowledge and elimination of stigmatization in first-line caregivers (186).This education may include topics such as new infection control guidelines (188). Also cultural competency in TB programme has become increasingly important. Efforts to promote health as well as prevent and treat TB within culturally diverse groups are needed (188).

Furthermore, human rights arguments can be used to reduce vulnerability by modifying laws, policies, regulations or practices, e.g. by ensuring freedom from discrimination in all spheres of society (188). It is important that employees and healthcare professionals understand the determinants of TB stigma to ensure that they prevent violation of human rights, that patients seek timely advice and achieve good treatment adherence and thus better treatment outcomes.

Without knowledge of the causes of stigma and discrimination associated with TB, it is difficult to devise discrimination-reduction strategies that are likely to work. Therefore, a need to investigate the causes of discrimination in depth from patients' and families' perspectives in different contexts is necessary since what is functioning in one place might not work in another.

The results of review (Paper No 5) give an idea about perceptions, impact and management of TB related stigma worldwide. However, the review was limited only to the studies found in English language. The studies were mainly qualitative in their character, thus they do not give information about the prevalence of stigma; further, descriptive studies do not provide information about effective interventions. In addition, some of the studies were small and issues like DOTS in relation to stigma, and religious affiliation in relation to stigma, were only supported with one study; further, findings related to gender-based stigma varied a lot between countries, probably suggesting cultural differences in gender roles; however, based on a few studies deeper analysis is not possible. Thus more research is needed in this area. Moreover, in many studies reviewed no theoretical framework was specified and used to guide the study.

Methodological considerations

The strengths of the study

The study provided baseline information, which will help Khartoum state to strengthen the TB control programme which had not been assessed before. The study provides also new knowledge from TB KAP, stigma and illness perceptions among Gezira population.

Further, the strengths include the used standard, generic WHO KAP Questionnaire and standard indicators for evaluating the TB control programme as well as pre-test of the questionnaire; the latter probably helped to make the questions simple and easily understood. A high response rate gives further strength to the study. In the focus group discussion, the participants were chosen to represent the different levels of TB control programme in order to overcome selection bias. The strengths of the population study were: high response rate, having controls without TB diagnosis, and the data collected by trained health care workers as well as relatively good reliability, measured by Cronbach's alpha, of the scales used.

Limitations of the study

The study was conducted in the two most populated states of Sudan, Khartoum and Gezira, to represent the Sudanese TB programme performance, meaning that the results might not be generalized to other states in Sudan. However, due to similarities in the health care systems, other states might benefit from certain points in the recommendations. Several administrative changes and practical obstacles meant that the TB programme evaluation and the population study could not be done in the same state, which hinders linking the findings of the two study parts together. However, Khartoum and Gezira have rather similar TB situation and also the two states had to some extend same population characteristics.

Another limitation is that translation of the instruments from English to Arabic and back to English might have affected the meaning of certain statements.

The study was not intended to address all aspects of TB control programme in Khartoum state. Therefore important issues such as political commitment, TB patients' point of view of the TB programme, equity, access to treatment and cost-effectiveness of the TB programme, were not covered.

The study was designed to evaluate the TB control programme at different levels in Khartoum state (central, locality, health area, and health facility); however, unfortunately the study could evaluate the programme neither at locality nor health area levels as there was no data documentation found at these levels.

The study used focus group discussion as an instrument for the qualitative part of the study; the respondents might have felt peer pressure to give similar answers, which might have affected the data obtained from the discussion. The focus group discussions were run in Arabic language and then translated into English, which to some extent might have affected the data quality. Further limitations of this study include external validity and the generalizability of the study results. The findings concerning the TB programme are therefore most applicable to Khartoum state and not to other states in Sudan.

On the other hand, potential limitations of the population study to study TB awareness, stigma, illness perceptions and quality of life were: social desirability bias in responding the interview questions and the fact that the study conducted in Gezira state might not describe the situation in other Sudanese states.

7. RECOMMENDATIONS

In-order for the tuberculosis control programme in Khartoum state to achieve the global targeted goals and to perform in the standard quality manner, it needs: a new tuberculosis prevalence survey to calculate the new annual risk of infection, building a system of proper data documentation at lower levels, activate defaulters tracing system, build a system for sero-prevalence of HIV among TB patients and formulate a plan for regular check for multi-drug resistant tuberculosis (MDR-TB). The following specific recommendations can be given:

1. Counseling and education tailored according to different target group needs.
2. Empowering both TB patients and communities by increasing their knowledge through proper education programmes will effectively contribute to the effort of controlling TB.
3. Strengthen TB information, education and counselling.
4. Increase the level of education.
5. Co-ordination between ministry of health and ministry of education to discuss the findings of this study.

8. CONCLUSION

The tuberculosis control programme in Khartoum State does not achieve the targeted global goals. TB cases and their controls in Gezira state had good level of awareness about TB. Despite of this good TB awareness, the problems of low case detection and high default rate exist. Mild degree of TB stigma and negative TB illness perceptions may be incriminated in these problems; thus inexpensive programmatic interventions such as health education, defaulters tracing (and especially practical problems related to transport hindering defaulter tracing), training and increasing motivation can quickly and dramatically improve the TB control programme in Khartoum state. The solutions - if successfully applied – could bring improvements towards achieving the global goals of good quality TB control programme and to achieve the health-related millennium development goals.

The relatively good level of TB awareness needs to be maintained to facilitate future prevention and control of the disease. Promoting approaches that tackle underlying roots of stigma, empowering TB patients and communities by increasing their knowledge through proper education programmes, will effectively contribute to alleviate or decrease the stigma among the TB patients and their community, which will further improve case finding and holding.

Negative illness perceptions should be targeted so that they will not deter patients from seeking for TB treatment and adhere to it. The negative illness perceptions and quality of life impact of TB calls for programmes to strengthen TB information, education and counselling and doing it considering the socio-demographic characteristics of the target population. These acts could further enhance the effective TB control among the Gezira population. Context-specific causes of poor TB treatment adherence need to be studied further in order to tailor interventional strategies.

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10. APPENDICES

10.1 CORE DEFINITIONS

Tuberculosis case definitions

CASE DEFINITIONS AND CLASSIFICATION (86):

Pulmonary smear-positive
Two out of three sputum smear-positives for AFB by microscopy or one out of three sputum smear-positives with chest X-ray consistent with PTB and decision to treat made by a physician.

Pulmonary smear-negative
First set of three sputum smear negative for Acid alcohol Fast Bacilli (AFB). Lack of clinical response despite two weeks of a broad-spectrum antibiotic. Second set of three sputum smears still negative, taken at least two weeks apart from the first set. X-ray consistent with Pulmonary Tuberculosis (PTB), and decision to treat made by a physician. Or severely ill patient with three sputum smear-negative for AFB and X-ray consistent with extensive PTB and decision to treat made by a physician.

Extra pulmonary tuberculosis
Strong clinical evidence of active extra pulmonary TB and a decision by a physician to start anti-TB treatment.

TYPES OF PATIENTS (86):

New
A patient who has never been treated for TB or who has taken TB drugs for less than four weeks.

Relapse
A patient who has been declared cured of any form of TB after taking a full course of chemotherapy but he/she reports back with sputum smear-positive.

Treatment failure
A previously sputum smear-positive patient who, while on treatment, remained or became again smear-positive five months or later after commencing treatment. It is also a patient who was initially smear-negative before starting treatment and became smear-positive after the second month of treatment.

Treatment after interruption (TAI) (default)
A patient who has taken at least four weeks of treatment but has subsequently interrupted treatment for two months or more, and returns to the health service with smear-positive sputum.

Transfer in
A patient who has been transferred into the reporting unit from another reporting unit.

Other
Cases that do not fit any of the above definitions.

TREATMENT OUTCOMES (86):

Cured
Patient who was smear-positive at diagnosis and became smear negative at, or one month before, the completion of treatment and on at least one previous occasion.

Treatment completed
Smear-positive patient who has completed treatment but without proof of cure as determined by smear examinations or smear negative patient who has completed treatment.

Treatment failure
Patient who remains or becomes again smear-positive at five months or later during treatment.

Died
Patient who dies for any reason during the course of treatment.

Treatment interrupted (default)
Patient whose treatment was interrupted for two months or more
Transfer out
Patient who has been transferred to another reporting unit and for whom the treatment outcome is not known.

TB control programme indicators definitions:
TB case detection rate (111):
The percentage of TB cases detected (diagnosed and reported to the national health authority) among the total number of TB cases estimated to occur countrywide each year.

TB treatment success rate (111):
The percentage of a cohort of TB cases registered in a specified period that successfully completed treatment, whether with bacteriologic evidence of success ("cured") or without ("treatment completed").

TB cases notification rate (111):
The number of TB cases reported to the NTP per year per 100,000 population.

TB cases cure rate:
The percentage of TB cases that were registered in a specified period and were cured. All TB cases recorded as cured must have a negative sputum smear result recorded during the last month of treatment and on at least one previous occasion during treatment.

TB cases completion rate (111):
The percentage of TB cases registered in a specified period that completed treatment.

TB cases death rate (111):
The percentage of TB cases registered in a specified period that died during treatment, irrespective of cause.

TB cases treatment failure rate (111):
The percentage of TB cases registered in a specified period that were treatment failures.

TB cases default rate (111):
The percentage of TB cases registered in a specified period that interrupted treatment for more than 2 consecutive months.

TB cases transfer out rate (111):
The percentage of TB cases registered in a specified period that were transferred to another basic management unit from which there is no treatment outcome information.

10.2 RESEARCH INSTRUMENTS

1. Assessment of tuberculosis control programme in Khartoum state research
Central level assessment sheet

Date……..time……investigator……

Indicator	Calculation	1st quarter of 2006	2nd quarter of 2006	3rd quarter of 2006	4th quarter of 2006	Year 2006
1.Global Indicators						
1.1 TB Case detection rate (all forms)	Numerator: Number new and relapse TB cases detected Denominator: Estimated number of new TB cases					
1.2 TB case detection rate (new smear positive)	Numerator: Number new smear-positive TB cases detected Denominator: Number of estimated new smear-positive TB cases					
1.3 Treatment success rate	Numerator: Number of new smear positive pulmonary TB cases registered in a specified period that were cured plus the number that completed treatment Denominator: Total number of new smear positive pulmonary TB cases registered in the same period					
1.4 Population covered by DOTS	Numerator: Population of the administrative areas implementing the DOTS strategy Denominator: Total population of all administrative areas					
1.5 Surveillance of MDR-TB	Yes/No					
1.6 Surveillance of HIV seroprevalence among TB cases	Yes/No					
2.Routinely reported programme outcomes						
2.1 Case notification rate – new TB cases	Numerator: Number of new TB cases reported in the past year					

Indicator	Calculation	1st quarter of 2006	2nd quarter of 2006	3rd quarter of 2006	4th quarter of 2006	Year 2006
	Denominator: Total population in the specified area X 100,000					
2.2 Case notification rate - new smear positive pulmonary cases	Numerator: Number of new smear-positive pulmonary TB cases reported Denominator: Total population in the specified area X 100,000					
2.4 Proportion of TB cases classified as retreatment in the past year	Numerator: Number of retreatment cases registered during a specified time period Denominator: Total number of TB cases registered in the same period					
2.5 Proportion of new extra-pulmonary TB cases	Numerator: Number of new extra-pulmonary TB cases registered during a specified time period Denominator: Total number of new TB cases registered in the same period					
2.6 Proportion of new TB cases with no smear conversion result	Numerator: Number of new smear positive pulmonary TB cases registered in a specific period who were examined at the end of the initial phase of treatment Denominator: Total number of new smear positive pulmonary TB cases that were registered during the same period					
2.7 Sputum conversion rate at the end of the initial phase of treatment	Numerator: Number of new smear positive pulmonary TB cases registered in a specified period that are smear negative at the end of the initial phase of treatment Denominator: Total number of new smear positive pulmonary TB cases registered for treatment in the same period					
2.8 Percent of new smear positive cases that were cured (Cure rate)	Numerator: Number of new smear positive pulmonary TB cases registered in a specified period that were cured Denominator: Total number of new smear positive pulmonary TB cases registered in the same period					
2. 9 Percent of new smear	Numerator: Number of new smear positive pulmonary					

Indicator	Calculation	1st quarter of 2006	2nd quarter of 2006	3rd quarter of 2006	4th quarter of 2006	Year 2006
positive pulmonary cases that completed treatment (Treatment completion rate)	TB cases registered in a specified period that completed treatment and did not meet the criteria for cure or failure Denominator: Total number of new smear positive pulmonary TB cases registered in the same period					
2.10 Percent of new smear positive cases that died (Death rate)	Numerator: Number of new smear positive pulmonary TB cases registered in a specified period that died during treatment, irrespective of cause Denominator: Total number of new smear positive pulmonary TB cases registered in the same period					
2.11 Percent of new smear positive cases that were treatment failures (Treatment failure rate)	Numerator: Number of new smear positive pulmonary TB cases registered in a specified period that remain smear positive or become smear positive again at 5 months or later after initiating treatment Denominator: Total number of new smear positive pulmonary TB cases registered in the same period					
2.12Percent of new smear positive cases that defaulted (Default rate)	Numerator: Number of new smear positive pulmonary TB cases registered in a specific period that interrupted treatment for two or more months Denominator: Total number of new smear positive pulmonary TB cases registered in the same period					
2.13 Percent of new smear positive cases that were transferred to another state (Transfer-out rate)	Numerator: Number of smear positive pulmonary TB cases registered in a specified period that were transferred to another basic management unit for whom there is no treatment outcome information Denominator: Total number of new smear positive pulmonary TB cases registered in same period					
2.14 HIV Seroprevalence among all TB patients	Numerator: Total number of newly registered TB patients who are HIV positive in a specified time period Denominator: Total number of newly registered TB patients registered in the same period					
3.Diagnoses						
3.1 Existence of comprehensive laboratory	Yes/No					

Indicator	Calculation	1st quarter of 2006	2nd quarter of 2006	3rd quarter of 2006	4th quarter of 2006	Year 2006
network						
3.2 Proportion of all microcopy units with adequate population coverage	Numerator: Number of TB microscopy laboratories that cover a population of a size within a recommended range Denominator: Total number of microscopy units					
3.3 Proportion of TB microcopy units with adequate workloads [at least 60 slides per month]	Numerator: Number of TB microscopy laboratories with an average daily staff workload within a recommended range Denominator: Total number of TB microscopy laboratories for which data are available					
3.4 Proportion of TB microscopy units participating in Quality Assurance (QA) activities	Numerator: Number of TB microscopy laboratories for which QA results are available during the reporting period Denominator: Total number of laboratories performing TB smear microscopy during the same period					
3.6 Proportion of all smear negative cases properly diagnosed	Numerator: Number of adult smear negative cases diagnosed with at least three negative smears Denominator: Total number of adult smear negative cases diagnosed during the same period					
3.7 Proportion of all detected smear positive cases registered for treatment (inverse of primary default rate)	Numerator: Number of new smear positive cases registered for treatment during a specified time period Denominator: Total number of new smear positive cases detected during the same period					

Indicator	Calculation	1st quarter of 2006	2nd quarter of 2006	3rd quarter of 2006	4th quarter of 2006	Year 2006
4.Case Management &Treatment						
4.1 Proportion of public health facilities using directly observed treatment	Numerator: Number of public health facilities that use directly observed therapy to administer medication to TB cases Denominator: Total number of public health facilities					
4.2 Proportion of new TB cases treated with the correct regimen – continuation phase	Numerator: Number of new TB cases that completed the continuation phase of treatment during the last reporting period that were prescribed the correct regimen of medications Denominator: Total number of new TB cases that completed the continuation phase of treatment during the last reporting period					
5. Drug Supply						
5.1 Existence of a quality assurance system	Yes/no					
5.3 Existence of buffer stock at central level facility	Yes/No					
5.4 Percentage of time TB drugs are out of stock – storage facilities	Numerator: Total number of stock out days for all first-line drugs x 100 Denominator: 365 x number of anti-TB drugs					
6. Recording and Reporting						
6.1 Completeness of reporting to state	Numerator: Number of localities that submitted quarterly case finding and treatment outcome reports to the state Denominator: Total number of localities required to submit case finding and treatment outcome reports to the state each quarter					

Indicator	**Calculation**	**1st quarter of 2006**	**2nd quarter of 2006**	**3rd quarter of 2006**	**4th quarter of 2006**	**Year 2006**
6.2 Accuracy of reporting to state	Numerator: Number of TB case finding and treatment outcome reports that were recorded completely and accurately Denominator: Total number of TB case finding and treatment outcome reports examined					
7. Supervision						
7.1 Supervision of DOTS from Central level to the localities	Numerator: Number of supervisory visits performed at the locality level during a specified time period Denominator: Number of supervisory visits planned from the central to locality level according to annual work plan during the same period					
7.2 Supervision of DOTS from central level to the health facilities level	Numerator: Number of supervisory visits performed at the health facility level during a specified time period Denominator: Number of supervisory visits planned from the central to health facility level according to annual work plan during the same period					
7.4 Existence of Supervision guidelines	Yes/No					

Indicator	**Calculation**	**1st quarter of 2006**	**2nd quarter of 2006**	**3rd quarter of 2006**	**4th quarter of 2006**	**Indicator**
8. Human Resource Development						
8.1 Proportion of TB microscopy units with (at least) one laboratory technician trained in AFB microscopy	Numerator: Number of TB microscopy units with at least one laboratory technician trained in acid fast bacilli (AFB) in the last three years Denominator: Number of laboratories involved in TB diagnosis					
8.2 Proportion of all health care units with at least one health care professional trained in TB case detection and treatment	Numerator: Number of health care units with at least one health care professional trained in TB case detection and treatment Denominator: Total number of health care units					
8.3 Adequate staffing at all levels to enable implementation of DOTS	Yes/No					

2. Assessment of tuberculosis control programme in Khartoum state research
Health facility level assessment sheet

Locality……health facility…….
type……...Date…….
investigator……

Indicator	Calculation	result	Comment
1. Diagnosis and treatment			
1.1Availability of stander diagnosis and treatment guidelines	Yes / no		
1.2 health care professional prescribe treatment according to the stander guidelines	Yes / no		
1.3 health care professional classified patient correctly	Yes / no		
1.4 health care professional prescribe treatment to failure cases correctly	Yes / no		
1. 5 health care professional prescribe treatment to defaulter cases correctly	Yes / no		
1.6 health care professional trace defaulter cases	Yes / no		
2. Recording and reports			
2.1 availability of patient registration cards	Yes / no		
2.2 availability of sputum investigation forms	Yes / no		
2.3 availability of patient transfer cards	Yes / no		
2.4 health care professional fill the registration book correctly	Yes / no		
3. Drugs			
3.1 availability of the TB drugs according to the stander	Yes / no		
3.2 storage of the TB drugs according to the stander	Yes / no		
4.Laboratory			
4.1 availability of microscopes	Yes / no		
4.2 availability of equipments and materials for sputum microscopic diagnosis	Yes / no		
4.3 keeping of all smear positive slides and 10% of smear negative slides for quality assurance	Yes / no		
5. Defaulter tracing			
5.1 availability of defaulters tracing registration book	Yes / no		
5.2 health care professional knows how to fill in defaulter tracing registration book correctly	Yes / no		
5.3 defaulter classified correctly	Yes / no		
5.4 availability of transportation method to trace defaulters	Yes / no		
6. TB patient contacts			
6.1 health facility trace positive TB patients contacts	Yes / no		
6.2 availability of TB patients contacts registration book	Yes / no		

3. Instrument Title: Focus Group Discussion Guide

Total focus group time: 2 hours
Break: 15 minutes

OVERALL QUESTIONS TO ANSWER IN FOCUS GROUP DISCUSSIONS

The challenges and needs for performing a good standard tuberculosis control programme in Khartoum State.

General guide for leading the focus group discussion

I. Introduction

1. Welcome participants and introduce yourself.
2. Explain the general purpose of the discussion and why the participants were chosen.
3. Discuss the purpose and process of focus groups
4. Explain the presence and purpose of recording equipment and introduce observers.
5. Outline general ground rules and discussion guidelines such as the importance of everyone speaking up, talking one at a time, and being prepared for the moderator to interrupt to assure that all the topics can be covered.
6. Reviews break schedule and where the restrooms are.
7. Address the issue of confidentiality.
8. Inform the group that information discussed is going to be analyzed as a whole and that participants' names will not be used in any analysis of the discussion.

Discussion Guidelines:

We would like the discussion to be informal, so there's no need to wait for us to call on you to respond. In fact, we encourage you to respond directly to the comments other people make. If you don't understand a question, please let us know. We are here to ask questions, listening, and make sure everyone has a chance to share.

If we seem to be stuck on a topic, we may interrupt you and if you aren't saying much, we may call on you directly. If we do this, please don't feel bad about it; it's just our way of making sure we obtain everyone's perspective and opinion is included.

We do ask that we all keep each other's identities, participation and remarks private. We hope you'll feel free to speak openly and honestly.

As discussed, we will be tape recording the discussion, because we don't want to miss any of your comments. No one outside of this room will have access to these tapes and they will be destroyed after our report is written.

Helping are my assistant's _____ and _____. They will be taking notes and be here to assist me if I need any help.

Issues for focus group exploration:

1. Technical issues:

1. TB patient management (diagnosis, treatment, and follow-up in form of guidelines and methods).
2. TB control programme reporting system (methods, frequency, distribution, feedback).
3. TB control programme supervision (methods, frequency, feedback, benefits).
4. TB control programme meetings (frequency, feedback, benefits).

5. Human recourses:

1. Staffing (adequacy, training, motivation, and relations)

6. Logistics:

1. Drug supply (availability, quality, methods of distribution, and storage).
2. Laboratory supply (availability, quality, methods of distribution, and storage).
3. Registration and reporting materials (availability, quality, and methods of distribution).
4. Programme materials and guidelines (availability, simplicity, and quality,).

7. TB programme financing:

1. TB control programme budget at all level (adequacy, continuity, and timely**)**

4. Focus group discussion questions

Technical issues

1. Is the system of tuberculosis diagnosis and treatment in the state is well functioning?
2. Do you think tuberculosis data documentation system works as it should?
3. What about tuberculosis supervision system at different levels?
4. Do you agree with meetings system for tuberculosis control programme at Khartoum state at different levels?

Human resources

5. Do you think the staffing number at each level is enough to conduct the programme activities?
6. What do you think about the training system for the staff who works in the programme at different level?

Logistics

7. Is the drug supply system is perfect system?
8. Is the laboratory supply system is perfect system?
9. Do you think all the logistics need for performing different programme activities are available?

Defaulter and contact tracing systems

10. What do you think about defaulter and contacts tracing systems?

5. Standard WHO indicators for assessment of tuberculosis control programme

Compendium of Indicators for Monitoring and Evaluation of Tuberculosis Control Programs

Indicator	Calculation	Data Source	Level	Frequency	Function*
1. Indicators for global reporting					
1.1 TB case detection rate†	1) *Numerator*: Number of new TB cases detected *Denominator*: Estimated number of new TB cases countrywide 2) *Numerator*: Number of new smear-positive TB cases detected *Denominator*: Estimated number of new smear-positive TB cases countrywide 3) *Numerator*: Number of new smear-positive TB cases detected under DOTS *Denominator*: Estimated number of new smear-positive TB cases countrywide	Quarterly reports on TB case registration, TB register, WHO estimates of incidence for each country	National	Annually	1, 2, 3, 4
1.2 Treatment success rate‡	*Numerator*: Number of new smear-positive pulmonary TB cases registered in a specified period that were cured plus the number that completed treatment *Denominator*: Total number of new smear-positive pulmonary TB cases registered in the same period	Quarterly reports on treatment outcomes, TB register, TB treatment card	National, regional, district, facility	Quarterly, annually	1, 2, 3, 4
1.3 DOTS coverage	*Numerator*: Population living in the area of basic management units implementing the DOTS strategy *Denominator*: Total population	NTP reports, census statistics	National	Annually	1, 2, 3
1.4 Surveillance of multidrug-resistant TB	Yes/no	NTP data and reports	National	If no, annually; if yes, every 2 to 5 years	3, 4

Indicator	Calculation	Data Source	Level	Frequency	Function*
1.5 HIV seroprevalence among TB patients	1) *Numerator*: Total number of newly registered TB patients (registered over a given period of time) who are HIV positive *Denominator*: Total number of newly registered TB patients (registered over the same given time period) who were tested for HIV and included in the surveillance system 2) *Numerator*: Total number of newly registered smear-positive TB patients (registered over a given period of time) who are HIV positive *Denominator*: Total number of newly registered smear-positive TB patients (registered over the same given time period) who were tested for HIV and included in the surveillance system	Modified TB register or separate TB/HIV register, sentinel surveillance, special surveys	National, regional, district	Quarterly, annually if routinely collected otherwise 2 to 3 years	1, 2, 3
† All of the indicators commonly known as "rates" in this compendium are, technically, percentages. ‡ This same definition is used to calculate outcome among other cohorts (or case types), e.g., new smear-negative cases, relapse cases, treatment-after-failure cases, and treatment-after-default cases.					
2. Indicators for program outcomes					
2.1 Case notification rate	1) *Numerator*: Number of new TB cases reported in the past year (× 100,000) *Denominator*: Total population in the specified area 2) *Numerator*: Number of new and relapse TB cases reported in the past year (× 100,000) *Denominator*: Total population in the specified area 3) *Numerator*: Number of all TB cases reported in the past year (× 100,000) *Denominator*: Total population in the specified areas	Quarterly reports on TB case registration, census statistics	National, regional, district	Annually	1, 2, 3
2.2 Case notification rate—new smear-positive pulmonary TB cases	*Numerator*: Number of new smear-positive pulmonary TB cases reported (× 100,000) *Denominator*: Total population in the specified area	Quarterly reports on TB case registration, census statistics	National, regional, district	Annually	1, 2, 3

Indicator	Calculation	Data Source	Level	Frequency	Function*
2.3 New pulmonary TB cases with no smear result	*Numerator*: Number of new pulmonary TB cases registered during a specified time period that do not have results of sputum smear examinations on diagnosis *Denominator*: Total number of new pulmonary TB cases registered during the same period	Quarterly reports on TB case registration, TB register, TB laboratory register	National, regional, district	Quarterly, annually	1, 2, 3
2.4 New adult smear-positive cases	*Numerator*: Number of new smear-positive adult (age 15 and older) TB cases registered during a specified time period *Denominator*: Total number of new adult pulmonary TB cases registered during the same period	Quarterly reports on TB case registration, TB register	National, regional, district	Annually	1, 2, 3
2.5 Retreatment TB cases	*Numerator*: Number of retreatment TB cases registered during a specified time period *Denominator*: Total number of TB cases registered in the same period	Quarterly reports on TB case registration, TB register	National, regional, district	Quarterly, annually	1, 2, 3
2.6 New extrapulmonary TB cases	*Numerator*: Number of new extrapulmonary TB cases registered during a specified time period *Denominator*: Total number of new TB cases registered in the same period	Quarterly reports on new cases and relapses of tuberculosis, TB register	National, regional, district	Quarterly, annually	1, 2, 3
2.7 New TB cases with no smear conversion result	*Numerator*: Number of new smear-positive pulmonary TB cases registered in a specific period that were not examined at the end of the initial phase of treatment *Denominator*: Total number of new smear-positive pulmonary TB cases registered during the same period	Quarterly reports on smear conversion or program management, TB register	National, regional, district	Quarterly, annually	1, 2, 3
2.8 Sputum conversion rate at the end of the initial phase of treatment	*Numerator*: Number of new smear-positive pulmonary TB cases registered in a specified period that were smear negative at the end of the initial phase of treatment *Denominator*: Total number of new smear-positive pulmonary TB cases registered for treatment in the same period	Quarterly reports on smear conversion, TB register	National, regional, district	Quarterly, annually	1, 2, 3

Indicator	Calculation	Data Source	Level	Frequency	Function*
2.9 Cure rate‡	*Numerator:* Number of new smear-positive pulmonary TB cases registered in a specified period that were cured *Denominator:* Total number of new smear-positive pulmonary TB cases registered in the same period	Quarterly reports on treatment outcomes, TB register	National, regional, district	Quarterly, annually	1, 2, 3
2.10 Treatment completion rate‡	*Numerator:* Number of new smear-positive pulmonary TB cases registered in a specified period that completed treatment and did not meet the criteria for cure or failure *Denominator:* Total number of new smear-positive pulmonary TB cases registered in the same period	Quarterly reports on treatment outcomes, TB register	National, regional, district	Quarterly, annually	1, 2, 3
2.11 Death rate‡	*Numerator:* Number of new smear-positive pulmonary TB cases registered in a specified period that died during treatment, irrespective of cause *Denominator:* Total number of new smear-positive pulmonary TB cases registered in the same period	Quarterly reports of treatment outcomes, TB register	National, regional, district	Quarterly, annually	1, 2, 3
2.12 Treatment failure rate‡	*Numerator:* Number of new smear-positive pulmonary TB cases registered in a specified period that are smear positive 5 months or later after initiating treatment *Denominator:* Total number of new smear-positive pulmonary TB cases registered in the same period	Quarterly reports of treatment outcomes, TB register	National, regional, district	Quarterly, annually	1, 2, 3
2.13 Default rate‡	*Numerator:* Number of new smear-positive pulmonary TB cases registered in a specified period that interrupted treatment for more than 2 consecutive months *Denominator:* Total number of new smear-positive pulmonary TB cases registered in the same period	Quarterly reports of treatment outcomes, TB register	National, regional, district	Quarterly, annually	1, 2, 3
2.14 Transfer-out rate‡	*Numerator:* Number of new smear-positive pulmonary TB cases registered in a specified period that were transferred to another basic management unit and for which there is no treatment outcome information *Denominator:* Total number of new smear-positive pulmonary TB cases registered during the same period	Quarterly reports of treatment outcomes, TB register	National, regional, district	Quarterly, annually	1, 2, 3

Indicator	Calculation	Data Source	Level	Frequency	Function*
2.15 Retreatment failure rate (chronic TB rate)	Numerator: *Number of retreatment smear-positive pulmonary TB cases registered in a specified period that are smear positive at the end of the retreatment regimen* *Denominator*: Total number of retreatment smear-positive pulmonary TB cases registered in the same period	TB register	National, regional, district	Quarterly, annually	1, 2, 3
‡ This same definition is used to calculate outcome among other cohorts (or case types), e.g., new smear-negative cases, relapse cases, treatment-after-failure cases, and treatment-after-default cases.					
3. Political commitment					
3.1 TB control is among stated priorities	Yes/no	Government planning and strategy documents	National	Annually	If no = 2 If yes = 3
3.2 National TB policy	Yes/no	Ministry of Health (MOH) policies and/or directives regarding TB control at the national level, checklist of key policy components	National	Annually	If no = 2 If yes = 3
3.3 National TB program manual	Yes/no	Manual of norms and procedures for NTPs, checklist of key manual components	National	Annually	If no = 2 If yes = 3
3.4 NTP medium-term development plan and budget	Yes/no	NTP MDP and budget	National	Annually	If no = 2 If yes = 3
3.5 NTP annual work plan and budget	Yes/no	NTP annual plan and budget, MDP	National	Annually	2, 3
3.6 Peripheral units with work plan and budget	*Numerator*: Number of peripheral management units for which a work plan and budget are available *Denominator*: Total number of peripheral management units with budget and planning responsibility	Work plans and budgets, checklist of key components for annual work plans	Regional, district	Annually	2, 3

Indicator	Calculation	Data Source	Level	Frequency	Function*
3.7 Financial resources committed to NTP from the government	*Numerator*: Total funding from the national government for the annual plan of activities *Denominator*: Total budget required for full implementation of the annual plan of activities (consistent with MDP)	Annual TB work plan and budget, MDP budget	National	Annually	2
3.8 Annual NTP budget allocated to implement DOTS as required by medium-term development plan	*Numerator*: Total amount of funds allocated for DOTS-based TB control in the previous year's NTP budget *Denominator*: Total amount of funds budgeted for DOTS-based TB control in the previous year's NTP budget as described in the annual plan	Annual NTP work plan and budget, MDP budget	National, regional	Annually	2, 3
3.9 Key NTP staff positions filled	*Numerator*: Number of key NTP positions filled by local staff *Denominator*: Total number of key NTP positions, as described in the NTP human resources development plan	NTP organizational diagram, human resource development plan	National	Annually	2, 3
3.10 Interinstitutional coordination of TB control	Yes/no	Reports from coordination meetings, joint planning documents, recording and reporting forms	National	Annually	2, 3
3.11 Existence and dissemination of NTP annual report	Yes/no	NTP annual reports, dissemination records	National	Annually	2, 3
3.12 National TB control policy addresses links between TB and HIV	Yes/no	Policy audit of MOH and NTP records and policies, checklist of key components for policy	National	Annually	2

Indicator	Calculation	Data Source	Level	Frequency	Function*
4. Diagnosis and laboratories					
4.1 Existence of comprehensive laboratory network	Yes/no	TB laboratory register and forms	National	If no, measure annually; if yes, measure every 5 years	If no = 2 If yes = 3
4.2 TB microscopy coverage	1) *Numerator*: Number of TB microscopy units that cover a population of a size within a recommended range *Denominator*: Total number of TB microscopy units 2) *Numerator*: Total population *Denominator*: Total number of TB microscopy units	Census statistics, NTP records, MOH records	National, regional, district	Annually	3, 4
4.3 TB microscopy units with adequate workloads	*Numerator*: Number of TMUs with an average daily staff workload within a recommended range *Denominator*: Total number of TMUs for which data are available	TB laboratory register	National, regional, district, facility	Annually	1, 2, 3
4.4 TB microscopy units submitting slides for rechecking	*Numerator*: Number of TB microscopy units for which slide rechecking results are available during a specified period *Denominator*: Total number of units performing TB smear microscopy during the same period	Laboratory records containing quality assurance results	National	Quarterly, annually	2, 3
4.5 TB suspects who are smear positive	*Numerator*: Number of TB suspects found to be smear positive during a specified period *Denominator*: Number of TB suspects identified clinically during the same period	TB laboratory register or cough register	National, regional, district	Quarterly, annually	1, 2, 3
4.6 Smear-negative cases properly diagnosed	*Numerator*: Number of adult smear-negative pulmonary TB cases diagnosed with at least three negative smears and chest radiograph according to NTP-recommended algorithm during a specified time period *Denominator*: Total number of adult smear-negative cases diagnosed during the same period	NTP diagnostic algorithm for smear-negative TB, TB laboratory register, TB treatment cards	District, facility	Annually	1, 2, 3

Indicator	Calculation	Data Source	Level	Frequency	Function*
4.7 Detected smear-positive cases registered for treatment (inverse of primary default rate)	*Numerator:* Number of new smear-positive pulmonary TB cases that have initiated treatment during a specified time period *Denominator:* Total number of new smear-positive cases detected during the same period	TB laboratory register, TB register	National, regional, district, facility	Quarterly, annually	2, 3
5. Case management and treatment					
5.1 Patients under direct observation of therapy	*Numerator:* Number of new smear-positive pulmonary TB patients who report observation of every dose of medication per NTP guidelines *Denominator:* Total number of new smear-positive pulmonary TB patients interviewed regarding direct observation of therapy	Survey of TB patients and staff	National, regional, district	Annually	2, 3, 4
5.2 New TB patients who were prescribed the correct regimen	*Numerator:* Number of new TB patients who were prescribed the correct regimen of medications during a specified period *Denominator:* Total number of new TB patients who completed treatment during the same period	NTP treatment guidelines, TB register, individual medical records, facility survey	District, facility	2 to 3 years	2, 3, 4
6. Drug management					
6.1 Existence of a quality assurance system for drug management	Yes/no	MOH documents, National Pharmaceutical Committee documents	National	Annually	If no = 2 If yes = 3
6.2 Anti-TB drugs meeting international minimum quality standards	*Numerator:* Number of batches of anti-TB drugs procured locally and internationally where a batch certificate was received and showed acceptable results during a specified time period *Denominator:* Total number of batches of anti-TB drugs procured during the same time period	Procurement agency records, drug registration authority records	National	Annually	2, 3
6.3 Existence of buffer stock at central, regional, or district-level facility	Yes/no	TB drug quantification records, procurement records	National, regional, district	Annually, biannually	2, 3

Indicator	Calculation	Data Source	Level	Frequency	Function*
6.4 Accuracy of stock records for anti-TB drugs	*Numerator:* Number of stock records that correspond with physical counts × 100 *Denominator:* Total number of stock records examined	Storage facility stock cards for individual drugs, physical observations at the facility	National, regional, facility	Biannually	2, 3
6.5 Time anti-TB drugs are out of stock—storage facilities	*Numerator:* Total number of stockout days for all first-line drugs stocked × 100 *Denominator:* 365 × number of anti-TB drugs	Storage facility stock cards of individual drugs	National, regional, district	Quarterly	2, 3
6.6 Time anti-TB drugs are out of stock—treatment facilities	*Numerator:* Total number of stockout days for all first-line drugs stocked × 100 *Denominator:* 365 × number of anti-TB drugs in treatment facilities	Facility stock cards of individual drugs	National, regional, district	Quarterly	2, 3
6.7 Basic management units where anti-TB drugs are available	*Numerator:* Number of basic management units visited where anti-TB drugs are present *Denominator:* Total number of basic management units visited	Drugs stocked in TB BMUs	National, regional, district	Quarterly	2, 3
6.8 Anti-TB drug samples that fail quality control tests	*Numerator:* Number of anti-TB drug samples that failed quality control testing × 100 *Denominator:* Total number of anti-TB drug samples tested in the country's quality control analysis laboratory	Quality control laboratory register, MOH reports	National	Annually	2, 3
7. Recording and reporting					
7.1 Completeness of reporting to NTP	*Numerator:* Number of basic management units that submitted case-finding and treatment outcome reports to the NTP in the previous quarter *Denominator:* Total number of basic management units required to submit case-finding and treatment outcome reports to the NTP each quarter	NTP statistics and reports	National, regional, district	Quarterly, annually	1, 2, 3
7.2 Accuracy of reporting to NTP	*Numerator:* Number of TB case-finding and treatment outcome reports that were recorded completely and accurately *Denominator:* Total number of TB case-finding and treatment outcome reports examined	NTP statistics and reports, TB register	National, regional, district	Quarterly	2, 3

Indicator	Calculation	Data Source	Level	Frequency	Function*
8. Supervision					
8.1 Supervision of DOTS implementation	*Numerator*: Number of supervisory visits performed during a specified time period *Denominator*: Number of supervisory visits planned according to the annual work plan during the same period	Annual work plan, reports of the supervisory visits	National	Annually	2
8.2 Existence of supervision guidelines	Yes/no	NTP supervision documents	National	Annually	If no = 2 If yes = 3
9. Human resources development					
9.1 TB microscopy units with at least one laboratory technician trained in AFB microscopy	*Numerator*: Number of TB microscopy units with at least one laboratory technician trained in AFB in the past 3 years *Denominator*: Number of TB microscopy units	NTP training records, list of certified laboratory technicians and laboratory of employment, interviews with staff members	National, regional, district	Annually	2, 3
9.2 Health care units with at least one health care professional trained in TB case detection and treatment	*Numerator*: Number of TB treatment facilities with at least one health care professional trained in TB case detection and treatment (within the past 3 years) *Denominator*: Total number of TB treatment facilities	NTP training records, employee training certificates, facility training registers, interviews with staff members	National, regional, district	Annually	2, 3
9.3 Adequate staffing at all levels to enable implementation of DOTS	Yes/no	Staffing documents or rosters, interviews with staff members	National, regional, district, facility	Annually	2
10. Health systems					
10.1 Equitable distribution of DOTS	*Numerator*: Number of TB patients living in poverty notified under DOTS in specified time period *Denominator*: Total number of TB patients notified under DOTS in specified time period × the percentage of the population living in poverty	Quarterly reports on TB case registration, census statistics, special surveys	National	Annually	2, 3, 4

University of Southern Denmark

Faculty of Health Sciences

Unit for Health Promotion Research

Tuberculosis, prevalence of stigma, knowledge, attitudes, and practice towards tuberculosis, illness perception and quality of life in Gezira state

KAP Survey Questionnaire

(Patient questionnaire)

University of Southern Denmark
Faculty of Health Sciences

Unit for Health Promotion Research TB-related risk factors, knowledge, attitudes, stigma and health-seeking practices among TB patient s and their neighbors in Khartoum state, Sudan.

Date: ___ / ___ / ___ locality: _____health area: _____
area: _____ interviewer: _____

Part (1)

Information to read to respondent:

We wish to learn about your knowledge, attitudes and practices regarding tuberculosis (TB) as well as risk factors for TB. We hope to understand your needs and the best way to bring information to you, as well as barriers to seeking medical care. The information you provide will be used to improve TB control.

Your answers will not be released to anyone and will remain anonymous. Your name will not be written on the questionnaire or be kept in any other records. Your participation is voluntary and you may choose to stop the interview at any time.
Thank you for your assistance.

Interviewer: Place an X in the box of the selected answer(s).Do not read responses unless the directions indicate.

General and demographic questions		
1. How old are you?		
	1. Under 30	
	2. 31–40	
	3. 41–50	
	4. Over 50	
2. What is the interviewee gender?		
	1. Male	
	2. Female	
3**. What is your marital status**?		
	1. Married	
	2. Single	
	3. Divorced	
	4. Widower	
4.What is the highest level of education you have completed?		
	1. No school	
	2. Elementary	
	3. High school	
	4. College	
	5. Higher education (professional or post-graduate)	
	6. Religious schooling only	
	7. Literacy classes only	
5. What is the type of your residency?		
	1. City	
	2. Village	
	3. Camp	
	4. Other	

6. What is your current occupation?		
	1. Employee	
	2. Laborer	
	3. Pensioner	
	4. Student	
	5. House wife	
	6. Non worker	
	7. Others (define) ----------	
7. What is the number of your family members (including yourself)?		
	1. 1 – 3	
	2. 4-7	
	3. More than 7	
8. What is the number of rooms in your house?		
	1. 1 – 2 rooms	
	2. 3 – 4 rooms	
	3. More than 4 rooms	
9. How far do you live from the nearest health clinic or hospital?		
	1. Less than 2 kilometres	
	2. 3–5 kilometres	
	3. 6–10 kilometres	
	4. More than 10 kilometres	
Health-seeking behaviour		
10. Where do you usually go if you are sick, or to treat a general health problem?		
	1. Private clinic	
	2. Government clinic or hospital	
	3. Traditional or homeopathic healer	
	4. Clinic run by an nongovernmental organization or church	
	5. Other:	
11. How often do you generally seek health care at a clinic or hospital? (Check one)		
	1. Monthly or more	
	2. Four times a year or more	
	3. Twice a year or more	
	4. Once per year	
	5. Less than once a year but at least twice in past 5 years	
	6. Once in past 5 years	
	7. Never in past 5 years	
	8. Other: (defined)_____	
TB knowledge and awareness		
12.Do you have radio or television at home?		
	1. Yes	
	2. No	

13. Where did you first learn about tuberculosis or TB?		
	1. Newspapers and magazines	
	2. Radio	
	3. TV	
	4. Brochures, posters and other printed materials	
	5. Health workers	
	6. Family, friends, neighbours and colleagues	
	7. Religious leaders	
	8. Teachers	
	9. Other (please explain):	
14. The information you got about TB was understandable ?		
	1. Yes fully	
	2. Yes partly	
	3. No	
15. If partly or no why?		
	1. The information language used was difficult.	
	2. The information is not clear	
	3. Too much information	
	4. Information incorrect	
	5. Information not complete	
	6. Other (define) _____	
16. Do you think your information about TB is enough?		
	1. Yes	
	2. No	
17. IS TB a common diseases in your community?		
	1. Yes	
	2. No	
	3. I don't know	
18. In your opinion, how serious a disease is TB? (Check one)		
	1. Very serious	
	2. Somewhat serious	
	3. Not very serious	
	4. I have no idea	
19. How serious a problem do you think TB is in your country/region? (Check one)		
	1. Very serious	
	2. Somewhat serious	
	3. Not very serious	
	4. I have no idea	
20. How many types of TB have you heard?		
	1. One type (define)	
	2. Two types (define)	
	3. More than two (define)	

21. What are the signs and symptoms of TB? (Please check all that are relevant)		
	1. Cough	
	2. Cough that lasts longer than 3 weeks	
	3. Coughing up blood	
	4. Severe headache	
	5. Weight loss	
	6. Fever	
	7. Fever without clear cause that lasts more than 7 days	
	8. Chest pain	
	9. Shortness of breath	
	10. Do not know	
22. How can a person get TB? (Please check all that are relevant)		
	1. Through handshakes	
	2. Through the air when a person with TB coughs or sneezes	
	3. Through sharing dishes	
	4. Through eating from the same plate	
	5. Through touching items in public places (doorknobs, handles in transportation)	
	6. Do not know	
23. How can a person prevent getting TB? (Please check all that are relevant)		
	1. Avoid shaking hands	
	2. Covering mouth and nose when coughing or sneezing	
	3. Avoid sharing dishes	
	4. Washing hands after touching items in public places	
	5. Closing windows at home	
	6. Through good nutrition	
	7. By praying	
	8. Do not know	
	9. Other (please explain):_____	
24. In your opinion, who can be infected with TB? (Please check all that are relevant)		
	1. Anybody	
	2. Only children	
	3. Only women	
	4. Only old people	
	5. Only poor people	
	6. Only homeless people	
	7. Only alcoholics	
	8. Only drug users	
	9. Only people living with HIV/AIDS	
	10. Only people who have been in prison	
25. Can TB be cured?		
	1. Yes	
	2. No	
	3. I have no idea	

26. How can someone with TB be cured? (Check all that apply/are relevant.)		
	1. Herbal remedies	
	2. Home rest without medicine	
	3. Praying	
	4. Specific drugs given by health centre	
	5. Do not know	
	6. Other:_____	
27. How long is the TB treatment?		
	1. Less than 3 months	
	2. 3 months	
	3. 6 months	
	4. 9 months	
	5. 1 year	
	6. I have no idea	
28.Where the TB patient can get the treatment?		
	1. Governmental hospital	
	2. Health centers	
	3. Private hospitals	
	4. Private clinic	
	5. Non-governmental organization clinic,	
	6. Elsewhere	
	7. I have no idea	
29 Do you think there is vaccination against TB?		
	1. Yes	
	2. No	
	3. I have no idea	
30. If Yes, do you think that TB vaccination will protect you against TB?		
	1. Yes	
	2. No	
	3. I have no idea	
31. Does any of your family members have TB?		
	1. Yes	
	2. No	
32. Does any of your neighbours have TB?		
	1. Yes	
	2. No	

33. Does any of your friends have TB?		
	1. Yes	
	2. No	
34. What was your reaction when you found out that you have TB? (Choose one)		
	1. Fear	
	2. Surprise	
	3. Shame	
	4. Embarrassment	
	5. Sadness or hopelessness	
35.Who did you talk to about your illness?		
	1. Doctor or other medical worker	
	2. Spouse	
	3. Parent	
	4. Child(ren)	
	5. Other family member	
	6. Close friend	
	7. No one	
36. What the first thing you did when you had symptoms of TB? (Check all that apply)		
	1. Go to health facility	
	2. Go to pharmacy	
	3. Got to traditional healer	
	4. Pursue other self-treatment options (herbs, etc.)	
	5. Wait and see	
	6. Other:	
37. How expensive do you think TB diagnosis is in this country? (Please check one)		
	1. It is free of charge	
	2. It is reasonably priced	
	3. It is somewhat/moderately expensive	
	4. It is very expensive	
	5. Interviewer: If respondent gives monetary amount, note the amount here:	
38. How expensive do you think treatment is in this country? (Please check one)		
	1. It is free of charge	
	2. It is reasonably priced	
	3. It is somewhat/moderately expensive	
	4. It is very expensive	
	5. Interviewer: If respondent gives monetary amount, note the amount here:	
TB attitudes and stigma		
39. In your community, how is a person who has TB usually regarded/treated?		
	1. Most people reject him or her	
	2. Most people are friendly, but they generally try to avoid him or her	
	3. The community mostly supports and helps him or her	
	4. Other (please explain):_____	
40. Do you think that HIV positive people should be concerned about TB?		

	1. Yes, why ( )	
	2. No, why ( )	
	3. Do not know	
41. Do you feel ashamed if you have TB?		
	1. Yes, why ( )	
	2. No, why ( )	
	3. I don't know	
42. Do you hide your TB disease from the others?		
	1. Yes	
	2. No	
	3. I don't know	
43. Do you think TB will affect your social relations?		
	1. Yes	
	2. No	
	3. I don't know	
44. Do you think TB will affect your work?		
	1. Yes	
	2. No	
45. Do you think TB will affect your marital relation?		
	1. Yes	
	2. No	
	3. I don't know	
46. Do you prefer to live isolated?		
	1. Yes	
	2. No	
	3. I don't know	
47. Do you think TB affects the chance for marriage ?		
	1. Yes	
	2. No	
	3. I don't know	
48. Do you think TB leads to infertility for women?		
	1. Yes	
	2. No	
	3. I don't know	
49. Do you think TB affects your family responsibilities?		
	1. Yes	
	2. No	
	3. I don't know	
TB awareness and sources of information		

50. Do you wish you could get more information about TB?		
	1. Yes	
	2. No	
51. What are the sources of information that you think can most effectively reach people like you with information on TB? (Please choose the three most effective sources)		
	1. Newspapers and magazines	
	2. Radio	
	3. TV	
	4. Billboards	
	5. Brochures, posters and other printed materials	
	6. Health workers	
	7. Family, friends, neighbours and colleagues	
	8. Religious leaders	
	9. Teachers	
Satisfaction about TB services		
52. What do you think about TB center services offered?		
	1. Excellent	
	2. Very good	
	3. Good	
	4. Bad	
53. What do you think about TB health care workers attitude towards patients?		
	1. Positive	
	2. Negative	
	3. Neither positive nor negative	
54.What do you think about TB center appearance?		
	1. Excellent	
	2. Very good	
	3. Good	
	4. Bad	
55. What do you think about number of people seeking treatment in TB center?		
	1. Too many	
	2. Many	
	3. Few	
	4. Very few	
56. What do you think about waiting time in TB center ?		
	1. 15 minutes	
	2. 15 – 30 minutes	
	3. 30 minutes – 1 hour	
	4. More than 2 hours	

Part (2) Illness perception

1. How much does your TB disease affect your life?

0 1 2 3 4 5

No affect at all **affects my life severely**

2. How long do you think your TB disease will continue?

0 1 2 3 4 5

a very short time **forever**

3. How much control do you feel you have over your TB disease?

0 1 2 3 4 5

Absolutely no control **extreme amount of control**

4. How much do you think your treatment can help your illness?

0 1 2 3 4 5

Not at all **extremely helpful**

5. How much do you experience symptoms from your TB disease?

0 1 2 3 4 5

No symptoms at all **many severe symptoms**

6. How concerned are you about your illness?

0 1 2 3 4 5

Not at all concerned **extremely concerned**

7. How well do you feel you understand your TB disease?

0 1 2 3 4 5

Don't understand at all **understand very clearly**

8. How much does TB disease affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?

0 1 2 3 4 5

Not emotionally affected at all **extremely emotionally affected**

9. Please list in rank-order the three most important factors that you believe caused your TB disease.

The most important causes for me:-

1. _____

2. _____

3. _____

Part(3) SF

1.Overall, how would you rate your health in the <u>past month?</u>		
	1. Excellent	
	2. Very good	
	3. Good	
	4. Fair	
	5. Poor	
	6. Very poor	
2. During the <u>past month</u>, how much did your TB disease limit your usual physical activities (such as walking or climbing stairs)?		
	1. Not at all	
	2. Very little	
	3. Somewhat	
	4. Quite a lot	
	5. Could not do physical activities	
3. . During the <u>past month</u>, how much difficulty did you have doing your daily work, both at home and away from home, because of your TB disease?		
	1. Not at all	
	2. Very little	
	3. Some	
	4. Quite a lot	
	5. Could not do daily work	
4. How much bodily pain have you had in the <u>past month</u>?		
	1. None	
	2. Very mild	
	3. Mild	
	4. Moderate	
	5. Severe	
	6. Very severe	
5. During the <u>past month</u>, how much energy did you have?		
	1. Very much	
	2. Quiet a lot	
	3. Some	
	4. A little	
	5. None	
6. During the <u>past month</u>, how much did your TB disease limit your usual social activities with family or friends?		
	1. Not at all	
	2. Very little	
	3. Some	
	4. Quite a lot	
	5. Could not do social activities	

7. During the <u>past month</u>, how much have you been bothered by emotional problems (such as feeling anxious, depressed or irritable)?		
	1. Not at all	
	2. Slightly	
	3. Moderately	
	4. Quite a lot	
	5. Extremely	
8. During the <u>past month</u>, how much did personal or emotional problems keep you from doing your usual work, school or other daily activities?		
	1. Not at all	
	2. Very little	
	3. Some	
	4. Quite a lot	
	5. Could not do daily activities	

University of Southern Denmark

Faculty of Health Sciences

Unit for Health Promotion Research

TB risk factors, prevalence of stigma, knowledge, attitudes, and practice towards tuberculosis in Gazira state

KAP Survey Questionnaire

(control questionnaire)

University of Southern Denmark
Faculty of Health Sciences
Unit for Health Promotion Research

TB-related risk factors, knowledge, attitudes, stigma and health-seeking practices among TB patient s and their neighbors in Khartoum state, Sudan.

Date: ___ / ___ / ___ locality: _____health area: _____
area: _____ interviewer: _____

Part (1)

Information to read to respondent:

We wish to learn about your knowledge, attitudes and practices regarding tuberculosis (TB) as well as risk factors for TB. We hope to understand your needs and the best way to bring information to you, as well as barriers to seeking medical care. The information you provide will be used to improve TB control.

Your answers will not be released to anyone and will remain anonymous. Your name will not be written on the questionnaire or be kept in any other records. Your participation is voluntary and you may choose to stop the interview at any time.
Thank you for your assistance.

Interviewer: Place an X in the box of the selected answer(s).Do not read responses unless the directions indicate.

General and demographic questions		
1. How old are you?		
	1. Under 30	
	2. 31–40	
	3. 41–50	
	4. Over 50	
2. What is the interviewee gender?		
	1. Male	
	2. Female	
3**. What is your marital status**?		
	1. Married	
	2. Single	
	3. Divorced	
	4. Widower	
4.What is the highest level of education you have completed?		
	1. No school	
	2. Elementary	
	3. High school	
	4. College	
	5. Higher education (professional or post-graduate)	
	6. Religious schooling only	
	7. Literacy classes only	
5. What is the type of your residency		
	1. City	
	2. Village	
	3. Camp	
	4. Other	

6. What is your current occupation?		
	1. Employee	
	2. Laborer	
	3. Pensioner	
	4. Student	
	5. House wife	
	6. Non worker	
	7. Others (define_____)	
7. What is the number of your family members, (including yourself)?		
	1. 1 – 3	
	2. 4-7	
	3. More than 7	
8. What is the number of rooms in your house?		
	1. 1 – 2 rooms	
	2. 3 – 4 rooms	
	3. More than 4 rooms	
9. How far do you live from the nearest health clinic or hospital?		
	1. Less than 2km	
	2. 3–5 kilometres	
	3. 6–10 kilometres	
	4. More than 10 kilometres	
Health-seeking behaviour		
10. Where do you usually go if you are sick, or to treat a general health problem?		
	1. Private clinic	
	2. Government clinic or hospital	
	3. Traditional or homeopathic healer	
	4. Clinic run by an nongovernmental organization or church	
	5. Other:_____	
11. How often do you generally seek health care at a clinic or hospital? (Check one.)		
	1. Monthly or more	
	2. Four times a year or more	
	3. Twice a year or more	
	4. Once per year	
	5. Less than once a year but at least twice in past 5 years	
	6. Once in past 5 years	
	7. Never in past 5 years	
	8. Other:(define_____)	
TB knowledge and awareness		
12. Do you have radio or television at home?		
	1. Yes	
	2. No	

13. Where did you first learn about TB?		
	1. Newspapers and magazines	
	2. Radio	
	3. TV	
	4. Brochures, posters and other printed materials	
	5. Health workers	
	6. Family, friends, neighbours and colleagues	
	7. Religious leaders	
	8. Teachers	
	9. Other (please explain):	
14. The information you got about TB was understandable ?		
	1. Yes fully	
	2. Yes partly	
	3. No	
15. If partly or no; why?		
	1. The information language used was difficult.	
	2. The information is not clear	
	3. Too much information	
	4. Information incorrect	
	5. Information not complete	
	6. Others(define)	
16. Do you think your information about is TB enough?		
	1. Yes	
	2. No	
17. IS TB a common disease in your community?		
	1. Yes	
	2. No	
	3. I don't know	
18. In your opinion, how serious a disease is TB? (Check one)		
	1. Very serious	
	2. Somewhat serious	
	3. Not very serious	
	4. I have no idea	
19. How serious a problem do you think TB is in your country/region? (Check one.)		
	1. Very serious	
	2. Somewhat serious	
	3. Not very serious	
20. How many types of TB have you heard of?		
	1. One type (define)	
	2. Two types (define)	
	3. More than two (define _____)	

21. What are the signs and symptoms of TB? (Please check all that are relevant)		
	1. Cough	
	2. Cough that lasts longer than 3 weeks	
	3. Coughing up blood	
	4. Severe headache	
	5. Weight loss	
	6. Fever	
	7. Fever without clear cause that lasts more than 7 days	
	8. Chest pain	
	9. Shortness of breath	
	10. Do not know	
22. How can a person get TB? (Please check all that are relevant)		
	1. Through handshakes	
	2. Through the air when a person with TB coughs or sneezes	
	3. Through sharing dishes	
	4. Through eating from the same plate	
	5. Through touching items in public places (doorknobs, handles in transportation, etc.)	
	6. Do not know?	
	7. Other (please explain):_____	
23. How can a person prevent getting TB? (Please check all that are relevant)		
	1. Avoid shaking hands	
	2. Covering mouth and nose when coughing or sneezing	
	3. Avoid sharing dishes	
	4. Washing hands after touching items in public places	
	5. Closing windows at home	
	6. Through good nutrition	
	7. By praying	
	8. Do not know?	
	9. Other (please explain):_____	
24. In your opinion, who can be infected with TB? (Please check all that are relevant.)		
	1. Anybody	
	2. Only children	
	3. Only women	
	4. Only old people	
	5. Only poor people	
	6. Only homeless people	
	7. Only alcoholics	
	8. Only drug users	
	9. Only people living with HIV/AIDS	
	10. Only people who have been in prison	
25. Can TB be cured?		
	1. Yes	
	2. No	
	3. I have no idea	

26. How can someone with TB be cured? (Check all that apply/are relevant)		
	1. Herbal remedies	
	2. Home rest without medicine	
	3. Praying	
	4. Specific drugs given by health centre	
	5. Do not know	
	6. Other:	
27. How long is the TB treatment?		
	1. Less than 3 months	
	2. 3 months	
	3. 6 months	
	4. 9 months	
	5. 1 year	
	6. I have no idea	
28. Where can the TB patient get the treatment?		
	1. Governmental hospital	
	2. Health centers	
	3. Private hospitals	
	4. Private clinic	
	5. Non-governmental organization clinic	
	6. Elsewhere	
	7. I have no idea	
29. Do you think there is vaccination against TB?		
	1. Yes	
	2. No	
	3. I have no idea	
30. If yes, do you think that TB vaccination will protect you against TB?		
	1. Yes	
	2. No	
	3. I have no idea	
31. Does any of your family members haveTB?		
	1. Yes	
	2. No	
32. Does any of your neighbours haveTB?		
	1. Yes	
	2. No	

33. Does any of your friends have TB?		
	1. Yes	
	2. No	
34. What would be your reaction if you found out that you had TB? (Choose one)		
	1. Fear	
	2. Surprise	
	3. Shame	
	4. Embarrassment	
	5. Sadness or hopelessness	
	6. Other:	
35. Who would you talk to about your illness?		
	1. Doctor or other medical worker	
	2. Spouse	
	3. Parent	
	4. Child(ren)	
	5. Other family member	
	6. Close friend	
	7. No one	
36. What would be the first thing you would do if you had symptoms of TB?		
	1. Go to health facility	
	2. Go to pharmacy	
	3. Got to traditional healer	
	4. Pursue other self-treatment options (herbs, etc.)	
	5. Wait and see	
	6. Other:	
37. How expensive do you think TB diagnosis is in this country? (Please check one)		
	1. It is free of charge	
	2. It is reasonably priced	
	3. It is somewhat/moderately expensive	
	4. It is very expensive	
	5. Interviewer: If respondent gives monetary amount, note the amount here:	
38. How expensive do you think TB treatment is in this country? (Please check one)		
	1. It is free of charge	
	2. It is reasonably priced	
	3. It is somewhat/moderately expensive	
	4. It is very expensive	
	5. Interviewer: If respondent gives monetary amount, note the amount here:	
TB attitudes and stigma		
39. In your community, how is a person who has TB usually regarded/treated?		
	1. Most people reject him or her	
	2. Most people are friendly, but they generally try to avoid him or her	
	3. The community mostly supports and helps him or her	
	4. Other (please explain):	
40. Do you think that HIV positive people should be concerned about TB?		

	1. Yes why ( )	
	2. No why ( )	
	3. Do not know	
41. Would you feel ashamed if you had TB?		
	1. Yes, why ( )	
	2. No why ( )	
	3. I don't know	
42. Would you hide TB if you had it from the others?		
	1. Yes	
	2. No	
	3. I don't know	
43. Do you think TB would affect your social relations?		
	1. Yes	
	2. No	
	3. I don't know	
44. Do you think TB would affect your work?		
	1. Yes	
	2. No	
45. Do you think TB would affect your marital relation?		
	1. Yes	
	2. No	
	3. I don't know	
46. Would you prefer to live isolated if you had TB?		
	1. Yes	
	2. No	
	3. I don't know	
47. Do you think TB affects the chance for marriage ?		
	1. Yes	
	2. No	
	3. I don't know	
48. Do you think TB leads to infertility for women?		
	1. Yes	
	2. No	
	3. I don't know	
49. Do you think TB would affect your family responsibilities?		
	1. Yes	
	2. No	
	3. I don't know	
TB awareness and sources of information		

50. Do you wish you could get more information about TB?		
	1. Yes	
	2. No	
51. What are the sources of information that you think can most effectively reach people like you with information on TB? (Please choose the three most effective sources)		
	1. Newspapers and magazines	
	2. Radio	
	3. TV	
	4. Billboards	
	5. Brochures, posters and other printed materials	
	6. Health workers	
	7. Family, friends, neighbours and colleagues	
	8. Religious leaders	
	9. Teachers	
Satisfaction about TB services		
52. What do you think about TB center services offered?		
	1. Excellent	
	2. Very good	
	3. Good	
	4. Bad	
53. What do you think about TB health care workers' attitudes.toward patients?		
	1. Positive	
	2. Negative	
	3. Neither positive nor negative	
54.What do you think about TB center appearance?		
	1. Excellent	
	2. Very good	
	3. Good	
	4. Bad	
55. What do you think about the number of people seeking treatment in TB center?		
	1. Too many	
	2. Many	
	3. Few	
	4. Very few	
56. What do you think about waiting time in TB center ?		
	1. 15 minutes	
	2. 15 – 30 minutes	
	3. 30 minutes – 1 hour	
	4. More than 2 hours	

Thank you very much for participating in our survey.

10.3 CONSENT LETTER

Questionnaire for Tuberculosis in Sudan TB awareness, prevalence of TB stigma, illness perceptions and quality of life in Gezira state

SerialNumber…….....…… Date……
Name of Respondent ….....……..…… Locality …….……

Introduction: My name is…….. I'm working for Tuberculosis control programme in Sudan . We are interviewing TB patients as well as other patients attending this health facility.

Confidentiality and consent: I'm going to ask you some questions. Your answers are completely confidential. We will use your name and the serial number just for the purpose of matching and completeness of the information we received from you and other information we need from your documents. You may end this interview at any time you want. However, your answering to these questions will help us to assess the system to strengthen it. We would greatly appreciate your help in responding to our study. The interview will take about 2 hours. Would you be willing to participate?

(Signature of interviewer certifying that informed consent has been given verbally by the respondent.)

Signature……..... Date……..

10.4 ORIGINAL PAPERS