

The influence of TB on participation in community activities in Grahamstown East

From the perspective of TB patients and others in the community



Name: Elma Knol

Student number: 291358

University: Erasmus University Rotterdam
Institute of Health Policy and Management

Master: Zorgmanagement

Supervisor: dr. Harry Finkenflügel

Second supervisor: dr. Anna Nieboer

Third supervisor: prof. Valerie Møller

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Dutch summary

Zuid-Afrika is een van de 22 landen met het hoogste aantal tuberculose (TB) gevallen in de wereld. TB is jaarlijks verantwoordelijk voor twee miljoen doden wereldwijd. Als een direct gevolg van de spreiding van Aids/HIV stijgt het aantal mensen met TB tot epidemische proporties. Deze scriptie gaat over de participatie van TB patiënten in gemeenschappelijke activiteiten.

TB heeft vaak impact op het lichamelijke, sociale en mentale welbevinden van TB patiënten. De ervaren impact is afhankelijk van de cultuur waar de geïnfekteerde persoon in leeft. Er is een grijs gebied tussen sociale stigmatisatie en gedrag dat erop wijst dat men een TB infectie wil voorkomen. In de literatuur geven TB patiënten aan dat de reactie van hun omgeving nogal negatief is. Daarnaast is in de literatuur te vinden dat in sommige culturen het gebruikelijk is om je partner te verlaten, wanneer deze geïnfecteerd is met TB. In sommige studies wordt gesuggereerd dat de impact van TB groter is voor vrouwen dan voor mannen.

Onder gemeenschappelijke activiteiten wordt verstaan; alle activiteiten in de gemeenschap waarin mensen van alle leeftijden samenkomen, na werk of school. De participatie in deze activiteiten wordt beïnvloed door het voorbeeld dat mensen in de gemeenschap geven. De dagelijkse activiteiten van TB patiënten worden beïnvloedt door de effecten van TB. Soms richten TB patiënten zich alleen op hun ziekte en verliezen zij hun interesse in hun werk of andere aspecten van het leven.

Deze studie is uitgevoerd in de township in Grahamstown, beter bekend als Grahamstown East. Deze township ligt aan de rand van Grahamstown, een plaats in de Oost Kaap provincie in Zuid-Afrika. Tijdens het veldwerk zijn er verschillende groepen geïnterviewd, namelijk patiënten waarbij TB is aangetoond en die onder behandeling zijn, mensen uit de gemeenschap, medewerkers binnen de gezondheidszorg en vrienden en familie van TB patiënten. Voor de dataverzameling is gebruik gemaakt van interviews, observaties en focus groepen.

Het merendeel van de respondenten denkt niet dat anderen een probleem maken van TB, omdat volgens hen TB geaccepteerd is. De reden hiervoor is hoofdzakelijk dat TB geneesbaar is en de meeste mensen hiervan op de hoogte zijn. De algemene gedachte is dat TB patiënten niet anders zijn dan mensen die geen TB hebben. Veel TB patiënten houden zich desalniettemin bezig met wat anderen van hen vinden, omdat er veel geroddeld wordt over TB patiënten. TB is tegenwoordig vooral een probleem, omdat het gelinkt wordt aan Aids/HIV. Vanwege het besmettingsgevaar van TB, willen sommige mensen TB patiënten niet dichtbij laten komen. Dit duidt op een gebrek aan informatie bij sommige mensen uit de gemeenschap.

Het grootste gedeelte van de TB patiënten voelt zich gesteund door familie, vrienden en soms door burens. Ze geven aan een gezonde relatie te hebben met de mensen in hun gemeenschap. De hechtheid van de mensen in Grahamstown East wordt beïnvloedt door; ieders gevoel van welbevinden, de geografische locatie, overeenkomst in achtergrond en leefomstandigheden, de sociale banden, verblijfsduur in de gemeenschap en tijdsindeling. De respondenten geven aan dat de gegeven steun afhankelijk is van de relatie die mensen in de gemeenschap onderling hebben, evenals hun kennis van TB. Een kleine meerderheid van de gevraagde respondenten denkt dat de bewering 'TB ziekte van afstand' waar is of waar kan zijn. De meeste respondenten die denken dat de bewering onjuist is, waren de TB patiënten. TB patiënten worden niet altijd geïsoleerd door anderen, maar zonderen ook zichzelf af. Enkele respondenten, voornamelijk vrouwen, geven de aanwezigheid van stigma aan, welke wordt weersproken door respondenten die TB vergelijken met hoge bloeddruk. Zij geven aan dat TB niet gestigmatiseerd wordt, omdat het geaccepteerd is, anderen zeggen dat TB geaccepteerd is, maar gestigmatiseerd wordt. Leden van de gemeenschap geven aan dat de omgeving van Grahamstown East niet goed is voor de mensen, een veelgenoemd voorbeeld is het alcoholprobleem. Niet iedereen spreekt TB patiënten aan, omdat je anders kans hebt om bekeurd te worden vanwege smaad en laster. Zowel de helft van de vrouwelijke als de helft van de mannelijke TB patiënten hebben alleen hun familie verteld van de diagnose. Het grootste deel van de patiënten merken geen belangrijke veranderingen in hun leven. Dit geldt zowel voor mannelijke als voor vrouwelijke patiënten. De verschillen die wel worden genoemd hebben betrekking op; lichamelijke veranderingen, relaties met anderen, hun dagelijkse activiteiten (waaronder werk) en de behandeling. Geen van de TB patiënten is zich bewust van verschillen in de consequenties van TB voor mannelijke en vrouwelijke patiënten. Slechts enkele respondenten denken dat TB gebruikt zal worden als reden om te scheiden. De meerderheid van de respondenten geeft aan dat vrouwen voorzichtiger zijn met hun gezondheid dan mannen.

Om het begrip gemeenschappelijke activiteiten in te leiden, is eerst gevraagd naar de vrijetijdsbesteding. In sommige gemeenschappen worden gemeenschappelijke activiteiten georganiseerd, zoals vergaderingen over de ontwikkelingen in de buurt. Volgens de respondenten zijn er niet veel gemeenschappelijke activiteiten. De meeste TB patiënten geven aan niet te participeren in deze activiteiten gedurende hun TB behandeling. Dit geldt zowel voor mannelijke als voor vrouwelijke patiënten. Sommigen zeggen geen zin te hebben, maar voornamelijk worden lichamelijke oorzaken, zoals zwakte genoemd. Er wordt door TB patiënten aangegeven dat ze wel willen meedoen als ze zich weer sterker voelen. Een andere reden om niet te participeren in activiteiten, is dat TB patiënten zich alleen op hun gezondheid focussen. De vraag kan gesteld worden of stigma ook een rol speelt, vanwege het verband tussen TB en Aids/HIV. Veel respondenten noemen dit verband. Belangrijk is dat zij opmerken dat zij voor de diagnose TB ook niet veel participeerden. Geen van de respondenten sluit TB patiënten buiten bij activiteiten, maar sommigen kennen mensen die dat wel doen. Slechts een minderheid van de TB patiënten merkt op dat zij buitengesloten worden door anderen van gemeenschappelijke activiteiten. De andere kant is dat sommige TB patiënten zichzelf van anderen isoleren.

English summary

South Africa is one of the 22 countries with the highest burden of tuberculosis in the world. TB is responsible for two million deceased a year in the world. As a direct result of the spread of HIV the number of people with TB have increased to epidemic proportions. This thesis is about the participation of people with TB in community activities.

TB often has an impact on the physical, social and mental well-being of sufferers of TB. The experienced impact depends on the cultural environment of the infected person. In most literature TB infected people mention a negative reaction of their environment, although there is a grey area between social stigmatisation and behaviour that indicates people desire not to catch TB. The literature reveals that in some cultures, it is common to abandon your partner if they are infected with TB. Some studies suggested TB's impact on quality of life might be greater for woman than men.

The concept of community activities can be outlined as, all activities in the community in which people of all ages engage after work or school hours. The participation in community activities is influenced by the examples given in the community. The daily activities of a TB patient depend on the effects of TB. Some TB infected persons only focus on their disease and therefore lose their interest in work and other aspects of life.

The study was conducted in the township in Grahamstown also known as Grahamstown East. This is a township community at the edge of Grahamstown, a place in the Eastern Cape Province, Republic of South Africa. During the fieldwork several groups of people were interviewed namely; patients with proven TB, community members, friends and family members of TB patients and health care workers. The instruments used to gather the data are interviews, observations and participation in existing focus groups.

Most respondents do not think that other people make a problem about TB, they say: "TB is accepted". The main reason for the acceptance of TB is that it is curable, what most people know. The general thought is that people with TB are not different from people who do not have TB. A main problem of TB is that patients wonder what other people will think, because there is a lot of gossip about TB patients. TB is a problem now because people link it to Aids/HIV. Taking it as the most serious and contagious disease, some people would not allow TB patients to come closer to them as if it would infect them. That is because of the lack of information of some people. A majority of the TB patients mention that they are supported by family, friends and sometimes by neighbours and that they have a healthy relationship with their communities. The majority of the respondents say that the support depends on the kind of relationship people have with them as well as their knowledge about TB.

A small majority of the respondents asked, do think the statement 'TB disease of distance' is or can be true. Most of the respondents who think the statement is false were the TB patients themselves. TB patients are not always isolated by others, but also isolate themselves. None of the TB patients notices differences between male or female TB patients. Only a few respondents think that TB will be used as a reason to divorce. A majority of the respondents mention that women handle their health in a more careful way. Some respondents, mainly females, point out the presence of stigma. On the other hand some respondents compare TB with high blood pressure. The respondents do not agree about the presence of stigma. Some say that TB is not stigmatised anymore, because it is accepted. Others say that TB is accepted, but stigmatised.

The people in Grahamstown East are bonded by the following aspects; sense of well-being of the community members, the geographical location, similar backgrounds and living circumstances, social ties, their time horizon and time schedules. Some community members say that the environment of Grahamstown East is not good for the people. The majority of the respondents addressed the drinking in the area as a problem. A few respondents mentioned that they only talk to TB patients, if they come to them, because they are afraid to get a fine. Half of the male and half of the female patients only told their family members about their TB diagnosis. Most patients do not notice any big changes in their lives. However some patients noticed there have been changes. There are mentioned several changes named which influences the life of TB patients, issues like, their physical well-being, patients relation with other people, daily activities (including work) and the treatment.

The concept of community activities needs more introduction. Therefore first the respondents were asked what they like to do in their spare time. According to most residents there are not many activities organized in Grahamstown East. Sometimes the community organises activities. In some locations they organise things like community meetings about what is going on in the location. The majority of the patients are not participating in community activities during their TB treatment. There is no difference in this finding for male and female respondents. TB patients name physical causes for not participating in community activities, mainly the weakness, which comes with TB, keeps the patients from participation in activities. Another reason for not participating is that some TB infected persons only focus on their disease and therefore lose their interest in work and other aspects of life. Although in general most of the patients mention that the TB did not have much influence on their lives. It is questionable if also stigma plays a role in some cases, due to the link between Aids/HIV and TB. A lot of respondents do mention this link. An important note is that most patients were not really active in community activities before they got TB. All the respondents stated that they do not exclude TB patients from community activities, but that they do know others who exclude TB patients. Only a minority of the TB patients notice that others exclude some of them from community activities.

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Chapter 1 – Introduction

1.1 Theme relevance

This thesis is about the participation of people with tuberculosis (TB) in community activities. It is a component of the Sanpad research project 'TB Stigma and Quality of Life in the Eastern Cape'. The Sanpad research project inquires how the stigma associated with TB influences the health behaviour and well being of TB patients. The participation of people with TB in community activities has been researched to get a better understanding of the influence of TB on a patient's life.

"TB is the most common infection for people living with HIV/AIDS. No cure has been found yet for HIV/AIDS to date the origin of the stigma attached to the disease is recent. In contrast TB, the older disease, can be successfully treated, but sufferers and their families are nevertheless burdened by a stigma of ancient origin. Recently TB issues have been neglected in favour of AIDS studies. The proposed Sanpad research aims to restore the balance" (Sanpad Research Project 2005).

The World Health Organisation (WHO) has declared TB as a global emergency (Sanpad Research Project 2005). In South Africa the TB epidemic has developed into one of the worst in the world. The present aim of TB control is to break the cycle of transmission by treating TB cases as early and efficiently as possible. However, attitudes and beliefs about the disease may influence the effectiveness of even the best-designed TB control programs. Therefore this study will examine several social points of view (health care workers, family and friends of TB patients and community members) and their social influence on TB patients. For instance the influence and importance of the role of the community for TB patients are part of the study. Not only the attitude of community members but also the desire of TB patients with regard to participation in community activities will be examined. This is of interest to survey whether TB patients want to participate in a different way than they are doing now. Also the social influence of TB patients on others is part of the study. In short, this study examines to what extent the social component plays a role in the lives of TB patients in Grahamstown East, South Africa. This research entails the living conditions in the community, beliefs and attitudes of the community and TB patients.

1.2 Background tuberculosis

TB is caused by an infection of the bacterium 'Mycobacterium tuberculosis' and spreads through the transfer of sputum by air. Patients with open lung TB, which is the most frequent form of TB, are coughing and sneezing, which releases the TB bacteria into the atmosphere.

“Only those with open lung TB can pass on the infection” (KNCV 2006). The infection risk is the highest in small and badly ventilated areas.

“Not everyone who comes into contact with the bacilli, and who is therefore infected, actually develops TB. Someone who is infected only will not be aware of this, and has no symptoms. In this way the bacilli can nestle in the body for years. The anti-bodies produced by the body are often strong enough to prevent the disease from breaking out. Somebody with normal resistance has around a ten-percent chance of developing TB. This can happen as a result of normal resistance becoming reduced, for example, due to a particular disease. Without proper treatment, however, the patient may steadily deteriorate and eventually even die. Early diagnosis and treatment of TB is therefore essential. Fortunately TB is easy to cure with a course of various antibiotics” (KNCV 2006).

An effective long-term treatment for TB is named the Directly Observed Treatment Short course (DOTS). It is difficult to diagnose TB when there are no bacteria in the sputum and that is the reality in 50% of the cases (AZG 2005). When in this study TB infected people are mentioned, this means who are diagnosed with active open (lung) TB.

As a direct result of the spread of HIV the proportions of people with TB have increased to epidemic proportions (Davey & Seale 2002). TB is responsible for two million deceased a year (KNCV 2006). TB has its greatest impact on adults between the ages of 15 and 59. These are the most economically productive people in society, and are also the parents on whom survival and development of children depend, therefore the social and economic burden of TB must be great (Hudelson 1996).

1.3 Tuberculosis in South-Africa

South Africa is one of the 22 countries with the highest burden of TB in the world. Nine out of ten countries with the highest TB incidence rates are in the African continent, but more of the world's cases reside in five South-east Asian Countries (Uplekar et al. 2001). 47% of the TB cases in the African Region are located in the Southern bloc, where South Africa is located (see appendix 1).



Figure 1: Map of South Africa



Figure 2: Map of Eastern Cape

South Africa Demographic and Health Survey (SADHS) findings imply a total between the 35.000 and 40.000 new TB cases annually province-wide in the Eastern Cape (Mahlalela et al. 2000). The Eastern Cape was home to 7.035.000 people according to the statistics of 2005 (Statistics South Africa 2005). "37% of the Eastern Cape population is urbanised and 41% of the households live in typically circular mud huts with thatched roofs. The people of the Eastern Cape tend to be more traditional and rural but also significantly poorer and less developed than other parts of the country" (Cocks & Møller 2002:389). TB is called an epidemic in the Eastern Cape. An illustration of this is given by the fact that 8 out of 21 TB hospital centres operating countrywide, are located in the Eastern Cape. One of these hospitals is located in Grahamstown. TB is a problem among men as well as among women and both face social and economical problems because of the TB infection (Liefoghe et al. 1995). Stigma and misinformation about TB are still major barriers to TB screening and treatment in some countries. Health workers are often not aware of the beliefs, attitudes or the behaviour about TB of the community, which they do research in (Edginton, Sekatane & Goldstein 2002).

1.4 Main research objective

What is the influence of TB on the participation of TB patients in community activities?

Research questions:

1. Which values and beliefs are common in the community on TB patients?
2. What is the self-perception of a TB patient?
3. Are there differences in attitudes and consequences of TB between male and female patients?
4. Which community activities can be found in Grahamstown East?
5. To what extent do TB patients participate in community activities?

1.5 Reading instructions

This chapter reveals the relevance and the background of this study. Also the main research question and the other underlying research questions are formulated. Chapter two describes the theoretical framework. It clarifies which information is known about the subject of the study and what is not yet known. Contradictions and implications found in the literature will be described. The next chapter will describe which research methods are used to find the data to answer the research question. Chapter four will expose the research results; a description will be given of the way the research has developed and an exposure of the collected data. An interpretation of the results by discussing them in the light of the research problem will be presented in chapter five. Chapter six will describe the conclusions, recommendations, further research questions and answers to the question what others could learn from this research.

Chapter 2 – Theoretical frame work

This study uses different perspectives to address the possible influence of TB on the participation of TB patients in the community. This chapter reveals an overview of the values, beliefs, causes and attitudes, which exist in the community, as well as amongst friends and family, about TB patients. This will also be pointed out from the perspective of TB patients. The current knowledge about the self-perception of TB patients and their reactions about their diagnosis will be described. Also a definition of community and community activities will be given, as well as the elements in which people engage in joint activities. Previous studies on the influence of TB on the daily activities, participation, social and job aspects of TB patients will be summarized. Reported differences, in the current literature, in self-perception, consequences and attitudes of male and female TB patients will be discussed.

2.1 Values and beliefs in the community about TB patients

There are several associations, beliefs, causes and reactions found in the literature referring to TB and TB patients. Gibson et al. (2005) observe a grey area between social stigmatisation in a community with TB patients and behaviour that indicates people's desire not to catch TB.

2.1.1 *Beliefs about the causes of TB*

The literature shows that in general TB is still associated with dirt, poverty (and therefore exposure to cold), poor nutrition, smoking, alcohol, hard work, low living standards and sharing facilities with TB patients (Westaway & Wolmarans 1994, Liefoghe et al. 1997, Yamada et al. 1999, Long et al. 2001, Edginton et al. 2002). Different cultures mention different causes of TB. Long et al. (2001) reveal that TB often is discussed in the same group of diseases as leprosy and not only in terms of its incurability, as perceived by people, but also the association with the social consequences. In some cultures the community members believe that inheritance and familial association could cause TB, which constitute a mechanism of transmitting TB (Liefoghe et al. 1997). The belief that even after a complete course of treatment a TB patient remains contagious seems to be widespread in most (non-western) countries. For instance in the Punjabi community there is a widespread belief that pregnancy reactivates TB infection by a former TB sufferer (Liefoghe et al. 1995). "In a rural district of South Africa (...) there is a strong belief that TB is the result of breaking cultural rules that demand abstinence from sex after the death of a family member and after a spontaneous abortion of a woman" (Edginton et al. 2002:1075). In the Filipino culture it is commonly believed that TB can be contracted by passing a sufferer on the street, engaging in a casual conversation or by sharing food, telephones, beds or other facilities (Yamada et al. 1999). Some families in Vietnam did no longer allow TB patients to share facilities with their family (Long et al. 2001).

The belief that TB is given by God as a punishment for their sins is accepted in many cultures (Chang et al. 2004). According to African belief systems good health is holistic and extends to the person's social environment.

2.1.2 Attitudes and reactions of the community, friends and family to TB patients

The literature reveals that the general attitude toward sufferers of TB is stigmatisation, in other words, "the infected individual is thought to be dirty and is outcast or shunned by society" (Yamada et al. 1999:497). TB is called the disease of distance and contact with TB victims is feared (Bennstam et al. 2004, Chang et al. 2004). Members of a Kenyan community sometimes take preventive measures to limit the danger of infection (Liefoghe et al.1997). Isolation and stigmatisation are the methods used to protect society from the TB threat (Bennstam et al.2004, Westaway & Wolmarans 1994, Long et al. 2001). The perception of TB in the Kenyan community strongly influences the attitudes towards TB patients. In this community not only the TB patients, but also their family could be isolated. Sometimes relatives even stop children from having contact with their TB infected parents (Liefoghe et al. 1997). "When TB affects someone, his or her family and friends do not see that individual any longer as a person, they only see the TB within the body" (Bennstam et al. 2004:311). The main reason Bennstam et al. (2004) found, for healthy people to keep their distance to the TB infected people, is the fear of dying. In some surveys people in the community talked about the possibility of passing by the house of an infected person to say hello, but in other surveys this was not even a possibility. A study in a Congolese community noticed that the members of the society have to respect the rules and that they are supposed to be loyal to the TB victims in return. The TB patients there perceive protection from other members in the society. "Only a generation earlier, those who were infected with TB were sent out into the forest to stay alone in a secluded house" (Bennstam et al. 2004:305).

A majority of the families seem to be deeply shocked or react in denial when the diagnosis is disclosed and they have serious difficulties in accepting it (Liefoghe et al. 1995, Marra et al. 2004). After acceptance of the diagnosis mostly the family became very supportive by finding proper care and giving financial support (Liefoghe et al. 1995). The literature reveals that in some cultures, for instance in the Mai Ndome District, Congo, it is common to abandon your partner if they are infected with TB. In this district it is also common that a young person with TB has less chance to get married, even after recovery (Bennstam et al. 2004). In some cultures, like the Limpopo Province in South Africa, there is a belief that husband and wife cannot have intercourse while one of the other has TB. This could result in family and social disharmony, because the unaffected partner may then look elsewhere for sexual fulfilment (Edginton et al. 2002, Yamada et al. 1999). Divorce is an example of family disharmony (Liefoghe et al. 1995, Liefoghe et al. 1997). However it is hard to discover in the study in Vietnam if TB was the sole cause of divorce, it could have only played a certain role in the divorce (Long et al. 2001). The same research reveals that sometimes patients wished to isolate themselves, but that family members did not stay away and even asked them to eat and stay together as usual.

2.1.3 Importance of knowledge of the beliefs

To understand the patients and the effect of TB, it is important to have information on gender differences, stigma and isolation due to TB (Long et al. 2001). "Health workers are all too often not aware of the beliefs and attitudes about TB of the community they serve, nor of the behaviour concerning illness expected by local custom" (Edginton et al. 2002:1076). This can be illustrated by the reaction of the health workers in the Limpopo Province, South Africa, when the result of the study were presented to them, even those who had lived and worked there for some time, were unaware of local beliefs about TB (Edginton et al. 2002). In a survey held in Pakistan it was suggested that health workers share the same cultural beliefs about TB as the rest of Pakistani society. (Khan et al. 2000). In order to control TB and help the victims of TB, the values and beliefs about TB must be well known.

2.2 Perception of TB patients

TB often has an impact on the physical, social and mental well-being of TB patients (Rajeswari et al. 2005). Another element of impact is the perception of others in the community about TB, which influences the self-perception of TB patients. It is remarkable that most of the literature shows a part of TB victims which do not believe that they could be completely cured, even after a full course of treatment (Long et al. 2001, Liefoghe et al. 1995, Liefoghe et al. 1997).

2.2.1 Perceptions of TB patients about their diagnosis TB

Bhatia et al. (2000) and Lawn (2000) concluded that patient perceptions about TB remain largely unknown. Yet the literature shows a lot of reactions of TB patients to the disclosure of their diagnosis TB. These reactions included feelings of loneliness, depression, suicidal thoughts, fear, apathy, shock, concern, surprise (in relation to the lack of symptoms) and acceptance (Marra et al. 2004, Rajeswari et al. 2005). Concern for themselves, as they know relatives of friends who had previously been infected with TB and had experienced prolonged hospitalisation or death (Marra et al. 2004). In relation to others, some TB patients felt guilty were ashamed or concerned. "Concern for others in terms of passing the disease on to family and friends" (Marra et al. 2004). Rajeswari et al. (2005) reveal that possible reasons for these emotions may be "physical rehabilitation, illiteracy, lack of knowledge of TB or fear of loss of income on account of long duration of treatment". The literature shows TB patients who consider TB as a contagious disease, which can be spread by sputum. However some did not perceive TB as an infectious process, but attributed the disease to a mechanical cause, a physical cause or to 'sins' (Liefoghe et al. 1995). Some researchers concluded that there were TB patients who rejected the diagnosis due to feelings of anger and distress or because they had become mentally incapacitated. Mainly the denial of the disease seems to be based on the diagnostic 'label' of the disease (Liefoghe et al. 1995, Yamada et al. 1999).

2.2.2 Attitudes to TB patients from the perspective of TB patients

In the greater part of the literature TB infected people mention a negative reaction of their environment. TB patients in Sialkot, Pakistan, perceive the reaction of their neighbours and friends' attitudes towards them as rather negative (Liefoghe et al. 1995). People mentioned to be isolated in some way by their family and being ignored (at least not greeted) by the community members and friends. This neglect continues for a long time, sometimes even when the treatment was already finished. TB patients in Vietnam had a smaller chance of being with other people and were described as feeling lonely. Even in hospitals, TB patients said to be isolated from other patients who suffered from diseases other than TB (Long et al. 2001). Very few participants, in the research of Long in Vietnam (2001) felt that their TB had affected their relationships with friends and family. The experienced isolation seems to be depending on the culture of the infected person's environment. Some people in an Aboriginal community in Canada reported no stigmatisation from their neighbours, but they felt that health care professionals treated them less well because of their TB (Gibson et al. 2005). In Mexico City half of the survey population thought that they were not received back in their homes and 15% believed that their families would reject them when TB was diagnosed (Chang et al. 2004).

2.2.3 Influence of TB at the social life of TB patients

The influence of TB can be illustrated by the observation, which appear in several surveys, that many patients gave false addresses to the tuberculosis centre (Khan et al. 2000, Rajeswari et al. 2005). The African tradition is to share food and to eat and drink from the same dishes and cups stated Edginton et al. (2002). Some TB patients can no longer do this because that would put their family at risk. Therefore this effect of TB could be socially disruptive (Edginton et al. 2002). In Sialkot, Pakistan, TB patients felt to be feared and that contact had been avoided at least during the treatment (Liefoghe et al. 1995). Research of Liefoghe et al. (1997) in a Kenyan community reveals that because of the negative reactions of their environment some patients try to hide their disease. This is complex because TB patients still need their support. Figure 3 shows elements of the community, which influence the behaviour of TB patients. The self-perception of a TB patient is influenced by the existing health-related beliefs in the community, the culture of the community, which a TB patient lives in, and the expected health behaviour of a TB patient by the community. TB patients may become ashamed of their disease, because of the condemnation of the society. The TB patients in the research at the Mai Ndome District, Congo, are convinced that they also would react negatively, if one of their friends would be infected with TB (Bennstam et al. 2004).

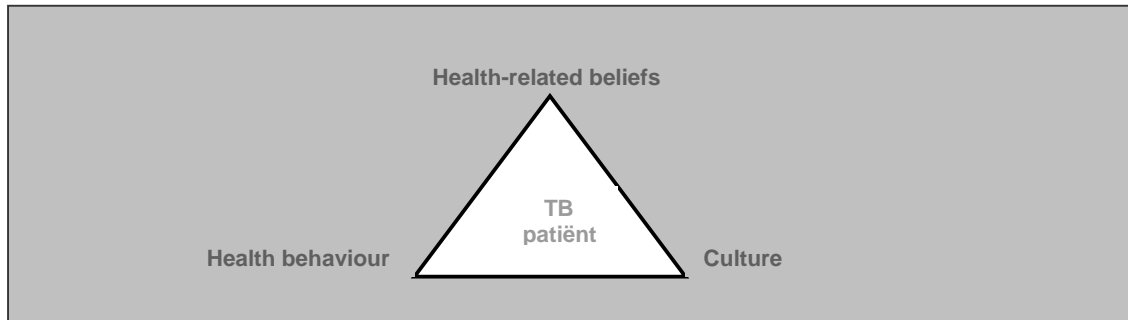


Figure 3: Position of the TB patient (Based on Liefoghe et al. (1997))

2.3 Differences in attitudes and consequences regarding male and female TB patients

Both male and female TB patients face social and economical problems. A few studies suggested TB's impact on quality of life might be greater for woman than men. As TB affects women mainly in their economically and reproductively active years, the disease also has a strong impact on the care of their children and families and their ability to undertake household activities (Uplekar et al. 2001, Chang et al. 2004, Liefoghe 2001). The literature also reveals that in poor countries women in general report sick less often than men do and often they have lower socio-economic status and reduced access to economic resources, lower education and less information than men (Uplekar et al. 2001, Long et al. 2001).

Worldwide, the data shows that relatively more men than women are diagnosed with TB and die from the disease. However TB is still a leading infectious cause of death among women, which seems to have a higher fatality rate among woman than men (Uplekar et al. 2001, Long et al. 2001). Uplekar et al. (2001) conclude that research is lacking to explain the impact of gender inequalities in access to care on reported sex ratios for TB.

2.3.1 Differences in self-perception of male and female TB patients

The main difference, which becomes clear in the literature, is that male patients often have their concern about economic-related problems, while female patients are worried about the social consequences of the disease. A reason for this could be that female patients are often socially and economically dependent on their husbands and family. Female patients appear to be more pessimistic than male patients (Long et al. 2001). Participants in the research of Long et al. (2001), in Vietnam, mentioned that male patients more easily accepted to eat and live normally with their whole family when family members requested them, because they felt that this was better for them. On the contrary, female patients often want to protect other family members from the disease and therefore, even when they were requested by family members to eat together, they continued to isolate themselves (Long et al. 2001).

2.3.2 Differences in attitudes towards male and female TB patients

Women must overtake more social and cultural obstacles before accessing health care services. The acknowledgement, that women often receive inadequate healthcare, increases.

Sometimes this is due to the difficulty of women recognising their needs (Long 2001 et al. Uplekar et al. 2001). In some cultures there are different perceptions and beliefs about male or female TB patients. In Vietnam this is considerably influenced by the role of a female in the family and in the social context (Long et al. 2001). In Sialkot, Pakistan, more male than female patients mentioned a positive attitude of their family towards their disease (Liefoghe et al. 1995). This image is supported by other surveys. Long et al. (2001) did not discover a clear difference between the duration of isolation by women or men in Vietnam.

2.3.3 Differences in consequences between male and female TB patients

The literature pictured that married women did not receive the same level of support as unmarried women. In some cultures unmarried women with TB were likely to have more difficulties finding a marriage partner than unmarried men with TB. In Vietnam it was generally mentioned that couples often support each other when one of them gets TB (Long et al. 2001). This is not a general thought, because Hudelson concluded, after a literature study about gender differences, that while male respondents expected and received care from their wives, "the reverse was seldom true" (Hudelson 1996:397). Divorce has been mentioned in some cultures, especially in female groups. Some women told that their husbands abandoned them and some were sent back to their natal homes until they were cured (Hudelson 1996). "And tuberculosis was perceived to be an excuse for divorce by couples already experiencing marital problems. As perceived by both male and female groups, men were more independent and did not worry much about divorce because they were described as 'stronger'" (Long et al. 2001:75).

2.4 Community

In the paper of Volker & Flap (2001), empirical evidence is shown that suggests that the local community still matter in the choices that people make. "Many people belong to a number of different communities; examples include the place where they live, the people they work with, or their religious group" (Maher 1999:763).

2.4.1 What is a community?

The concept of 'community' has a variety of definitions. In an article of Gibson et al. (2005: 933) community has been defined by La Bonte as "the more modest process of people organising themselves, or being organised into identity-forging, issue-solving groups". Another common definition is used by MacQueen et al. (2001): "emerged as a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings". Being part of a community is a subjective feeling, which is reflected by "the sense of belonging, the degree to which individuals are willing to sacrifice personal thoughts and for the willingness to behave solidary with others in the social context" (Lindenberg & Nieboer 2006).

In this thesis community will be described as a group of individuals with diverse characteristics, who have a sense of belonging and are linked by social ties, because of their similar living circumstances and engagement in joint activities in their geographical location and setting. This definition is composed of elements of the definition of both MacQueen et al. (2001) and Lindenberg & Nieboer (2006).

2.4.2 Elements that bind the people in a community together

In this thesis the concept of community is first of all based on the geographical location and setting where individuals live. These individuals could be for instance people with TB, health care workers or (un) employed people. It is reasonable that these individuals have diverse characteristics. In townships in developing countries the living circumstances are in general quite similar, for example people are often poor and unemployed. These elements influence both the amount of TB sufferers as well as the thoughts about TB in the community. Most of the people who live in a township are living there for many years in small, simple houses, which are close to each other. Therefore it is acceptable to suggest that, because of the geographical location, the setting and the similarity in circumstances, people will engage in joint activities. Like Lindenberg & Nieboer (2006) suggest; “the opportunities of people to form a community are all increased when they do not leave the neighbourhood to go to their work, when they have lived longer in the neighbourhood and when there is less residential turnover in the neighbourhood”. The social ties are created for instance in the street, at school, in the clinic, at the church or because people are family, friends or neighbours. As mentioned before the community is important because they influence the perception, participation and health behaviour of TB patients. The most relevant motivators in this study to engage in joint activities are scheduled below. This table is based on the introduction of the book 'The future of Community' (Lindenberg & Nieboer 2006) and by the article of Baker & Palmer (2006).

Motivator:	Explanation:
<i>Sense of well-being of community members</i>	Participation in leisure or recreational activities by many researchers is considered as an essential component of an individual's sense of well-being. This is because researchers have identified many positive benefits of leisure participation, such as self-improvement, family functioning etc.
<i>Geographical location</i>	When people live in the same geographical location, the opportunities of meeting people for informal contact are more frequent. These opportunities are most important for joint activities. This also includes that people run into each other at the clinic. Citizen pride of their community is related to decreased feelings of helplessness.
<i>Similar backgrounds</i>	It is made easier to take part in joint activities if people have a similar background, for example the education, homogeneity of income and family status.

<i>Similar living circumstances</i>	If the living circumstances are more similar, then there is a more common understanding and there are more similar preferences, as supposed to people who do not share the same living circumstances.
<i>Social ties</i>	If people know a lot of other people in their community, they will be far more interested in joint activities with them, than when they have a lot of friends and hobbies outside of the community. But they also do know more about the health of the people in their community.
<i>Time horizon</i>	If people own a house that does not only increase a person's interest in the neighbourhood, but enlarges the time horizon of living in a particular neighbourhood as well. The attachment of a resident to his community is positively related with his length of residency. This can have a positive influence on the social ties in the community.
<i>Time schedules</i>	This condition enables people to meet in the first place and to maintain a relationship afterwards.

Table 1: Conditions under which people engage in joint activities.

The participation in activities is influenced by the examples given of other people in the community. For instance the involvement of youth in activities after school hours reflects both the influence of family socialization and civic development. Activities after school hours can be promoted by parents through examples set by their personal involvement in activities, in the community and through affirmation of the interests of their children (Fletcher et al. 2000).

2.5 Community activities & participation

The previous paragraph introduced the elements, which influence the engagement in joint activities, as well as the participation in community activities. There are different concepts for activities in which people are participating, such as leisure activities, community activities, spare time activities, after school or work activities etc. In this thesis the concept of community activities will be used. This concept can be outlined as all activities in the community in which people of all ages engage after work or school hours. In the article of Møller 1996, the remark was made that within the same culture there will be no perfect fit between the given definition of an activity and its subjective meaning to the actor. More generally was the notion that most leisure activities involve social interaction that contributes to decisions to participate and to enjoyment. Researchers have found strong empirical and theoretical support for leisure services as being a key contributor to community life satisfaction and quality of life (Baker & Palmer 2006).

2.5.1 Spare time activities in a black township in South Africa

Møller has reported in several articles about the leisure activities in black urban townships in South Africa. In her research of 1991, she concluded that favourite leisure activities of young people (age 15-25 years) in an urban black township in South Africa are “socialising (especially at parties), listening to or playing music, playing sport (mainly soccer), passive

recreation including television, cinema, reading and radio, hobbies and playing cards or draughts” (Møller 1992: 321). For all ages the typical activities to pass-time are “watching television, relaxing, resting, meals or snacks and visiting away from home” (Møller 1996: 327). A distinction can be made in all kind of activities and participation, such as active and passive, homebound and away-from-home, and indoor and outdoor leisure. The amount of time people spend at active leisure or sports reduces regularly by generation, while passive leisure activities enlarge by generation (Møller 1996). Religious participation is also a way of community participation. In the township context organized religious participation comprises regular worship activities and support activities such as choir singing and practice (Møller 1996: 319). In the same article the suggestion is made by Allen and Ching-Sang (1990) that the leisure experience of women and men may differ because of their division between work and leisure. On average school children reported the highest number of activities in an urban black township in South Africa (Møller 1996). The most important obstacles to participate in activities were for the youngsters; lack of money, lack of facilities, lack of time and not having parental permission (Møller 1992). Møller suggests in 1996 that the sense of obligation and duty may be more pronounced in African societies than in other cultural settings. Her study pointed out that people were more likely to be discontent with their time use if they experienced alienation due to lack of fulfilment of social norms.

2.5.2 Influence of TB at the participation of TB patients

Daily activities of a TB patient depend on the effects of TB (Bennstam et al. 2004). According to Marra et al. (2004) is the social functioning of TB patients also affected as isolation, variable social support by family and friends, and the ability to continue with social and leisure activities. Some TB infected persons only focus on their disease and therefore loose their interest in work and other aspects of life (Yamada et al.1999). In the article of Khan et al. (2000) a survey held in Pakistan quoted, that patients often stopped working after TB was diagnosed. In a Pakistan survey, the average number of workdays lost because of TB and its treatment ranged from 28 to 68 days. Patients expressed fear of informing their employers about their diagnosis because of potential job loss. In the same survey however 83% of patients worked at the time of diagnosis and only 36% were still working by the time DOTS was initiated (Chang et al. 2004, Marra et al. 2004, Rajeswari et al. 2005). During a field research in South India, Rajeswari et al. (2005) discovered that prior to the start of treatment daily activities were affected for both men and women. The day-to-day activities such as cooking, cleaning and washing were affected for half of the women participating in the study in South-India prior to the start of treatment. By the end of the intensive phase and more at the end of the treatment, most patients were able to do their jobs (Rajeswari et al. 2005).

2.6 Conceptual framework

Participation of TB patients is the dependent variable in this study. The independent variables are the characteristics of the community.

Literature suggests that in the first place the characteristics of the community influence the life of TB patients. The following characteristics; self-perception, beliefs about TB and the physical condition, are crucial for individual TB patients according to the literature. The correlation between the community and TB patients mainly influence the social situation, the support, and health behaviour. Either a combination of the characteristics, or a single characteristic of the TB patients, influence the participation of TB patients in community activities. The behaviour and the participation of TB patients in turn influence the attitude of the community towards TB and TB patients.

The conceptual framework can be used for women as well as for men. The gender of a TB patient and the health behaviour of men and women plays a role in the consequences of TB. Some TB patients feel excluded from activities and their community, other TB patients exclude themselves. However, literature shows other cases where TB patients do not notice changes except physical changes. This framework will be used to study the impact of TB on people's lives in Grahamstown East.

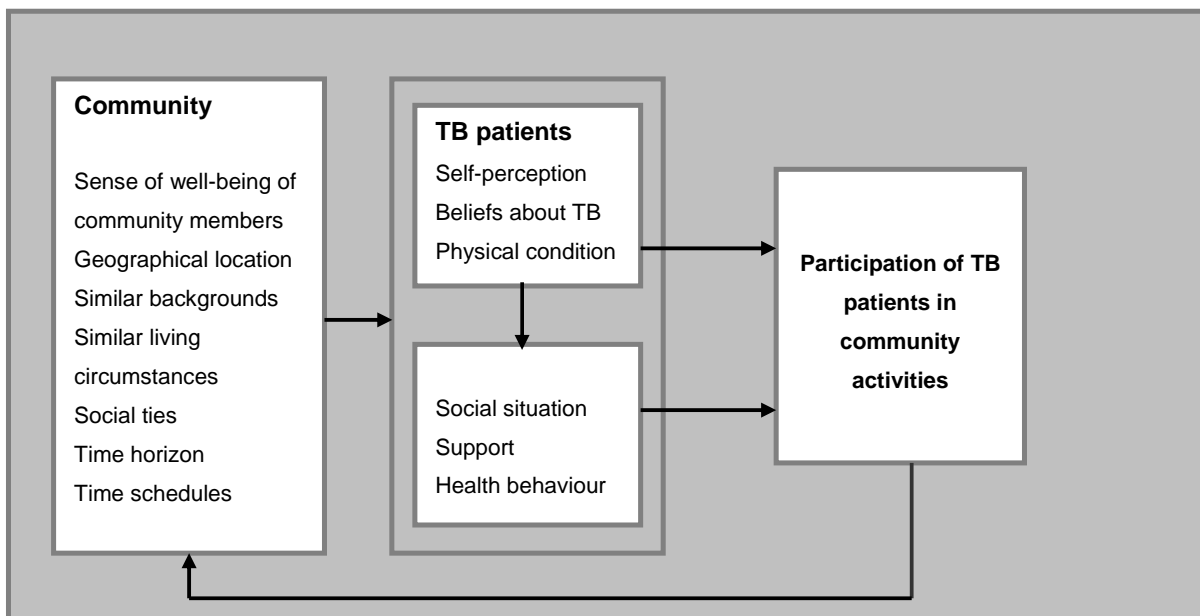


Figure 4: Conceptual framework thesis

Chapter 3 – Research Methods

3.1 Survey setting

The study was conducted in the township in Grahamstown also known as Grahamstown East. This is a township community at the edge of Grahamstown, a place in the Eastern Cape Province, Republic of South Africa. The majority of the population in Grahamstown speaks Xhosa. This black population consists of 70.000 to 80.000 inhabitants. The second important group are the Coloured consisting of 8.000 to 10.000 inhabitants. Most of them live in Grahamstown East. Another population group are the white people; containing around 10.000, mostly English speaking, inhabitants. There is also a small Hindu Indian population of about 500 inhabitants (author unknown 2003).

In Grahamstown East there are seven clinics where TB, among other diseases, is treated. There is also a TB Hospital located.



Figure 5: Map of Grahamstown

3.2 Data collection

A qualitative research study has been conducted during the period from December 2005 until July 2006. The case study of TB patients in the natural setting, Grahamstown East, was conducted from the 7th of March until the 7th of May. In this study several research methods are used but they are all interactive.

During the fieldwork several groups of people were interviewed:

- patients with proven TB
- community members
- friends and family members of TB patients
- health care workers

Patients who were willing to participate in the study were all found in several clinics and in the Santa Temba TB hospital in Grahamstown East. The head of the clinics or hospital indicated most of the patients who were interviewed. One of the reasons is that some patients were too ill to be interviewed. Appointments for an interview were not always strict. Sometimes a patient was not there or not feeling well and in that case another available patient had to be interviewed. One interview with a male patient could not be finished, because he was too ill. When we came back a week later he already passed away. This interview has not been included. The research included both male and female patients.



Figure 6: Clinic Extension 7



Figure 7: Santa Temba TB Hospital

Inclusion criteria TB patients:

- patients with proven TB
- patients between the age of 15 and 59.
- patients living in the region where the study took place

Other interviewed groups are the community members, health care workers and friends and family of TB patients. All the groups include male and female respondents of different ages. An overview of the respondents can be found in the next chapter and in appendix two. The methods used to gather the data are interviews, observations and participation in or data of existing focus groups.

Interviews

Personal face-to-face in-depth interviews were held with the TB patients, their friends and family members, health care workers and members of the community. The interviews were open, but structured by using a topic list. The research questions, based on the theoretical framework, were the guidelines of the topic list. The topic list has been changed after the first round of interviews because some of the issues were not applicable and the formulation of issues sometimes resulted in social desirable answers. The topic list had to be adjusted to the natural setting. With permission of the interviewed persons, all the interviews have been recorded. The interviews were held in English if possible, otherwise a local interpreter or a community worker at a clinic translated the interviews.

The first interviews took place with the health care workers, 2 community workers (DOTS), 2 nurses, an educator and 2 managers. These respondents worked in different clinics or hospitals; so several points of view were included in this study.

There were more than two meetings with DOTS, but the others were informal conversations. In total 12 patients were interviewed, 6 male and 6 female patients. The interviews were held in a room or outside a clinic or in the TB hospital. In three cases the interview was held at the patient's home. If possible one or more family members or friends were interviewed. This depended on who was available during the period of the fieldwork. In total 3 close friends and 4 family members of TB patients were interviewed. The majority of the working people of Grahamstown East work in the centre of Grahamstown. Of these working people 5 community members were interviewed at their job during an extra break.



Figure 8: Interview setting

Observations

Part of the fieldwork is making observations in the township, clinics and the TB hospital. The observed activities were determined to be open for all community members. However not all activities, in which TB patients could take place, are known. Two observed activities are the TB day in the Middle Terrace clinic and the Eastern Church Meeting at the Temba TB Hospital. While waiting in the clinics and hospitals field notes were taken. The observations are used as additional information for the interviews.

Focus Group Discussion (FGD)

During the period of the fieldwork for this study, the Sanpad project has set up FGD's in relation to their research project about stigma in relation to TB. The FGD's were already planned with the TB patients, members of the community and community workers. During this last focus group I was present. In this focus group researchers of the Sanpad project formulated the questions. However some questions specifically related to the current study have been added. All the data of the FGD's is available for the present study. The data has been read and relevant data for the current study has been analysed. Only a small part entails relevant information for this survey. Therefore the FGD's are used as additional information in relation to the interviews. The FGD's of the patients took place before the fieldwork of this study started. It was not possible to set up new FGD's, because of the short research period in the natural setting.

3.3 Data analyses

Some interviews are transcribed by two persons in order to increase the reliability of the data. The interviews are coded by the topics in the topic list. The codes are used to generate a small number of interconnected themes. In the chapter Discussion the themes and the results of the literature study are discussed. Eventually the interpretation of a broader perspective is described in the chapter 5. The same type of analysis is used for the results of the observations and the focus groups. The approach of data analyses has also focussed on the identification of the differences and similarities between the gathered data of the different research methods, for example between the data of the interviews and the data of the focus groups. At several moments in the study others have reflected on the written work.

3.4 Limitations of the study

Five out of seven clinics have been visited. Due to the shortness of the fieldwork period three clinics and the Temba TB Hospital have been the main study object. The respondents are mainly found in the Joza district in the Black area and in the Middle Terrace district in the Coloured area. This is due to the assistance of the health care workers in the Extension 7 Clinic, Joza Clinic, Middle Terrace Clinic and Temba TB Hospital, who were supportive in finding respondents.

Another limitation is the presence of the interpreter during the interviews and the focus group discussions. In general the fact that a white female conducts a research in a Coloured and Black area will influence the results.

Chapter 4 – Research findings

The interviews with the four groups of respondents are primarily used in this chapter. Secondly, the data of the focus groups and the observations provided additional information. The contacts for the interviews are made by introducing myself and by having small talks in the clinics and the TB hospital. It was very important to show interest in the work of the health care workers and to talk with them. Mainly an educator in the clinic, a DOTS worker and a manager have helped me find respondents and introduced me to respondents. Sometimes it was necessary to hire an interpreter, other times a health care worker was willing to translate. Some interviews were held in the house of the patient, others in the neighbourhood of the clinic or the TB hospital. The manager of the biggest local supermarket arranged community members from Grahamstown East who were willing to be interviewed at their work in the supermarket during an extra break.

Overview of interviewed persons in Grahamstown East¹:

Group:	<i>TB Patients</i>	<i>Friends & Family members of TB patients</i>	<i>Community members</i>	<i>Health Care Workers</i>
Number of <i>female</i> respondents:	6	3	3	5
Number of <i>male</i> respondents:	6	4	2	2
Total respondents:	12	7	5	7

Table 2: Overview respondents interview.

Data of the focus groups is gathered in the following groups:

Focus group:	<i>Middle aged women</i>	<i>Seniors</i>	<i>High school youth</i>	<i>TB patients</i>	<i>Out-of-school youth</i>	<i>Community health workers</i>	<i>Middle-aged men and women</i>
Number of respondents:	8	8	7	8	8	8	7

Table 3: Overview respondents' focus groups.

¹ A more specific overview can be found in appendix 3.

4.1 Values and beliefs in the community about TB and TB patients

In this paragraph the opinions of community members, health care workers, family members and friends about TB and TB patients will be outlined. Family members of TB patients were interviewed in their homes and friends of TB patients in the patient home. During an extra break at work the community members were interviewed. The health care workers have been interviewed in the clinic or TB hospital where they work.

4.1.1 Beliefs about the causes of TB

The respondents mention several causes of TB, namely the cold, staying in wrong places, bad behaviour, poverty, drinking, smoking and not taking good care of themselves. They even think that sometimes people are born with TB from their mother. Some community members say that the environment of Grahamstown East is not good for the people. One of them named the fact that dead animals are left behind at the site of the road. In the focus group with community-health-care-workers some people said that TB is hereditary. Some seniors mention in a focus group that everybody has TB in their body, but it depends on how you are living and what you are eating if it develops in active TB. Some of the interview respondents and also the out-of-school-youth emphasize this. This can be illustrated by the fact that a female family member, as well as a female community member compares TB with high blood pressure. The reason for this is that you can be cured if you take your medicines. The seniors also concluded that women are the most vulnerable as they are the ones doing the sweeping in dusty places.

There are not many cultural beliefs discussed during the interviews. Only one nurse mentioned that some of the patients' belief that it helps against TB to drink a special kind of water, to slaughter a goat or to drink a special kind of coffee. In the focus groups some beliefs, which are present in the community, are mentioned. There seems to be a part of the community who believe in the bird called Inyoni, which when it lands on your house will tell that there is a TB patient. None of the respondents said they believed in this themselves.

A minority of the, mainly older, respondents in the focus groups could explain that some Xhosas believe that when you vomit blood, 'Impundulu' (a kind of evil spirit) has kicked you. Another belief, which was mentioned in the focus group, was present in a church in the community. The people who belong to that church are not allowed to use clinical treatment. Instead when people feel they are sick, they would go there and would use their tea as a form of treatment. They share the belief that the special tea will cure them.

4.1.2 Attitudes and reactions of the community, health care workers, friends and family to TB patients

In general the first thought is that people with TB are not different from people who do not have TB.

"They live with us and sometimes they smoke and eat with us. They do not live far away from my place. They like to talk a lot about their lifestyle and the TB. (..) There is not so much difference in our lifestyles" (Community member Male 2, 2006).

The majority of the respondents think that most people have an understanding of TB and know that TB is curable. One respondent mentions that because it is curable everybody should get treatment. Some respondents noticed that people always talk. They say that therefore TB patients wonder what other people think about them, because others have false assumptions. For instance if people see you at the clinic, they wonder why are you going for treatment? However some people do not want other people to know they have TB, because they are afraid what other people will say. Therefore it became questionable if TB patients will tell others about their diagnosis. This statement becomes stronger when the middle-aged-men-and-women mentioned the following in a focus group.

“Nowadays people hide that they have TB because of its association with Aids/HIV” (Focus group respondents Middle-aged men and women ISER, 2006).

The health care workers say that some patients find it difficult to talk about TB, because they are afraid of the reactions of others due to stigma. However they do believe that most people will tell at least their relatives and some patients will tell everyone, especially women.

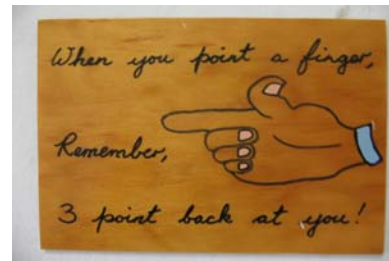


Figure 9: Woodwork in the office of a nurse in a clinic in Grahamstown East

Some patients or their family need to be educated before they talk about the TB diagnosis. Most family and friends mentioned they do not know if TB patients would tell them. But some do believe that most TB patients will tell their relatives, because they know from experience. On the one hand most of the community members do think that TB patients would not tell them their diagnosis. On the other hand they say that TB patients will eventually tell when they notice TB is accepted.

“TB patients are the same as me; because it is infectious even I can get it. Other people are afraid of the disease, afraid of the infection. Although I think that most people do know it is curable, because we do talk a lot of times about subjects like that” (Family Friend Male 4, 2006).

It is remarkable that the same person said the following;

“Even if I would have TB or Aids, I will not go to the clinic, because as soon as you go your name will go around” (Family Friend Male 4, 2006).

This is remarkable because it illustrates that the knowledge that TB is curable and can happen to everyone, is less important than the fact that people will talk about you. This can also be illustrated by the following story of a health care worker.

In a focus group he mentioned the problem he had with the outer-end room, used for the TB treatment. Then there was a misunderstanding where people assumed that it were the people with HIV that go in there. He said that he had to explain to them that everything begins there where one receives the bottles for coughing and also by taking the TB treatment. The consequence of this was that people wanted to use the back door as they did not want to be seen going in there.

“People are gossiping. Some are afraid to be contaminated and some know that TB is curable, but they just want to put stigma at anyone. Some of them know that TB is curable, however the symptoms of TB and Aids/HIV are the same” (Health Care Worker Male 2, 2006).

The respondents do not agree about the presence of stigma. Some say that TB is not stigmatised anymore, because it is accepted. Others say that TB is accepted, but stigmatised.

“When the people have TB my idea is that people must not drink. TB is not bad it is the same as having a high blood pressure, by taking the medicines you are ok (...) Nowadays more people are telling others about their lives, something that before was a secret. (...) If you go to the doctor and other people are seeing you in the street they are calling you names, like ‘you Aids/HIV+’...because other people are afraid to get TB” (Community member Female 2, 2006).

It happens quite a lot that people do not accept other people who have TB. Some people take TB as the most serious and contagious disease and therefore they would not allow TB patients to come close to them. During the focus group with the middle-aged-females, the remark was made that people should not use the same eating utensils, as the one who has TB. They added that it depends, when receiving treatment, it is not contagious, but if treatment is not followed, then it is contagious. In the next quote a health care worker mentions that TB sometimes causes distance.

“It does happen that people have to move out of their houses because their family does not want to live with them because they are having TB. Most of the times it is because they attach TB to Aids/HIV. Therefore we mainly educate families...However most TB patients will get support from their family” (Health Care Worker Male 1, 2006).

A male community member says that he only talks to TB patients, if they come to him. The reason is that he is afraid of getting a fine. He states that if you accuses somebody of having TB or Aids/HIV, that person can go to the police or a lawyer and you will get a fine. In the focus group of the out-of-school-youth they mention that there are a few people who stay away from TB patients. There are families who not accept people who have had TB, because they are thinking that they would continue living with TB until they die. That is because some people are not sufficiently educated. There are different ways in which people are educated about TB, namely by radio, by newspaper, in the clinic, in school or at the church. The majority agrees that there is enough education about TB.

Nevertheless in the focus group of the-middle-aged-women-and-men they state that the TB education in the community is scarce. Also a male health care worker thinks there is more that could be done. One of the female health care workers did not understand that there are still people who do not understand how they got TB. She said that she did not know how to educate in a different way that people do understand. If TB patients have completed their TB treatment and are cured, sometimes friends and neighbours do regard them as strong. The reactions differ due to the relationship people have.

4.1.3 Relation TB and Aids/HIV

TB is connected with Aids/HIV. According to some health care workers TB is currently a problem because people link it to Aids/HIV.

“There is a stigma on Aids/HIV and not on TB. The stigma is visible by pointing at somebody and calling TB patients names for Aids/HIV patients” (Health Care Worker focus group ISER 2006).

The health care workers of the focus group state that there is more stigma on Aids/HIV than on TB, because it is sexually transmitted. According to several health care workers and other respondents, the reality is that several TB patients do not go to the clinic because of the stigma.



Figure 10: Poster for patients who suffer from TB and Aids/HIV

If you discuss TB, people will also mention Aids/HIV, especially young people. This is called the dual stigma. Most respondents say that TB alone is not a problem, but it does make a difference if you also have Aids/HIV. A female patient mentioned that this is particularly true for men, because they think it has to do with sleeping around. The majority of the respondents state that it happens a lot that people mix up TB and Aids/HIV. One of the respondents clarifies that when people told her about Aids/HIV, they also told her that when you have TB you also have Aids/HIV. Another example a respondent gave about this connection is that if someone passes away, the people say that he had TB, however he did not. He actually was suffering from Aids/HIV. A health care worker confirms this by reporting that now people choose to die from TB while they have Aids/HIV. However, despite the given examples, at least the majority of the respondents do think that the people will know the difference between TB and Aids/HIV.

“The way Aids/HIV is stigmatised now, TB was stigmatised before, and actually it was worse than Aids/HIV is now” (Health Care Worker Female 4 2006).

4.2 Perception of TB patients

This paragraph shows how the patients think about TB and mainly how they think that other people think about them. Interviews took place with TB patients in clinics, at their home and in the TB hospital. Also the data of a focus group with TB patients is analysed, to get further insight into the patients perspectives.

4.2.1 Self-perception of TB patients

To get a better insight of a TB patient, they were asked, first what causes TB and secondly whether they see themselves differently now that they have TB.

Patients of both sexes agree that TB has to do with smoking and drinking which happens a lot in the area. While two male respondents say TB has to do with the circumstances people live in, like cold places to live, a female respondent says that TB does not have to do with being poor or rich. Some respondents, mainly females, point out the presence of stigma.

“When you are coughing, they say TB, TB, TB but what can you do? Nothing you can do because you have got it (Female Patient 2, 2006).

The greater part of the patients did not know or did not notice a difference in their self-perception due to the TB. They do notice physical changes.

“I look different at myself, because a lot of things changed. I regret that I depend on my family and I am busy to cope with the TB. I feel weak and sleep a lot. I know it is curable and I have hope that I will get better” (Female Patient 5, 2006).

A female patient changed her lifestyle, now she does not smoke and drink like she used to do. She feels responsible and she is proud of herself for having accomplished this. Also some other patients say they must stop drinking and think that they are doing a good thing to be treated. The behavioural change, in two cases, occurred only in the beginning of the TB, and then there was anger and non-acceptation. After taking the medication for a few months, the TB has been accepted and people start to feel strong again.

4.2.2 Telling others about the diagnosis TB

To reveal how accepted TB is in the community, the patients have been asked whom they told about their TB diagnosis.

Half of the male and half of the female patients told only their family members about their diagnosis TB. A young female patient said that she would not tell her best friend because then her friend would hate her. She explains that her friends would not understand and therefore she told them that she has the flu.

“Young people do think that TB is like Aids/HIV. My friends think like that, that is why I would like to stay at home” (Female Patient 3, 2006).

The other patients mention that they are not shy and talk about TB with everybody. However, one of the male patients clarifies that he only talks about TB, when people ask him about it. Another male patient said that even if you would tell your family about the TB, they would not always listen.

“I say that there are people in our communities that are scared to make public that they have TB because there still are people who laugh at people who have TB” (TB Patient focus group ISER 2006).

According to the sister and niece of a female patient, she did hide the disease in the beginning until she became very sick. They say that she was afraid to tell, especially to her 80-year-old mother because she was afraid that she would get a heart attack when she heard the news. The patient herself said that she told her family and did not try to hide the disease. Not all of the patients who have or had a job told their employer. Sometimes a family member did this for them. It also happened that the employer went to the clinic or hospital to gather information about this employee. The health care workers are obliged to tell the employer about TB, because of the risk to get others infected.

4.2.3 Attitudes to TB patients from the perspective of TB patients

Not all the TB patients had an idea about the thoughts of others about them.

“I do not know what people think about TB patients.... I think some of them are afraid of getting TB and others know it is curable and do not mind. (...) I do not notice any difference about the community people” (Female Patient 5, 2006).

Some TB patients, especially two females, mention not to care what others think of them.

“My friends and family do talk about me, because they are afraid, but I do not care. I told them that I am not going to die and take my treatment. Some are scared and not coming, others do come and see that I am not dying. They do talk to me now, because it is part of my life. I do not care about that, it is my health” (Female Patient 1, 2006).

Another female respondent stated that people came to offer help, for instance to talk but not in helping cleaning the house. Especially two male respondents emphasize that they did not judge anyone with TB. Male respondents as well as female respondents say that people joke about TB patients.

“We sometimes make jokes about Aids/HIV and other things, but it is a kind of joke we do not mean it... people will leave you alone when you have TB or Aids/HIV, you will have to party alone and walk alone in the street” (Male Patient 3, 2006).

A female patient agrees and says that sometimes people make jokes, which have to do with drinking and smoking.

A male TB patient agrees that there is talking behind the back of TB patients, because the symptoms at the body will tell about the TB. He also said that in general people do not talk about TB, because you can be arrested if you accuse somebody of TB or Aids/HIV. Another male respondent mentioned that he was afraid that people might look at him in another way, but now he is almost better he says that he was thinking nonsense. A male patient, who mentioned that he does not know what others think about TB patients, says that he does not want to go to the clinic. He explains this as follow; when you go to the clinic and the people there are ill, they will keep infecting others and you will not be cured.



Figure 11: Inside Extension 7 Clinic

Some of the TB patients think that they will be respected after finishing the treatment, because through education there is more understanding in the community. However there are also people who fail to understand that it is curable and they have a hard time trusting that TB patients would not infect them, even after finishing the treatment.

4.2.4 Influence of TB at the social life of TB patients

A majority of the patients mainly notice physical changes in their lives. However a few patients noticed there have been changes in their social life, for example in the relation with other people, concerning their support.

A part of the patients think about the danger to infect other people and therefore they change their behaviour. For instance some patients are more careful in making contact with other people. It also happens the other way around, TB patients have to change their behaviour because relatives are afraid of the infection. According to most TB patients a majority of them still share their spoons and plates with other people. Although one patient mentioned that her family was afraid to share the facilities.

“The reason I moved from my family to stay on my own, was that I did not want anyone to think that I spread the TB. My family was afraid to get infected. My family was moving me out with their behaviour, but they did not say that they were afraid directly to me (...) But I do not mind, because they love me now....” (Female Patient 4, 2006).

A majority of the patients say they still have contact with their family and some patients also with their friends and community members. A patient mentioned that she regrets the fact that she cannot do much for her children.

“My brothers and my sister are coming (...) my friends are not coming. They are lazy and sometimes they are coming drunk at the gate of Temba and then they cannot come in..... maybe they undermine they importance of a visit” (Male Patient 6, 2006).

Most TB patients do get support from the start at least from health care workers. The majority also feels supported by their relatives. They notice this for instance if a patient has a job and can not come in to the clinic to get pills, someone else in the family will pick them up. If they would not have support, nobody would come to take the pills for them. Another example is that people have to do more tasks in the household, most of them do not mind to do this.

“I have to do everything at the moment, but it was my choice because I do not want her to do those things, she first has to get better” (Family Friend Female 2, 2006).

Two patients said that their employers were very supportive to them, by bringing them food or money. They also have the possibility to go back to their job when they feel strong again. A few others said they did not feel supported by their employer, because they were fired and had to move from the farm where they worked and also lived.

4.3 Differences in attitudes, consequences and participation regarding male and female TB patients

The influence of TB on the relationship between men and women will be discussed. This will first be described from the perspective of TB patients and after that from the perspective of the other respondent groups.

4.3.1 Differences from the perspective of male and female TB patients

The reactions of the male and female TB patients can be divided in ‘no difference’ and ‘do not know’. None of the TB patients did notice differences. The majority of them think there are no differences in consequences between male and female patients or they do not know. Nor do they think that TB will be used as a reason to divorce. But the remark was made that you do not ask people for their reasons if they divorce.

“I can imagine that some men do not want to marry a woman who have or had TB. My boyfriend says; “hey do not cough in my face”, he wants me but not the TB” (Female Patient 4, 2006).

Both the male and the female patients agree that women handle their health in a more careful way and go more often to the clinic.

4.3.2 Differences from the perspective of others between male and female TB patients

The community members say there are no differences in the consequences of TB and gender. Most of the friends and family members of TB patients do agree with that point of view. However some of them do think there are differences in the consequences and the gender of TB patients. For instance that there will be more pointing fingers at women and some people say that it is their own fault for sleeping around.

“Some people think that it is something that a woman does to herself. There are people who think you can get TB from sleeping around” (Family Friend Female 3, 2006).

The health care workers do not think there are different consequences in relation to the gender of TB patients. They do mention that there are fewer barriers for women to come to the clinic and that men do not like to go to the clinic. Both other groups of respondents do agree that women go more and more easily to the clinic. Some respondents give examples of broken relationships because of the TB. The examples illustrate that females do not leave their partner who has TB permanently and that males do.

“It happens sometimes, but that is when women have TB, not if men have TB. I have friends who had girlfriends with TB and broke up because of that. The woman leaves forever. It is more that they are afraid of the reactions and being ashamed, than they are afraid to get infected. I guess that it has to do with the association with Aids/HIV. They do not say anything about the fact that I stay with my girlfriend with TB” (Family Friend Male 2, 2006).

However a majority of the respondents do not think that TB will be a reason for divorce. Some respondents mention that TB is not like Aids/HIV, so there are no differences in consequences. Some respondents mentioned that they never heard of such a thing, even a health care worker did not.

4.4 The community Grahamstown East

In this paragraph first a description of Grahamstown East and the living area will be given. Second the elements that bind the people in the community will be described and summarized.

4.4.1 Description of Grahamstown East

The township Grahamstown East is mainly divided in two areas, the small Coloured area and the larger Black area. In the Coloured area the people speak mainly Afrikaans and in the Black area the used language is Xhosa. Both areas are divided in several districts, for instance the Joza district is part of the Black area. The Joza district is divided in several locations, like Extension 1, Extension 2 etc. A majority of the respondents mention their district, or their location, when you ask to which community they belong. It shows that people have a sense of belonging to their area and not only because of their geographical location and setting. The people are also connected with social ties. Most of the people live with their families, for instance with their grandparents and aunts. It is common that the family is broken, and that the father and mother of the children in a household do not live together. Polygamy is not an exception. People get children, often at a young age, but do not get married together. Only two respondents live together with both their children and their partner. Two other respondents lived in a household with only females from three generations. Two third of the respondents live for a long time in Grahamstown East. The living circumstances are quite the same in both of the areas. The respondents mention that there are a lot of people in both of the area's who are drinking alcohol and smoking pot. A respondent, who lives in the Coloured area, said that people are very hard on each other.

She thinks that that has to do with the drinking, which makes people fight. Another respondent states that, also in the Joza district, in the Black area, there is a lot of fighting and drinking (which starts at very young ages). The problem of violence seems to be more present in the Coloured area than in the Black area. Although the areas do seem to be difficult to compare. Like the following quote illustrates:

“There is a huge difference in the attitudes in both areas. Down there, in the area around Temba, nobody cares about each other, even if you are sick. Here, in Extension 7, people are more close and accept each other, everyone takes care of each other and looks after each other” (Family Friend Male 2, 2006)

The DOTS worker who translated the interview gave also his opinion, which is conflicting with the first opinion given.

“In Extension 7 the crime rate is much higher than in the area around the Temba hospital” (Health Care Worker 1, 2006).

Almost one third of the respondents live in Grahamstown East for a few years. This can influence how close they are with the people in their location. The more people respondents know in their area, the closer they describe the relations in the area. The majority of the respondents say that the people in their community will help out if necessary. Although the opinions on how close the people in the several locations are differ. More female, than male, respondents notice differences between the locations. Half of the respondents say that there is no difference in the closeness between the people in the different locations. Most of the differences in the locations have to do with things like the crime rate. The majority of the respondents live in their area for almost all their life, but in different locations. It is not common that people move between the Coloured and the Black area. There seem to be more problems in the locations where a lot of mixed people live.



Figure 12: Children playing in their location, Extension 7

In some locations the people are not afraid to ask, ‘ how are you?’ if they think you are sick. But in other locations people are afraid to mention that to somebody.

“The people in the community do not care about each other here, people do not talk about TB. If you accuse somebody of TB or Aids/HIV they can arrest you for that, they do not want any advice about TB” (Male Patient 6, 2006).

People from the church seem to be affectionate to the patients, according to both the patients and the other church members. Some respondents say that most of the people in the location know each other. They also notice that there are locations where people do not care about each other. There is a lot of gossiping in these locations. Most people do know what happens in somebody else's home. At least if they see something, they make up their own story about what is happening. Some respondents say that young people do think differently than others in the community, for instance about drinking and also about TB and Aids/HIV. The youngsters seem to be less safe while having intercourse, and yet also accept TB less than others.

4.4.2 Elements that bind the people in a community

The elements, which bind the people in Grahamstown East, can be summarized in the following table:

Motivator:	Description:
<i>Sense of well-being of community members</i>	The sense of well-being is influenced by the support people get from each other, but also depends on what people expect from each other.
<i>Geographical location</i>	People meet each other informally in the street, at the clinic or in the church. The offered help depends on how well the people know each other in the community. This is also influenced by the period people live in the community. Two respondents spoke about some rituals performed in the Xhosa community, like making beer together. They say that it is common to invite other people and drink together. Another Xhosa ritual is to sacrifice a cow at a funeral to welcome the ancestors of the dead people. There seems to be no rituals related to TB.
<i>Similar backgrounds</i>	Most of the people in the community (either the Black or the Coloured area) have similar backgrounds. The majority leave school when they finished high school and then they go look for a job or sometimes girls get pregnant. Only a minority of the people have a job, so the average income is low.
<i>Similar living circumstances</i>	The living circumstances are pretty similar for the people in Grahamstown East. In both of the areas there is a lot of drinking and the average crime rate is quite high. Because of the low income people do not have much choice in what they eat and where they do their shopping.
<i>Social ties & Time horizon</i>	Most of the people live with their families, for instance with their grandparents and aunts. Two-third of the respondents live in the same community their entire life, therefore they know most of the people in their area and for instance in their church, which connects the people.
<i>Time schedules</i>	The greater part of the respondents was present in the community the whole day. They cook, clean, watch TV and have social chats with the neighbours. The people who work, mainly focus on their work, but also feel to be a part of the community for instance during the Sunday services or at community meetings.

Table 4: Conditions that bind the people in Grahamstown East.

4.5 Community activities

The concept of community activities needs more introduction. Therefore first the respondents were asked what they like to do in their spare time. Most respondents, including patients, like to spend their time together with others. A minority of the patients also mentioned they like some time alone, to get rest. People who have a job visit their friends and family less than others do.

4.5.1 Spare time activities in Grahamstown East

The next table will show which spare time activities the people in Grahamstown East undertake, either alone or with other people.

Spare time activities	Outlined:
Friends and family	Visiting/ chatting friends and family Helping relatives Spending time with their children
Religion	Church choir Going to the church or temple Preaching Reading the bible
Indoor activities	Watching TV (Generations) Listen to music (R&B, Reggae) Playing music Woodworking (men) Carpeting (men) Reading Stay at home and do nothing Crafting (women)
Outdoor activities	Working in the yard (men) Attending a meeting (men) Drinking with others (at home or in a tavern) Watching people Going for a walk in the area Dance parties Playing cards Gambling Political forums
Social activities	Look after people who need help Visit people in Temba Community board
Sport activities	Netball (only women) Soccer (mainly men) Gym Rugby (only men) Jogging

Table 5: Overview of the undertaken spare time activities of the people in Grahamstown East.

4.5.2 Community activities

Community-health-care-workers mentioned in a focus group that they do not organise activities in the clinic, without TB patients. Another person in the same focus group point out that TB patients do not consider themselves as patients, but as a normal person. When TB patients engage in community activities, others would never believe that they are TB patients. In some locations the community organize community meetings about what is going on in the location. Only a few participants know about this kind of meetings, but not all the locations have these meetings. Five male respondents said that they find it important to attend these kinds of meetings. There are not many sport activities organised for the community.

“There are not many activities because of the crime, that stops things. If you are a sportsman you are not going all over, you have to watch yourself. It has to be safe” (Community member Male 1, 2006).

In one location there seems to be a local netball team, but not all the respondents, living in that location, mention that. One respondent brought up that even if there are no activities organized in the location, people could do something for the community, like just talking to people, share your wisdom with others or you can go to the committee for the summer festival in Grahamstown City and ask what you can do for them. Some people of the working respondents said they are not looking for community activities.

4.6 Participation of TB patients in community activities

The majority of the patients are not participating in community activities during their TB treatment. Some say they do not want to, others say they would like to join the community activities when they feel stronger.

4.6.1 TB patients about the participation in community activities

How active the people are in community activities depends on how they are feeling but also on the amount of activities organised. A female patient said that she likes to be on her own and also did not participate in community activities before she got TB. Only two out of six female TB patients mention that they were still active in community activities. One of them mentioned that she was going to church almost every day, because she has to pray and practice in the choir. The other one plays soccer in the street. However there are also patients who first mention that they are going to church, but who remark in the same conversation that they are not going. The majority of the TB patients are not participating in community activities because they are not feeling strong enough physically. Other reasons are that people first want to finish their treatment, are not outgoing persons, are uncertain of what others think or have lack of transportation to go to activities.

“I do not feel like going out, partly because I do not know what they will think about me and partly because I do not feel strong at the moment” (Female Patient 5).

The patients, who like to go out, say that they will participate in activities again if they are cured. They mention that especially church members invite them to activities. Mainly TB patients notice that others exclude some of them, but that is only a minority. Most of this group of respondents does think the statement 'TB disease of distance' is false.

"Initially it does cause distance, but after people are educated about TB the disclosure disappears"
(Female Patient 4, 2006).

4.6.2 Other respondents about the participation of TB patients in community activities

A majority of these respondents do not really know if TB patients participate in community activities. Mainly the health care workers do not think that it is a problem if TB patients would participate. A community member made a remark about his motivation of participation of TB patients:

"A TB patient is likely to do those things, like my uncle is mentally ill. I take him out sometimes to help in my garden. He likes that very much" (Community member Male 1, 2006).

All the respondents stated that they do not exclude TB patients from community activities. Some respondents even said that they would not mind to play sport with TB patients because that would keep them active and healthy. Although there are respondents who do know others would exclude TB patients, but not all the respondents recognize this.

Some respondents were asked if they thought the statement; 'TB is a disease of distance', was true or false. Some respondents do think the statement can be true, but mentioned the fact that TB patients are not always isolated by others, but also isolate themselves. However, not all the respondents have been asked this question, for instance none of the health care workers were asked (without special reason).

4.6.3 Influence of TB at the participation of TB patients

Some patients say that they do no longer do most of the things they used to do, like the laundry, the dishes etc. But most patients and other respondents say that there is no, or little change in the daily activities of a TB patient. The focus is on the health of the patient, getting better is now the priority. It is new for patients that they have to take medicine every day. Therefore some patients have to go to the clinic every day and others have to stay at the Temba hospital for several months. All the respondents said that sometimes TB patients cough, sleep more, feel weaker and that they are losing weight. Two respondents mentioned depression as a result of the TB. Most patients who had a job stopped working. Most of the respondents still do the same things like watching TV and meeting family and friends. Although a majority of the patients admit to be at home more often and the ones who were used to play sport stopped playing.

"Before I had TB, I played soccer, but not anymore. When I am looking at others playing that frustrates me, because I am used to do that. So I do not watch them play anymore" (Male Patient 1, 2006).

The next table shows an overview of the different reactions of all the interview respondents about exclusion of TB patients by others of community activities:

<i>Do others exclude TB patients in community activities?</i>		Yes	No	Other opinions
Reactions of TB patients	N=12	2	7	3
Reactions of friends and family members	N=7		7	-
Reactions of community members	N=5	1	4	-
Reactions of health care workers	N=7		7	-
Total	N=31	3	25	3

Table 6 Reactions of others about exclusion of TB patients by others in community activities.

A majority of all the interviewed people in Grahamstown East do not think that the TB patients in Grahamstown East are excluded from community activities.

Chapter 5 – Discussion

To discover the influence of TB on the participation of TB patients in community activities in Grahamstown East, this chapter will discuss the literature concerning this subject and the discovered field research findings.

5.1 Limitations

Only TB patients who were strong enough to get treatment were interviewed. Because they did not always feel well during an interview, the interviews had to be shortened in some cases. There are a lot of people who also have TB, but are not on treatment. This study is not representative for the latter group. Some people were too proud to use the interpreter, even though they could not always express themselves very well in English, and therefore simplifying their answers. Another limitation is the fact that some of the questions and definitions were too complicated to understand for the study population. The way of thinking is very different in Grahamstown compared to Rotterdam. That difference has also influenced the depth of some of the interviews. For instance the term community activities is unknown and difficult to explain without putting words in their mouth. The adjustment of the research to the local culture could have been better in order to get better answers. In the local culture it is not polite to ask what is meant by a question when they do not understand, but they will give an answer anyways. The findings of this study are restricted to the area in which the study took place. It is difficult not to influence the interview setting because of safety reasons on one hand and because of politeness on the other hand. When interviews were administered at home, it was not an option to go there alone, most of the times a community health worker, who knew the people went with me. Another example is that during an interview with a family member, the patient entered the room and stayed with us for a while.



Figure 13: DOTS at work in the clinic Extension 7

5.2 Linking the theoretical framework to the research findings

In this paragraph a retrospective view on the theoretical framework and the research findings will be given. Like Long et al. (2001) stated, to understand the patients and the effect of TB, it is important to have information on gender differences, stigma and isolation due to TB. The literature and data about subjects like these will be discussed in this chapter.

5.2.1 Values and beliefs in the community about TB

This paragraph answers the first research question: *Which values and beliefs are common in the community on TB patients?*

The majority of the residents in Grahamstown East, mainly men, do perceive TB as an infectious disease, but they also attributed the disease to the circumstances they live in. This finding supports the literature which shows that most people perceive TB as an infectious disease and that in general TB is associated with; dirt, poverty, poor nutrition, alcohol, smoking, exposure to cold, low living standards and sharing facilities with TB patients (Westaway & Wolmarans 1994, Liefoghe et al. 1997, Yamada et al. 1999, Long et al. 2001, Edginton et al. 2002). Some respondents stated correctly that everybody could get TB, poor as well as rich people. But the circumstances and the way of living influence the stamina of a person. In the case of Grahamstown East this influence is experienced as negative. In contrast to the literature of Long et al. (2001) most people do believe that TB is curable after a complete course of treatment. This can be illustrated by the fact that some people compare TB with high blood pressure. In Grahamstown East the greater part of the people do not make a problem about TB, but they do gossip and joke about TB patients. In some surveys people of the community talked about the possibility of passing by the house of an infected person to say hello, but in other surveys this was not even a possibility. In Grahamstown East it was only a question if people are willing to visit TB patients, which does happen quite often. In other studies TB is called the disease of distance and contact with TB victims is feared (Bennstam et al. 2004, Chang et al. 2004). The statement 'TB is a disease of distance' is true or can be true according to a small group of the respondents in Grahamstown East. They mention that it also depends if TB patients hide themselves.

The belief that TB is given by God as a punishment for their sins is accepted in many cultures (Chang et al. 2004). But this belief does not seem to be present in Grahamstown East. None of the respondents mentioned during the interviews that they look at it that way. In the focus groups it became clear that there is a part of the community who share the cultural belief in the bird 'Inyoni' or the evil spirit 'Impundulu'. None of the respondents said they believed in this themselves, but they do know people in their community who share these beliefs. According to African belief systems good health is holistic and extends to the person's social environment, this can also be concluded for the way of thinking in Grahamstown East. Edginton et al. (2002) state that health care workers are too often not aware of the beliefs and attitudes about TB of the community they serve.

In Grahamstown East most health care workers are aware of the attitudes towards TB patients. That is why they emphasize the importance of education. A side effect of this is that TB patients tell the health care workers what they would like to hear instead of what they really felt. At this moment presumably the health care workers are not aware of that. A health care worker, in this case a DOT-worker, mentioned that he does not even ask his TB patients how they are doing. Probably he assumes that he knows what is going on in their lives. As suggested in a survey in Pakistan, some health care workers share the same cultural beliefs about TB as the rest of the community. Although health care workers are sometimes more positive about the influence of TB than others. They do not think that TB is stigmatised, but they do know that Aids/HIV is stigmatised and are aware of the connection people make between both diseases. Therefore it is questionable if they see TB in a broader perspective.

5.2.2 Perception of TB patients

The second research question contains: *What is the self-perception of a TB patient?* This question will be answered in this paragraph. First by illustrating the reaction to the diagnosis of TB patients, secondly by the perception of TB patients of the reactions of the community, health care workers, friends and family and by discussing the influence of TB on the lives of patients.

All the TB patients believed that TB is curable, however it was remarkable that mainly the women wanted to emphasize this. These results are in contrast with earlier surveys of Long et al. (2001) and Liefoghe et al. (1995, 1997). This has probably to do with the large amount of education and information available in the clinics, which is also communicated by the government through the radio and through posters.

Reaction to the diagnosis of TB patients

Some researchers concluded that there were TB patients who rejected the diagnosis due to feelings of anger and distress or because they were mentally incapacitated. Mainly the denial of the disease seems to be based on the diagnostic 'label' of the disease (Liefoghe et al. 1995, Yamada et al. 1999). The patients in Grahamstown East had feelings of anger and frustration in the beginning of TB. This feelings had to do with: "why me" and "how do we take care of everything now". Rajeswari et al. (2005) revealed reasons for these feelings are in some cases lack of knowledge of TB, physical rehabilitation, or fear of consequences. A lot of the people point out that there is a lot of gossip about people with TB. This diagnostic 'label' is the same as a stigma, which is still present in relation to TB. This has to do with the connection people make with Aids/HIV, because of the similarity of the symptoms of both diseases. This connection was made more clearly in Grahamstown East than found in the literature.

Research of Liefoghe et al. (1997) in a Kenyan community reveals that because of the negative reactions of their environment, some patients try to hide their disease. All the patients in Grahamstown East did tell their family members and close friends about their TB diagnosis. Not all of them did this immediately, because they were ashamed.

The statement of Rajeswari et al. (2005) that TB influences the self-perception of TB patients is not true according to the TB patients. But regarding some of their reactions at the disease the statement could be relevant for TB patients in Grahamstown East. Some TB infected patients only focussed on their disease and therefore, lost their interest in work and other aspects of life. Most patients were indeed not really active. Some of them always lived a passive life. Other patients quit their job and stayed at home, working around the house and did not go out very often. There were also TB patients hospitalised. For a small part it has to do with the stage of the disease and how much support they received. Like in the survey of Khan et al. in 2000 in Pakistan patients who had a job often stopped working after TB is diagnosed, because they first want to focus on their health.

The observation of Khan et al. (2000) and Rajeswari et al. (2005) that many patients gave false addresses to the tuberculosis centre is in a smaller extent also valid for the clinics in Grahamstown East. The reason people gave false addresses is that they do not want the DOTS coming around, because then the people in the neighbourhood know that something is going on. Most health care workers mentioned that since they work with the DOTS system, they do not have many defaulters. To what extent this is true is questionable because firstly the information is one-sided and secondly the municipality strongly values the amount of defaulters at a clinic.

TB patients perception of reactions of the community, health care workers, friends and family

In Congo, TB patients understood the reactions of their friends to stay away, because they would do the same. But that is not the case here, because almost all the patients said that they would help people with TB if they knew anyone. However a part of this group of respondents said they did not know people with TB. This cannot be true, because they see a lot of other TB patients in the clinic, because there is one room for TB treatment.

According to the literature most families seem to be deeply shocked or react in denial when the diagnosis is disclosed and they have serious difficulties in accepting it (Liefoghe et al. 1995, Marra et al. 2004). But after acceptance of the diagnosis, in many cases the family became very supportive. They helped to find the proper care and gave financial support (Liefoghe et al. 1995). According to the TB patients in Grahamstown East, most of the families were supportive from the start and if that was not the case, the patients said they became supportive in a later stadium. None of the patients mentioned that their family reacted in shock or had feelings of denial, but some did mention that their family had difficulties of accepting the TB in the beginning. It differs what some patients see as supportive.

Influence of TB on the life of TB patients

The majority of the patients did not know or did not notice changes in their lives, except physical changes, for example weakness. However most patients, who had a job, did not work anymore since they are sick (voluntary as well as not voluntary).

Also the treatment of TB influences their lives. In the research of Long et al. (2001), only a few patients felt that their TB had affected their relationship with friends and family.

This is in general the same way the TB patients in Grahamstown East felt. The impact of TB on the physical, social and mental well-being of TB sufferers is less than Rajeswari et al. (2005) mentioned, but TB definitely has influence. But this is mainly due to the connection people make between TB and Aids/HIV. The influence become clear when in some families in Vietnam TB patients were no longer allowed to share facilities with their family (Long et al. 2001). In Grahamstown East, most people do not eat together at the same time, however they do dish up from the same plate. Although this is not the situation for all the patients. Because some TB patients were hospitalised during their sickness they were not eating at home.

It is remarkable that the majority of the people, who think that TB is not a disease of distance, consist of TB patients. The reason for this could be that the TB patients do not want it to be true. Another reason could be that some of the patients are hospitalised and only get visits from their relatives. In Grahamstown East it is possible to visit a TB patient. The TB patients themselves also stated that their family and friends are still coming over. When patients see their family and friends less, this is most of the time because the patient is too weak and needs to rest. According to TB patients, most of their neighbours came to ask if they needed help or wanted to talk.

5.2.3 Differences in attitudes and consequences between male and female TB patients

This paragraph will answer the third research question: *Are there differences in attitudes and consequences between male and female TB patients?*

Although a few studies suggested that the impact of TB on quality of life might be greater for women than men, the people in Grahamstown East did not notice any differences in the consequences of TB between both sexes. The few people who reported some differences in consequences mentioned for instance that there is more pointing at women. Probably women are more aware of the opinions of others. The data also suggest that men have more influence in their community and that therefore some of them will speak out more to TB patients and others than women do.

Both sexes deal differently with TB. Men do not like to go to the clinic and they wait longer before they go and seek any kind of health care. Some of the male patients go first to a public hospital or a private doctor before they get their treatment in a clinic or at Temba TB hospital. There are fewer barriers for women to go to the clinic. Because women also go to the clinic when they are pregnant and visit the clinic with their children. The statements of Long et al. (2001) and Uplekar et al. (2001) that 'women have to negotiate more social and cultural obstacles before accessing health care services' and that 'they often receive inadequate healthcare', is therefore not valid for Grahamstown East.

The literature also reveals that in poor countries women in general report sick less often than men do (Uplekar et al. 2001). This is in contrast with the finding in Grahamstown East that men do not like to report sick and rather suffer in silence.

Long et al. (2001) report that female patients appear to be more pessimistic than male patients. This is not recognised in the findings of this research, where especially the female patients emphasized that TB was curable. Also more male than female patients admitted that they had to change their live. In Grahamstown East the pessimism is quite equal between both sexes.

The literature reveals that in some cultures, for instance in the Mai Ndome District, Congo, it is common to abandon your partner if they are infected with TB. Other researchers state that it is hard to discover if TB is the sole cause of a divorce, although it could play a certain role. A majority of the people in Grahamstown East do not think, and cannot even imagine, that this is happening in their community. But there are some examples given of broken relationships because one of the partners had TB. The examples illustrate that women are willing to come back when their partner is cured, but that men do leave permanent. A fact is that women are more supportive towards men than the other way around. This fits the finding reported by Hudelson in 1996.

5.2.4 The community

In order to answer the fourth and the fifth research question, the concept of community most become clear. Therefore this paragraph will describe the concept of community and the community of Grahamstown East.

In this thesis, community is described as a group of individuals with diverse characteristics, who have a sense of belonging and are linked by social ties, because of their similar living circumstances and engagement in joint activities in their geographical location and setting. The people of Grahamstown East are connected, based on their geographical setting because they live close to each other. In Grahamstown East the importance of religion, drinking of alcohol and polygamy are standard elements of the living area. Although the living circumstances are practically similar, there is a separation between the locations in the Coloured and the Black area. This means that there are actually two different communities according to this definition, with the exception of the geographical location. Nevertheless most of the people in either the Black or the Coloured area have the feeling that they are connected. Therefore we do see Grahamstown East, including the Coloured and the Black area, as one community. Although this community does exist of other communities. In Grahamstown East the people have a sense of belonging, but are not exceptional close. Nevertheless most people know what is going on in the house of others in their location and they will help out if necessary. Most of the people say they know the people who live in their location, but they do not know all the people in the community. The opinions about how close the people are in the several locations, within the community, differ. How strong their sense of belonging is and how much they appreciate this, depends on how long they live in the area (time horizon). The joint activities in a community are influenced by the closeness of the community.

5.2.5 Participation in community activities

The fourth and the fifth research question will be answered in this paragraph. The fourth research question is: *Which community activities can be found in Grahamstown East?*

The favourite leisure activities of young people in an urban black township in South Africa are “socialising, listening to or playing music, playing sport (mainly soccer), passive recreation including television, cinema, reading and radio, hobbies and playing cards or draughts” (Møller 1991: 321). These activities match with the activities that the people in Grahamstown East like to do in their spare time. The respondents did not mention that they would go to the cinema, presumably because it is too expensive and too far away. In Grahamstown East socialising includes visiting friends and family and to drink and smoke together with others. An important activity that is missing in this part of the literature is going to church or temple, which a lot of people in Grahamstown East do. Although the presence of this kind of activity is not entirely missing, because Møller (1996) describes that in the township context, religious activities are organized. A reason religious activities are missing in the literature could be that these young people did not see it as a leisure activity. The leisure activities as described above are based on the research of Møller (1991) on leisure activities among young people. The average age of the respondents in this study in Grahamstown East is 35 year. The difference in age could be an explanation for the different interest in leisure activities. This corresponds with the finding of Møller that passive leisure activities enlarge by generation. Also missing in the literature are the meetings, which the municipality organizes about what is happening in the area and about employment. The male community members mostly attend these meetings. There is also a community board that intermediates between the municipality and the community. There were not many respondents who want to participate in the community board.

In an article of Møller (1996) it is suggested that the leisure experience of women and men differ from each other, because of their division of work and leisure. This statement seems to be true for this research. In Grahamstown East the women are doing all the tasks in the household like cleaning and doing the dishes. If a man does not have a job, he is watching TV or socialising. Activities can be promoted by parents through examples set by their personal involvement in the community and through affirmation of the interests of their children (Fletcher et al. 2000). There are not many differences in the spare time activities of the younger and older people. A lot of females mentioned they like to play netball, only one woman was still playing it. The others only played it at school. The reason they gave for not playing anymore is that the ground is not always good or that there is no ball available.



Figure 14: A community yard next to the clinic in Extension 7

The following part of this paragraph will answer the fifth research question, which is: *To what extent do TB patients participate in community activities?*

The literature suggests that it is made easier to take part in joint activities if people's backgrounds are more similar, for example the education, homogeneity of income and family status. In Grahamstown East the majority of the people have the same background. However not many community activities are being organized according to most respondents. The majority of the patients are not participating in community activities during their TB treatment. Bennstam et al. (2004) mention that the daily activities of a TB patient depend on the effects of TB (Bennstam et al. 2004). That is also what the people in Grahamstown East say. TB patients first focus on getting better, because they are too weak to take part in joint activities. They also brought up that they would like to participate if they feel strong again and have time to do so. This last remark has to do with the patients who are hospitalised during their treatment. Although the patients mentioned they would participate if they feel strong again, I doubt that. Because some patients almost finished their treatment and still did not participate in joint activities. This contribute to the thought that stigma does plays a role here. There are not many TB patients who feel like participating. This could be because they actually do feel excluded, which they did not express in the interviews.

5.3 Conclusion

This paragraph will answer the main research objective: *What is the influence of TB on the participation of TB patients in community activities?*

TB did not change much in the lives of TB patients in Grahamstown East, according to the respondents. Although the research findings show that there is stigma attached to TB and TB patients due to the link between TB and Aids/HIV. There are elements, which could be changed in order to reduce the negative social aspects of TB patients.

A majority of the patients do not participate in community activities during their TB treatment. There is no difference in this finding for male and female respondents. The main reasons for not participating in community activities are physical causes, like weakness. Stigma also influences the participation, due to the social consequences. A lot of people in the community do not really know if TB patients participate in community activities. This emphasize that this is not an important issue in Grahamstown East. Only a minority of the community would prefer exclusion of TB patients, because of the TB related stigma. Only a small part of the TB patients notice this, however the majority do not feel excluded by others. Another reason for not participating is that some TB infected persons only focus on their disease and therefore lose their interest in work and other aspects of life. An important note is that most patients were not really active in community activities even before they got TB. According to most residents there are not many activities organised in Grahamstown East. Other people in the community mention to take part in some community activities, mainly religion related activities.

Chapter 6 – Recommendations

This chapter will describe a reflection of the conceptual framework and recommendations, which could be made after gathering and analysing the data. Also further research questions and what others could be learned from this research will be described.

6.1 Reflection conceptual framework

In general it can be concluded that the conceptual framework was useful to study the consequences of TB in Grahamstown East. Although the physical condition of a TB patient seems to be more important in the choice to participate in community activities, then the expected influence of the community. According to the people in Grahamstown East, the influence of the community is less and of less importance than suggested in the conceptual framework.

The conceptual model suggests that in the first place the characteristics of the community influence the life of TB patients. The gossiping of the people in the community about TB patients does influence the attitudes, health behaviour and support of TB patients. Sometimes this creates distance between people for a while, but in most cases family, friends, community members and health care workers are supportive. According to this the social ties of TB patients are important. In general the community of Grahamstown East share the thought that people with TB are not different from people who do not have TB. The gender of a TB patient does not play a significant role in the consequences of TB, but it does give an impression about their health seeking behaviour. The findings of the fieldwork reveal that the physical condition of TB patients is the main reason not to participate in community activities in Grahamstown East. Self-perception and beliefs about TB are important characteristics that influence participation, but less than the physical condition. TB patients do not feel excluded from community activities. The behaviour and the participation of TB patients do influence the attitude of the community towards TB and TB patients. This can be illustrated by the finding that some people in the community only participate in community activities with TB patients who are on treatment.

6.2 Recommendations

The recommendations are made with the purpose to create better care and to reduce the negative social aspects of TB patients. TB is contagious, but curable so there should not be any problems for TB patients, other than the physical problems due to TB.

- Temba TB Hospital takes care of TB patients during their treatment. Patients admit to get more rest there than at home. Therefore the TB Hospital should be expanded in order to get more support for the physical rehabilitation of TB patients.
- Besides distribution of the medicines, the clinics should organise sport activities for TB patients. This will improve the physical condition of TB patients, because exercising improves their health condition.
- TB patients and community members should arrange support groups for TB patients. That enables TB patients to deal with the consequences of TB. They can help each other and share their feelings about physical disabilities or other problems. Most importantly together they can find solutions for these things.
- The findings make clear that one of the biggest social problems is the link between TB and Aids/HIV. I recommend a clear differentiation of the treatment of TB in the clinic and by DOTS from the treatment of Aids/HIV. This is necessary to reduce the gossip and pointing fingers at TB patients due to the stigma attached to Aids/HIV. As long as TB is related to Aids/HIV, it should be better to have a well-known special outer-end room for TB patients. In order to avoid misunderstandings about the patients who use the room. Instead of all the DOTS workers will treat all the diseases, there must be a group of DOTS especially for TB. The people in the community must become aware of the DOTS who only treat TB patients. This can be arranged for example by introducing one colour for the clothes of the 'TB DOTS'.
- More education should become available on TB. Especially outside the clinics and closer to the living areas. The research findings show that there are still people who hear about TB from others and who do not get real education about TB. Therefore it might be helpful if every location would have several health educators. The task of these health educators would be to spread folders on TB and on other diseases. Besides this they have to organize meetings with other health educators in the community to share information and to plan actions. This would inform more people about the (true) causes of TB and how to deal with physical consequences. To provide education about TB in an effective way, it is important that the community members speak by themselves and that not only the educators talk to them.
- The health care workers also need more education on the social consequences of diseases. The findings show that health care workers do not always show interest in their patients, nor can all of them educate TB patients on how to deal with physical and social consequences of diseases. In the current situation the health care workers have to sign a confidentiality pact. But actually this is only a formality, because a lot of them do talk about their patients. Therefore their work must be formalized in order to reduce their negative influence at the social consequences of TB.

- A different attitude of the community is necessary. At first all the TB sufferers have to undergo their treatment so they can be cured. The data shows that there are still people who do not take or finish their TB treatment. Secondly the people in the community should be proud of the TB patients who do undergo their treatment and are cured. This is not always happening now. By rewarding them, people get even more motivated to do so. Also more education about TB, as suggested, could have a positive influence on this, because people must talk with each other about these subjects and share their (positive) experiences.
- It is desirable that there should be taken hold of the causes of TB. TB is related to poverty, dirt, drinking, smoking etc. Grahamstown East is an area in which most of the people live in poverty. A dirty area and a poor nutrition are part of the circumstances people live in. In the same way drinking and smoking are part of their lifestyle. However this is difficult to change, because most people have nothing to lose and are not willing to change. To realise certain changes, the local government has to invest much more in the area to create a healthier environment.
- Free home tests for TB should be developed and become available. Because the research data show that, especially men, have difficulties going to the clinic. Therefore they are diagnosed in a later stadium and they feel sick for a longer time of period. If they could be diagnosed in an earlier stage, this will decrease their period of treatment.
- The control on TB treatment should be improved to minimize the number of defaulters. When people can take the pills at their work or at school, their life is less influenced then if they have to go to the clinic every day. Therefore it would be desirable if a mentor at school or work, would support the TB patient and at the same time have a control function on the treatment.
- The respondents mention that there are not many activities in which they can choose to participate in. More community activities should be organised. This becomes clear in the finding that most female respondents like to play netball, but actually are not playing it.

6.3 Final considerations

During the research, the important influence of Aids/HIV became clear. Actually this knowledge shows the vicious circle. This research was undertaken because TB gets less attention, because all the attention goes to Aids/HIV. It appears that both diseases are strongly connected. Therefore more research on the connection between TB and Aids/HIV is necessary, in order to solve the social problems of the patient groups of both diseases. Also further research towards the influence at the community is desirable in order to get a better perspective of their influence on social consequences on TB patients.

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List of abbreviations

TB	Tuberculosis
ISER	Institute of Social and Economic Research
DOTS	Directly Observed Treatment Short course
Aids/HIV	Acquired Immune Deficiency Syndrome / Human Immunodeficiency Virus
Sanpad	South Africa Netherlands research Programme on Alternatives in Development
WHO	World Health Organisation
KNCV	Koninklijke Nederlandse Centrale Vereniging voor de bestrijding der tuberculose - Tuberculosefonds
Tuberculosefonds	tuberculose - Tuberculosefonds
SADHS	South Africa Demographic and Health Survey
FGD	Focus Group Discussion

Appendices

Appendix 1:

Spread of TB in the African continent

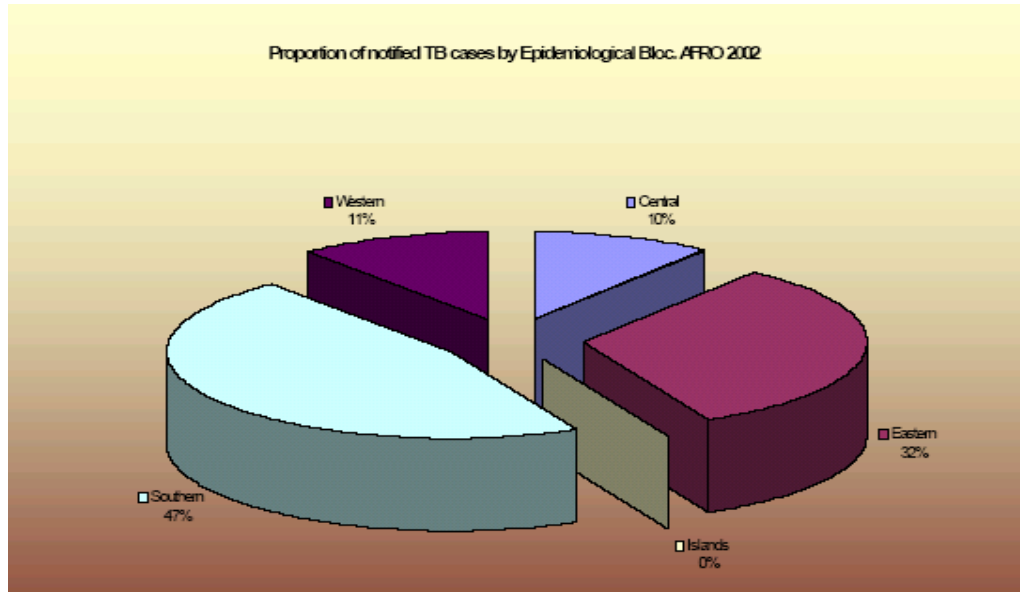


Figure 15: Spread of TB in the African continent (Kabore 2003)

Overview dividing African countries in epidemiological blocs

Central	Eastern	Islands	Southern	Western
1: Cameroon	1: Burundi	1: Cape Verde	1: Angola	1: Algeria
2: Central African Republic	2: Eritrea	2: Comoros	2: Botswana	2: Benin
3: Congo Brazzaville	3: Ethiopia	3: Mauritius	3: Lesotho	3: Burkina Faso
4: Congo Kinshasa	4: Kenya	4: Sao Tome & Principe	4: Madagascar	4: Cote d'Ivoire
5: Gabon	5: Rwanda	5: Seychelles	5: Malawi	5: Gambia
6: Chad	6: Tanzania		6: Mozambique	6: Ghana
7: Equatorial Guinea	7: Uganda		7: Namibia	7: Guinea Bissau
			8: South Africa	8: Guinea Conakry
			9: Swaziland	9: Liberia
			10: Zambia	10: Mali
			11: Zimbabwe	11: Mauritania
				12: Niger
				13: Nigeria
				14: Senegal
				15: Sierra Leone
				16: Togo

Figure 16: Overview dividing African countries in epidemiological blocs

Appendix 2:Overview respondents

	Patients	Family members/ close friends	Community members	Health care workers
Respondents:	12	7	5	7
Average age:	35 year	36 year	33 year	37 year

NB. There were three other respondents of whom the interviews did not count as an interview.

Nr.	Who?	Where?	Code?	Gender?	Function?	Interpreter?
1	Nelisa	Temba	HF5	Female	Manager	No (=N)
2	Chief nurse	Middle Terrace	HF6	Female	Chief nurse Clinic	N
3	-		HF4	Female	Manager ARV day clinic Settlers Hospital	N
4	-	Middle Terrace	MP1	Male	Patient A	Yes (=Y) : Afrikaans
5	-	Joza	FP1	Female	Patient B	N
6	-		FFM4	Male	Friend of patient A	Y: Afrikaans
7	-		FFM1	Male	Boyfriend of patient B	Y: Xhosa (DOT)
8	Meti	Joza/ Extension 7	HF1	Female	TB educator Clinic	N
9	-	Joza	MP2	Male	Patiënt C	N
10	Glen Madlingozi	Extension 7	HF3	Female	Nurse	N
11	-	Temba	MP3	Male	Patient D	Y : Xhosa
12	-	Temba	FP2	Female	Patient E	Y : Xhosa
13	-	Temba	MP5	Male	Patient F	Y : Xhosa
14	-	Extension 7	MP4	Male	Patient G	Y: Xhosa (DOT)
15	-	Temba	MP6	Male	Patient H	Y : Xhosa
16	-	Extension 7	FP3	Female	Patient I	N
17	-	Extension 7	FP4	Female	Patient J	Y: Xhosa (DOT)
18	-	Extension 7	FFF2	Female	Sister patient K	N

19	-	Extension 7	HM2	Male	DOTS	N
20	-	Extension 7	FP5	Female	Patient K	N
21	-	Extension 7	FFF3	Female	Niece patient K	N
22	-	Extension 7	FFF1	Female	Mother patient I	Y: Xhosa (DOT)
23	-	Extension 7	HM1	Male	DOTS	N
24	-	Extension 7	FFM2	Male	Boyfriend of TB patient	Y: Xhosa (DOT)
25	-	Extension 7	CF1	Female	Community member	N
26	-	Joza	CF2	Female	Community member	N
27	-	Joza	CM1	Male	Community member	N
28	-	Makana Kop	CM2	Male	Community member	N
29	-	Extension 3	CF3	Female	Community member	N
30	-	Joza	FFM3	Male	Son of a TB patient	N
31		Extension 7	FP6	Female	Patient	N

Appendix 3:Tables with quantitative overviews of the findings

Table 7: Common thoughts in Grahamstown East about TB and TB patients from the perspective of TB patients.

		I do not know	People talk about TB patients	Total
Male patients	N=6	3	3	6
Female patients	N=6	3	3	6
Total				
N=12		6	6	100%

Table 8: Common thoughts in Grahamstown East from the perspective of family members and friends of TB patients.

		Origin of TB	I do not know	Fair of the infection of TB	Understanding of TB
Males	N=4	2		1	1
Females	N=3		1		2
Total					
N=7		2	1	1	3

Table 9: Common thoughts in Grahamstown East from the perspective of community members.

		People will talk about TB patients	Fair of the infection of TB	Understanding of TB
Males	N=2		1	1
Females	N=3	2	1	
Total				
N=5		2	2	1

Table 10: Common reactions, values and beliefs in Grahamstown East from the perspective of health care workers.

	People will talk about TB patients	Association of TB with bad behaviour	Understanding of TB
Males N=2	1		1
Females N=5	1	1	3
Total N=7	2	1	4

Table 11: Reactions of TB patients about the influence of TB at their self-image.

	No change in self-image	Change in self-image		I do not know
		Physical	Mental	
Male patients (N=6)	1	2	3	
Female patients (N=6)	1	3		2
Total N=12	2	5	3	2

Table 12: Reactions of TB patients about their participation in community activities.

	Yes	No
Reactions of male TB patients (N=6)		6
Reactions of female TB patients (N=6)	2	4
Total N=12	2	10

Table 13: The opinions about the participation of TB patients in community activities from the perspective of community members, friends & family members and health care workers.

	Yes	No	Other opinions
Reactions of community members (N=5)		1	4
Reactions of friends and family members (N=7)	1		6
Reactions of health care workers (N=7)	4		3
Total N=19	5	1	13

Table 14: Reactions on the statement 'TB disease of distance'.

	<i>True</i>	<i>False</i>	<i>Non response</i>
Reactions of TB patients (N=12)	3	3	6
Reactions of friends and family members (N=7)	2		5
Reactions of community members (N=5)	1	1	3
Total N=24	6	4	14

Table 15: The reactions of patients about the differences between male and female TB patients.

	<i>No difference</i>	<i>I do not know</i>
Reactions male patients (N=6)	4	2
Reactions female patients (N=6)	5	1
Total N=12	9	3

Table 16: The reactions of the community members, friends and family members of the TB patients, and health care workers about the differences between male and female TB patients.

	<i>No difference</i>	<i>Difference</i>	<i>I do not know</i>
Reactions community members (N=5)	4		1
Reactions friends and family of patients (N=7)	4	2	1
Reactions health care workers (N=7)	3		4
Total N=19	11	2	6