



## “Pride, Dignity and Respect”

Determinants of (non-)compliance with treatment for people with  
Tuberculosis in the Eastern Cape;  
a Q-methodological study



Jane-Murray Cramm  
Studentnummer: 300955  
Afstudeerbegeleider: Harry Finkenflügel  
Afstudeerbegeleider: Valerie Møller  
Q-methodologie begeleider: Job van Exel  
Rotterdam September 2006

## **Summary**

2 billion people (equal to one-third of the world's total population) are infected with Tuberculosis (TB) bacilli. The World Health Organization (WHO) has declared TB a global emergency. TB is a major health problem in the Eastern Cape of South Africa. The TB epidemic there has developed into the worst of the world, made worse by poor adherence to and frequent interruption of treatment. Non-compliance causes increased transmission rates of TB, morbidity and costs of the TB control programmes. This research will focus on the determinants of (non-)compliance in the eyes of the TB patients in the Eastern Cape.

Q-methodology and qualitative research methods are used to reveal the attitudes and beliefs of the respondents. During the research, 34 TB patients who defaulted from treatment, 33 compliers and 14 community health workers were interviewed.

Prospects, self-efficacy, health motivation and motivation are important concepts associated with compliance. Looking at the results in search of most important determinants of non-compliance, a strong link is found with stigma, costs and barriers of TB treatment. The support of a government disability grant seems to be a perverse determinant.

In the literature, TB is described as a disease of the poor people. TB patients are seen as dirty people with unhygienic habits. Because of these beliefs, people did not want to even look at, walk by, eat or work with people with this disease. For these reasons, TB was considered a "social" disease. In this research no association is found between TB and poverty and/or dirty people with unhygienic habits. However, people with and/or cured from TB are considered to be weak and are less respected. A trip to the clinic and/or home visit from a DOT may bring the disease to light, which causes rejection and stigmatization of TB patients. Many people also believe TB will develop into HIV/AIDS and they have problems distinguishing them, which causes double stigmatized TB patients; stigma of TBC and the stigma of HIV. Therefore, TB is still considered a "social" disease, but for different reasons.

The patients who stayed at the hospital identify boredom as the main determinant of non-compliance. They say that more activities in the hospital would have a positive effect on their compliance behaviour. The government and/or municipalities should provide recreation and leisure facilities; sporting and arts/craft activities in the clinics. Boredom and stigmatisation are associated with increased non-compliance with TB treatment. Community health workers must recognize that their role is not simply treatment observation, but also motivating patient in adherence. Patient centered care will regain feelings of pride, dignity and respect of the TB patients, which will improve compliance and therefore the outcomes of TB treatment in the Eastern Cape.

## **Samenvatting**

2 biljoen mensen (gelijk aan één derde van de wereldbevolking) is geïnfecteerd met de Tuberculose (TBC) bacterie. De World Health organization (WHO) heeft TBC uitgeroepen tot een wereldomvattende urgentie. TBC is een enorm gezondheidsprobleem in de Oostkaap van Zuid-Afrika. De TBC epidemie heeft zich daar ontwikkeld tot de ergste van de wereld, verergert door een slechte mate van therapietrouw en regelmatige onderbreking van de therapie. Het niet volgen van de therapie veroorzaakt verhoogde transmissie, morbiditeit en kosten van de TBC controle programma's. Dit onderzoek is gericht op de determinanten van het wel/niet therapietrouw zijn in de ogen van TBC patiënten in de Oostkaap.

Q-methodologie en kwalitatieve onderzoeksmethodes worden gebruikt om de attitudes en geloofsovertuigingen van de respondenten te achterhalen. In deze studie zijn 34 TBC patiënten die niet therapietrouw zijn geweest, 33 TBC patiënten die wel therapietrouw zijn en 14 zorgprofessionals geïnterviewd. Toekomst verwachtingen, zelfeffectiviteit en (gezondheids-)motivatie zijn belangrijke concepten die sterke associaties hebben met de mate van therapietrouw. Uit de resultaten van het onderzoek naar de determinanten van niet therapietrouw zijn, is een link gevonden met stigma, waargenomen kosten en de barrières van het volgen van de therapie. De arbeidsongeschiktheidsuitkering blijkt een perverse incentive. In de literatuur wordt TBC omschreven als een ziekte van de arme bevolking. TBC patiënten worden gezien als vieze mensen met onhygiënische gewoontes, waardoor de gezonde populatie hen met een boog ontwijkt. Dit maakt TBC een "sociale" ziekte. In dit onderzoek is geen associatie gevonden met TBC en armoede, onhygiënische gewoontes en/of vieze mensen. Mensen met of genezen van TBC worden echter wel beschouwd als zwakke personen, waar men minder respect voor heeft. Een bezoek aan de kliniek of een thuisbezoek van een DOT kan de TBC status aan het licht brengen, wat verstoting door de gemeenschap en stigmatisering teweeg kan brengen. Daarnaast geloven veel mensen dat TBC zich ontwikkelt in HIV en mensen hebben moeite onderscheid tussen de ziektes te maken. Dit resulteert in een dubbel stigma voor TBC patiënten; TBC en HIV stigma. Dit maakt dat TBC nog steeds een "sociale" ziekte is, maar om andere redenen.

De patiënten uit het ziekenhuis identificeren verveling als determinant van niet therapietrouw zijn. Zij geven aan dat meer activiteiten in het ziekenhuis een positief effect zou hebben op de mate van therapietrouw. De overheid en gemeentes zouden moeten zorgen voor recreatie en ontspanning faciliteiten, sport- en creativiteitsactiviteiten. Door de genoemde problemen, is het noodzakelijk dat zorgprofessionals zich realiseren dat hun taak niet alleen observeren en controleren is, maar ook het motiveren en stimuleren van de patiënten. Patiëntgerichte/vraaggestuurde zorg draagt bij aan het herstellen van gevoelens van trost, eigen waarde en respect. Dit heeft een positief effect op de mate van therapietrouw en derhalve op de zorguitkomsten van TBC behandeling in de Oostkaap.

## **Table of contents**

1 Introduction	4
1.2 Research question	6
2 Compliance behaviour	7
2.1 Health Belief Model	7
2.1.1. Bounded Rationality	8
2.2 TB compliance model	9
2.3 Determinants of compliance with TB treatment	11
2.3.1 Determinants of (non-)compliance found in the literature	11
2.3.2 Determinants of (non-)compliance found in the Focus Groups	13
2.4 Conceptual model	14
3 research methods	16
3.1 Structured interview	16
3.2 Q-methodology	16
3.3 Semi-structured in-dept interview	21
3.4 reliability and validity	22
4 Results	23
4.1 Structured interview results	23
4.1.1 Demographic factors and social economic factors	23
4.1.2 Predisposing factors	24
4.2 Q-method results	24
4.2.1 Compliance group	24
4.2.2 Non-compliance group	28
4.3 Results from the semi-structured in-dept interviews	31
4.3.1 Reported level of default	31
4.3.2 Determinants of non-compliance	32
4.3.2 Determinants of compliance	33
5 Discussion	36
6 Reflection on the conceptual model and methods used	41
7 Conclusion and recommendations	43
<b>References</b>	<b>47</b>

**Appendix 1** Demographic and social economic factors of the non-compliance group

**Appendix 2** Demographic and social economic factors of the compliance group

## **1 Introduction**

Tuberculosis (TB) is the most important resurgent disease worldwide. It is primarily an illness of the respiratory system and is spread by coughing and sneezing. 2 billion people (equal to one-third of the world's total population) are infected with TB bacilli, the microbes that cause TB. About 9 million people contract TB annually. Despite the availability of potent chemotherapeutic agents, patients with TB continue to die. Each year nearly 2 million people die from this curable disease. It has the highest morbidity and mortality rate compared to any other single pathogen (World Health Organization, 2006).

The World Health Organization (WHO) has declared TB a global emergency. Deaths from TB comprises one quarter of all avoidable deaths in developing countries (WHO, 2005). Cape Town in South Africa has one of the highest incidence rates of TB in the world. Between 1997 and 2003, the number of new TB cases increased by 22% (City of Cape Town, 2003). There is an ongoing TB epidemic in South Africa (Walzl, Beyers & Helden, 2005). According to the WHO the mortality rate of new sputum smear-positives (ss+) patients should be less than 5 % but many countries do not achieve this goal. South Africa reported a mortality rate of new ss+ cases of 7% (WHO, 2005).

TB is a major health problem in South Africa and the Eastern Cape. The TB epidemic there has developed into the worst of the world, made worse by poor adherence to and frequent interruption of treatment (De Vallière & Barker, 2006). Lack of knowledge and the stigma that comes with the disease result in delay in diagnosis. Beside the problems around case finding, case holding is also an important problem. Even when diagnosed with TB, the stigma causes people to reject the diagnosis. Problems such as access to the TB treatment, patient perceptions of the disease and its care, social support, level of awareness about TB, alternative health care providers, patient-care provider relationship, and costs of treatment (financial and non-financial) are some of the reasons for a person not to fulfill treatment. This causes the infection of more people and makes them drug resistant (Barnhoorn, 1994).

Since 1996 a new control strategy known as DOTS (Directly Observed Treatment Short-course) is recommended by WHO to improve case finding and case holding. This strategy forms part of a global initiative which ensures that TB control is integrated into primary health care and supported at a national level. Completion of the prescribed treatment and outcome of treatment is supposed to improve throughout the constant observation of tuberculosis patients taking their drugs. Standardized treatment and direct observation of TB patients should result in the cure of ss+ patients and is supposed to prevent the spread of drug-resistant TB (Van der Walt & Swartz, 2002). Instead of hospitalization and other expensive treatments, the TB control program DOTS is one of the most cost-effective health interventions available (Murray et al., 1991). In reality however, the results aren't as positive

as they had hoped and wished for. There is still a growth in the global TB epidemic, fuelled by poverty, population growth, the Human Immunodeficiency Virus (HIV) epidemic and failing TB control programmes (Sudre, Dam & Kochi, 1992). Especially the rapid growth of the HIV epidemic in many countries like South Africa has resulted in an equally rise in the estimated number of new TB cases. HIV related TB continues to increase even in countries with well organized TB control programmes that have successfully implemented the DOTS strategy. This suggests that where HIV is fuelling the TB epidemic, full implementation of the DOTS strategy is not enough (WHO, 2004).

The greatest problem facing TB control programmes is how to ensure that all patients complete the prescribed duration of the treatment. TB can be cured with the right treatment and most important adherence to treatment. Unfortunately, the best health practices requires multiple drug therapy over a period of six months or more. This minimum of six months required drug intake and the fact that a patient after a while feels healthy and is symptom free, complicates adherence problems (Van der Walt & Schwartz, 2002).

The level of defaulting from treatment among TB patients is too high (WHO, 2005). It is therefore important to know more about the factors associated with TB treatment default and compliance. In the Eastern Cape, people with TB are treated with the 6 months drug intake treatment. Interruption of treatment presents a problem not only for patients, but also for their families and eventually the whole community. Within a couple of weeks of compliance with effective treatment, a previously infectious person becomes non-infectious; this in itself is an enormous gain of compliance. Left untreated, each person with active TB disease will infect on average between 10 and 15 people every year (WHO, 2006). People infected with TB bacilli will not necessarily become sick with the disease. The immune system "walls off" the TB bacilli. When someone's immune system is weakened, the chances of becoming sick are greater.

Another problem of non-compliance with treatment is that it leads to persistence and resurgence of TB and is regarded as the chief cause of relapse and drug resistance (Comolet, Rakotomalala & Rajaonarivoa, 1998). A particularly dangerous form of drug-resistant TB is multidrug-resistant TB (MDR-TB). While drug-resistant TB is generally treatable, it requires extensive chemotherapy (up to two years of treatment) that is often prohibitively expensive (often more than 100 times more expensive than treatment of drug-susceptible TB), and is also more toxic to patients (WHO, 2006). Non-compliance causes an increase in transmission rates of TB, morbidity and costs to the TB control programmes (Johansson, Long, Diwan & Winkvist, 1999).

## 1.2 Research question

In order for TB treatment to be effective, it is important to access the factors that influence compliance with treatment. Due to its importance in the fight against TB, this research will focus on the determinants of compliance and non-compliance in the eyes of the TB patients in the Eastern Cape. The research question is: *What is the patient's perspective on the determinants of compliance and non-compliance with treatment among TB patients in the Eastern Cape?*

Research problems:

- What information about the level of defaulting among TB patients in the Eastern Cape is available?
- What determinants of compliance with TB treatment are found in the literature?
- Which of the determinants found in the literature causes compliance among TB patients in the Eastern Cape and which influences compliance the most?
- Which of these determinants causes non-compliance and which influences non-compliance the most?
- What needs to change in order to improve compliance among TB patients in the Eastern Cape?

To answer the research question: “what is the patient's perspective on the determinants of compliance and non-compliance for a TB patient with a prescribed treatment regimen in the Eastern Cape”, an understanding of all the factors that influence and predict a person with TB to comply with the prescribed treatment is necessary. The Health Belief Model (HBM) is a common and frequently used social cognition model. Social cognitive models are used in health psychology to understand and predict health behaviour, such as compliance with a prescribed treatment. Social cognitive models are based on the belief that people's behaviour comes from optimal rationality. However, Simon proposed the notion of bounded rationality. He criticizes the theory of rational choice based on the argument that people's behaviour does not come from optimal rationality but from bounded rationality. The theory of bounded rationality will therefore also be discussed. For examining compliance behaviour, Barnhoorn and Adriaanse (1992), in search of factors responsible for non-compliance among tuberculosis patients in India, conceptualized and depicted the determinants of compliance and their interactions in a TB Compliance model. After reviewing the literature and transcripts from the Focus Groups held in Grahamstown this model is modified to the local context, leading to the conceptual model used in this research. The third chapter contains the used research methods and in the fourth chapter the results are presented. After a discussion on the findings, a reflection is made regarding the conceptual model and the research methods. Finally, conclusion and recommendations will be presented.

## **2 Compliance behaviour**

This chapter contains a literature study leading to a theoretical framework on compliance behaviour among TB patients in the Eastern Cape. First one must gain better insight and understanding of this particular type of health behaviour. Social cognition models increase our understanding of the different factors that influence health behaviour and are therefore a useful tool in search of the determinants of (non-)compliance.

### **2.1 Health Belief Model (HBM)**

The HBM is the most frequently used social cognition model. In the 1950s, US public health researchers began developing psychological models designed to enhance the effectiveness of health education programmes (Hochbaum, 1958; Rosenstock, 1966). Rosenstock (1974) attributed the first HBM research to Hochbaum's (1958) studies in response to the failure of a free TB health-screening program and since then the model is used many times in relation to TB. HBM studies have been applied to three broad areas of health behaviour among a wide range of populations. Preventive health behaviour, sick role behaviour (for instance compliance to the prescribed treatment) and clinic use (Conner & Norman, 2005).

The HBM is a psychological model which attempts to explain and predict health behaviour by focusing on the attitudes and beliefs of individuals. The model measures individual's perceptions of vulnerability to the health threat as separate from perceptions of the severity with which the threat may affect their lives. Perceptions of threat are seen to depend on two beliefs; the perceived susceptibility to the illness and the perceived severity of the consequences of the illness. When these two variables are put together, they determine the likelihood of a person following a health-related action.

The effect of the two variables is modified by individual differences in demographic variables, social pressure and personality. The specific health-related action is believed to be determined by the evaluation of available alternatives, focusing on the benefits or efficacy of the health behaviour and the perceived costs/barriers to perform this particular health behaviour. When individuals believe themselves to be susceptible to a condition which they also consider serious, and believe after a cost-benefit analysis that the benefits of the health-related action outweigh the costs, they are more likely to engage in this particular health behaviour.

Two other variables included in the HBM are; cues to action and health motivation. Cues to action are assumed to include internal or external triggers to the individual taking action. Internal triggers can be physical symptoms. The benefits of the treatment are heightened when the symptoms that come with the disease are elevated and the health status has worsened. The external triggers to the individual taking action can be mass media campaigns and/or advice from others, like direct observation. Furthermore, certain



individuals may be predisposed to respond to these cues to action because of the value they place on their health (health motivation). The HBM has proven to be a useful framework for examining sick role behaviour such as compliance with a prescribed treatment (Liefoghe, Michiels, Habib, Moran & Muynck, 1995; Barnhoorn & Adriaanse, 1992).

Apart from the HBM, the Theory of planned behaviour (TPB) and the Theory of Reasoned Action (TRA) are commonly used social cognitive models. The TRA and the TPB were originally designed and proposed to understand relative simple behaviours and the TRA assumes that behaviours are totally under the volitional control of the individual. These social cognitive models are based on the ability of a person to make only rational decisions without the emotional influences on decisions. TB patients cannot simply make rational decisions. The lack or gap in knowledge is a problem as well as stigmatization of TB patients. Social rejection, risk of losing a job and negative attitudes from the environment have more to do with feelings and emotions than they are based solely on pure ratio. These complex surroundings of TB patients result in reduction of volitional control. In developing countries money to buy food and the ability to pay for the bills are often more important. The risk of losing a job and becoming socially isolated have an enormous effect on their health behaviour, they are not totally under the volitional control of TB patients in the Eastern Cape. Contrary to the TRA, the TPB allows the fact that not all behaviours are entirely under volitional control. However, both models are considered entirely rational and do not provide explicit emotional fear-arousal elements such as perceived susceptibility to illness (Mullen, Hersey & Iverson, 1987). The fact that TPB as well as the TRA do not cater for emotional fear and arousal variables has led researches to believe that these models are limited to the rational part of human decision making. In this study emotional fear, stigmatization and social rejection are factors that play a significant role in compliance to therapy (Norman, Abraham & Conner, 2000). Therefore and because of the proven usefulness of the framework for examining sick role behaviour such as compliance, the HBM is chosen as the social cognitive model to be used in this research.

### **2.1.1 Bounded rationality**

The social cognitive models are based on the belief that people's behaviour comes from optimal rationality. In 1957 Simon proposed the notion of bounded rationality. Simon criticizes the theory of rational choice based on the argument that humans' rationality is not optimal. Bounded rationality describes a relationship between a person's mental abilities and the complexity of the problem he or she faces. The capacity of the human mind to solve complex problems is very small (Tamura, 2005). This is especially problematic for TB patients in the Eastern Cape; for them the sizes of the problems they face largely exceed

their capabilities. The fundamental notion is of cognitive limits. The ability to solve problems depends on a person's capability and the environment. Beside the constraints in cognitive abilities of people, bounded rationality is also that property of a human being that behaves in a manner that is nearly optimal with respect to its goals as its resources will allow (Simon, 1967). The priority of goals can shift over time; especially when a TB patient after a few weeks of drug intake is symptom free and feels healthy. Then, the cost-benefit analysis (HBM) regarding TB treatment made by an individual will result in favor of defaulting from treatment, because other goals become more important. When the symptoms have disappeared costs of adherence to TB treatment (time, money, social rejection, risk of losing income) are higher than the perceived benefits (cure from TB). Especially for people with low income; where time and money are scarce and people often have to face many problems from which they have to choose.

People are faced with many decisions to which they have to devote time, money and energy to. Bounded rationality does not assume that people make decision far ahead into the future, that encompasses the whole spectrum of values and in which each problem is interconnected with all the problems in the world. On the contrary, the environment in which people live is characterized by the unique nature of each problem. At different times people make different choices, because of different biological needs. These needs play especially in developing countries an important role. Sometimes hunger has priority, other times health, love, money etc. The most urgent need has to be satisfied first (Hanoch, 2002).

Simon (1959) suggests that researchers not limit their focus but look for all the data they can in order to uncover the underlying processes. He concludes by providing a lower bound of relevance to cognitive analyses: "*the exact ways in which neurons accomplish their functions is not important, only their functional capabilities and the organization of these*".

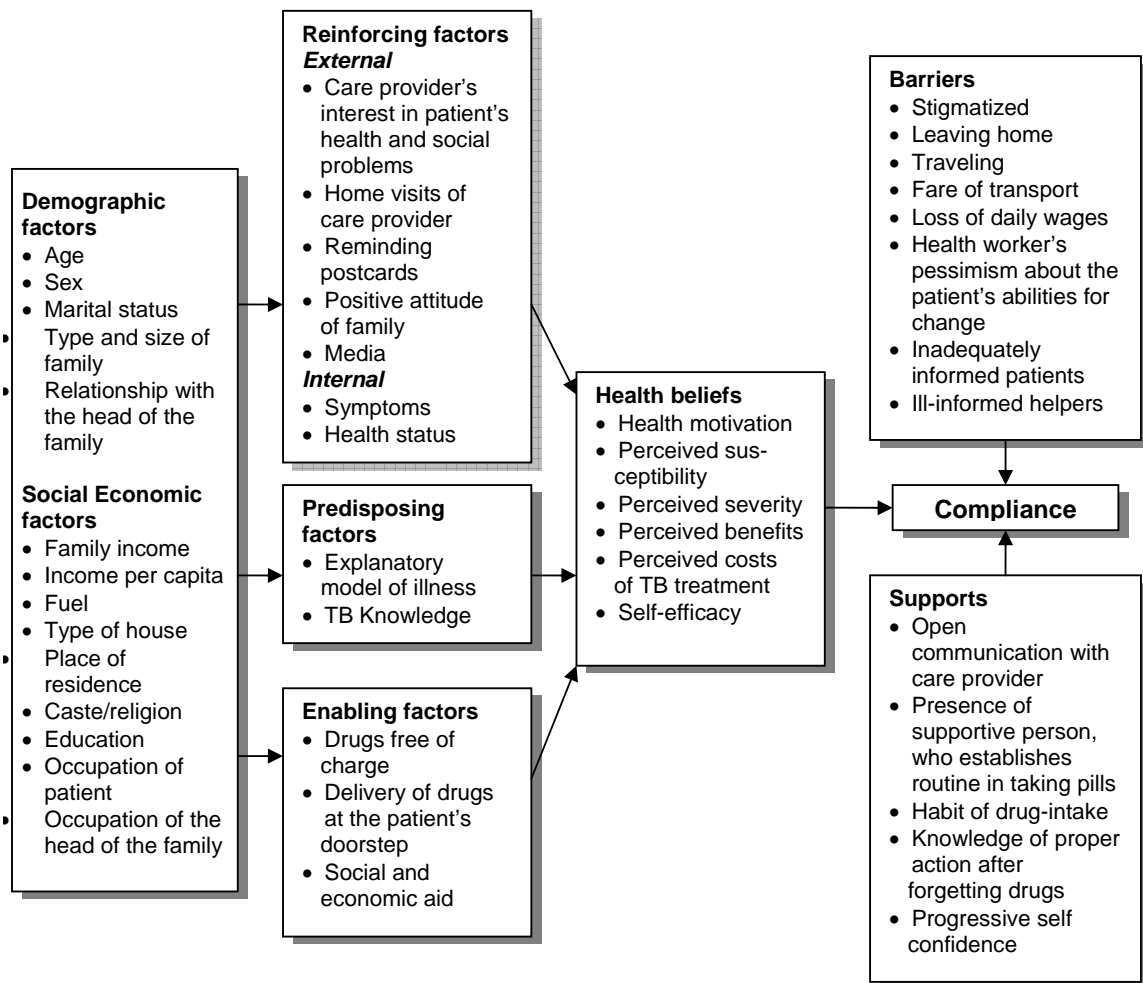
## **2.2 TB Compliance model**

For examining compliance behaviour a theoretical approach on the determinants of compliance and their interaction is needed. Barnhoorn and Adriaanse (1992), inspired by the HBM, conceptualized and depicted those factors in a TB Compliance model. In this model, TB treatment compliance is directly determined by *health beliefs*, *support mechanisms* and *barriers*; while *socio-economic* and *demographic factors* play an indirect role (Liefoghe et al, 1995).

The TB Compliance model assumes that people comply with regimens under a very specific set of conditions; they make a subjective cost-benefit analysis of the situation. Patients must possess a minimal level of health knowledge and motivation towards health; they must see themselves as vulnerable towards TB (perceived susceptibility) and believe in the serious nature of the disease. *Health beliefs* concern perceived severity (one's opinion of how

serious a condition and its consequences are) of the disease: expectations towards treatment and cure: health motivation: benefits of treatment regimens: and the personal advantage of continuing treatment given competing events. These *health beliefs* are influenced by *enabling factors*, *predisposing factors* and *reinforcing factors*. *Reinforcing factors* can be external (such as empathy of the staff) and internal (symptoms and health status). Furthermore, patients must be convinced in the ability to be cured from TB and that the benefits of treatment exceed the costs. When after the cost-benefit analysis the benefits exceed the costs, adherence is improved (Barnhoorn & Adriaanse, 1992).

**Figure 1 TB Compliance model (Barnhoorn & Adriaanse, 1992)**



Personal and environmental factors that influence compliance with a prescribed treatment regimen are summarized in the model. Attention to these factors and the level of influence of each one of these factors might improve the care and cure of TB patients.

## **2.3 Determinants of (non-)compliance with TB treatment**

The literature will be reviewed in search of determinants of (non-)compliance in developing countries. In addition, transcripts of Focus Groups held by Valerie Møller from the Rhodes University of Grahamstown are used to search for determinants of (non-)compliance in the local context. These transcripts contain the results of eight Focus Groups held with TB patients, community health workers and community members on TB stigma in the Grahamstown, the Eastern Cape.

### **2.3.1 Determinants of (non-)compliance found in the literature**

The major cause of failure in TB control programs is non-compliance to treatment. The influences of personal and environmental factors on compliance with a prescribed TB treatment have been studied in many countries. After reviewing the literature, the next five determinants are mentioned by researchers as the most important factors that effect compliance to TB treatment in developing countries.

- **The relationship between the patient and community health workers**

This factor is described as one of the main determinants of adherence to medical treatment (De Tullio et al, 1986; Solomon, De Jong & Jodrie, 1988; Barnhoorn & Adriaanse, 1992; Johansson, Diwan, Huong & Alberg, 1996; Black & Bruce 1998; Auer, Sarol, Tanner & Weiss, 2000; Van der Walt et al., 2002; Dodor & Afenyadu, 2005; Mishra, Hansen, Sabroe & Kafle, 2005). Dodor & Afenyadu (2005) found that forty-four percent of non-defaulters in their research said they were motivated to complete treatment because of a good relationship between the patient and community health workers. Satisfaction with the community health worker has a positive effect on the continuation of drug intake, which has a positive effect on case holding (Barnhoorn & Adriaanse, 1992; Auer et al., 2000). Negative attitudes of community health workers and lack of privacy are problems that contributed to patients' difficulty in continuing with treatment (Escott & Walley, 2005). In particular the community health worker's pessimism about the patients abilities to change, may serve as a barrier in the relationship between the community health worker and the patients (Barnhoorn & Adriaanse, 1992).

- **Economic situation**

The patient's economic situation is described as another important determinant of compliance and non-compliance (Johansson et al., 1996). Dodor & Afenyadu (2005) found that financial difficulties were mentioned by TB patients as the main reason for defaulting from treatment. Income per month is positively associated with compliance to treatment. People often believe that medicines should only be taken with food and supplementary

drugs. Lack of money to buy them can therefore be a reason for TB patients to default from treatment. In search of factors responsible for non-compliance among TB patients in Wardha district India, Barnhoorn and Adriaanse (1992) found that the income level was the most important factor from the demographic and socio-economic factors to determine compliance. People are afraid of losing their jobs after they have been diagnosed with TB, which causes a delay in case finding. Some are convinced they wouldn't be able to find a job again, because of a TB diagnosis. Security of income is often found to be more important than health, especially among people with low income (Barnhoorn, 1994).

- **Social isolation and stigmatization**

TB is considered a "social" disease, which causes social isolation and stigmatization, not only of TB patients but also for their families. Disease stigma can be defined as an ideology that identifies and links the presence of a biological disease agent (or any physical signs of a disease) to negatively-defined behaviours or groups in society. Disease stigma is negative social "baggage" associated with a disease that is generated by the stigmatization process and not justified by the medical effects of the disease on the human body (Deacon, Stephney & Prosalendis, 2005). In many developing countries, people believe TB is an incurable and dangerous, which mainly affects poor people (Johansson et al., 1996). In South Africa, TB is associated with unhygienic habits and TB patients are seen as dirty people who eat bad food (Westaway, 1989). TB is considered a disgrace, which consequently causes shame and blame. Because of these beliefs, people do not want to even look at, walk by, eat with or work with people with this disease (De Villiers, 1991).

Because of the stigma attached to TB, patients refuse to accept the diagnoses. Stigmatization forms a barrier for compliance. Even when patients do accept their TB diagnosis, they hide their condition from their employer, friends and family members (Johansson, et al., 1999). Taking treatment often causes feelings of embarrassment with TB patients; they describe feeling less respected by others (Johansson et al., 1996). Recurrent visits of the community health worker (DOT) or a trip to the tuberculosis clinic may bring the disease to light (Barnhoorn & Adriaanse, 1992) and causes compliance problems. The cost-benefit analysis made by an individual will then result in favor of defaulting from treatment. Costs (time, money, social rejection, risk of losing income) of adherence to treatment are higher for this group of people than the perceived benefits (cure from TB). Social rejection creates the potential to default, especially when patients soon feel better after starting the treatment.

- **Social support**

A conclusion drawn by Barnhoorn and Adriaanse (1992) is that compliance behaviour is positively associated with social support. Patients who knew that the attitude of their family regarding the regular intake of medicine was positive were more likely to be compliant. In the research of Liefhooghe et al. (1995), they found that families have a strong influence on decision-making and motivation. Family pressure may be a decisive factor in both acceptance and rejection of the diagnosis and subsequent adherence to treatment.

- **Knowledge**

An indication of an educational problem was the association between the compliance behaviour of a patient and his or her *knowledge* on specific aspects of the disease, the origin of tuberculosis and features of the drug regimen (Barnhoorn & Adriaanse, 1992). In a study on TB prevention strategies, they found that TB knowledge is positively linked to compliance. People who knew less about this disease were more likely to believe TB was not a health risk with which they need to be concerned about. This results in a negative influence on compliance to treatment (San Sebastian & Bothamley, 2000).

An important factor that influences default is a different kind of cultural related knowledge about TB. These are often different from the Western medical tradition. A belief in the Xhosa tradition is that TB is the result of wizardry. Some believe a person with TB is the victim of the *impundulu* (a bird). TB is seen as *ukufa kwama Xhosa*, a disease of the Xhosa speaking people. They do not believe White people possess any kind of knowledge of these kinds of diseases. Therefore, they see an *igirha* (fortuneteller) before they go to a clinic. They also believe that “western” medicines should not be taken together with traditional medicines (WHO, 2004). This *igirha* recognizes TB in a late stage when the person is coughing up blood (De Villiers, 1991). African American people in the United States even think of TB as a mystery (Barnhoorn, 1994).

### **2.3.2 Determinants of (non-)compliance found in the Focus Groups**

The next determinants of compliance were found in transcripts of eight Focus Groups held with TB patients, community health workers and community members on TB stigma in Grahamstown. Results from the Focus Groups show that not only the attitude from the patients' family, but also that *other people's opinion of TB treatment* is positively linked to compliance. Respondents also mention that *media* has improved TB knowledge in the Eastern Cape, which is positively linked to faith in and compliance with TB treatment. Patients mention experiencing difficulties with the *number of pills they have to take*, which has a negative impact on compliance behaviour. In the transcripts from the Focus Groups held, respondents also describe a negative association between *abstinence from smoking*

*and drinking, waiting time in clinics and following the rules and restriction that come along with the therapy.*

## **2.4 Conceptual model**

This research studies patients' perspectives, attitudes and beliefs on the determinants of compliance and non-compliance to TB treatment. It addressed the subjective items from the TB compliance model. The *demographic, socio economic factors, internal reinforcing factors* and knowledge related items are objective and therefore considered less important in the search of the TB patients' perspectives. They are displayed in grey (figure 2).

After reviewing the literature on the determinants of (non-)compliance to TB treatment in developing countries several factors are found. These are the blue items.

In addition, transcripts of Valerie Møller from the Rhodes University of Grahamstown are used to finalize the conceptual model used in this research. Determinants of compliance mentioned during these Focus Groups are shown in green.

Items positively linked to compliance are given a "+", items negatively associated with compliance a "-".

In the Eastern Cape they make no use of reminding postcards, therefore this item is excluded from the conceptual model.

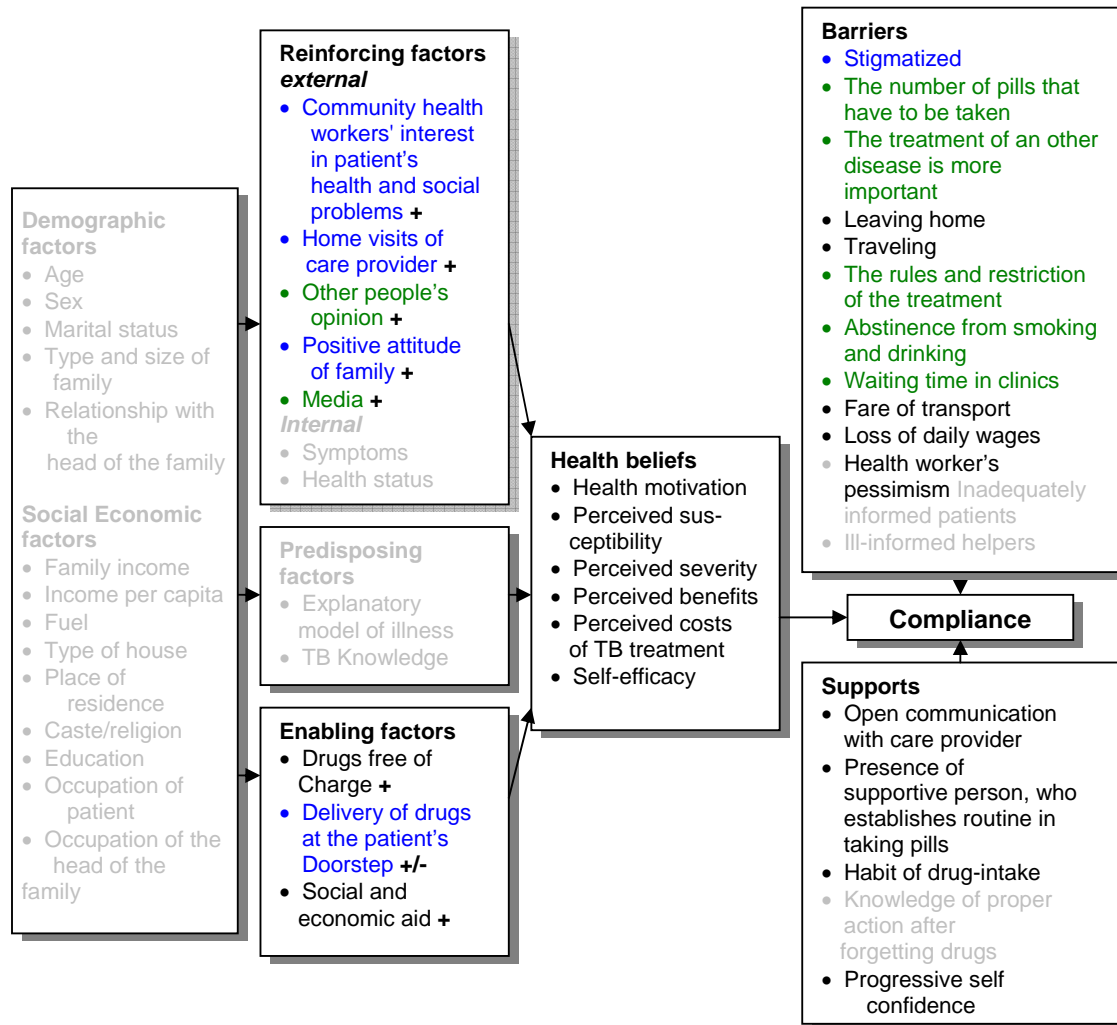
The *enabling factors* apply to the situation in the Eastern Cape where the DOTS system is implemented and a disability grant is given to TB patients. Therefore, these items are included in the conceptual model.

Patients in the Eastern Cape mention experiencing difficulties with the number of pills they have to take. Because of the negative association with compliance, this item is included in the model as a barrier. Transcripts from the Focus Groups describe that the rules and restriction that come along with the therapy, abstinence from smoking and drinking and waiting time in clinics are negatively linked to compliance. These items are also included in the conceptual model as barriers for compliance with TB treatment.

The rapid growth of the HIV epidemic in South Africa has resulted in an equally rise in the estimated number of new TB cases. TB is a leading killer among HIV-infected people with weakened immune systems; a quarter of a million TB deaths are HIV-associated, most of them being in Africa (WHO, 2006). Simon's theory of bounded rationality (1959) describes a relationship between a person's mental abilities and the complexity of the problem he or she faces. People are faced with many decisions to which they have to devote time, money and energy to. The most urgent need has to be satisfied first (Hanoach, 2002). Co-morbidity can negatively effect compliance and is therefore conducted in the conceptual model as a barrier. No strong association of the items left with compliance came to light after reviewing the literature and transcripts from the Focus Groups. However, Barnhoorn and Adriaanse (1992)

found a link between them and they could also determine compliance for TB patients in the Eastern Cape. Therefore, these items are included in the conceptual model used in this research.

**Figure 2 conceptual model**





### **3 Research Methods**

In this descriptive study, different research methods are used to uncover the determinants of compliance and non-compliance to TB treatment in the Eastern Cape. A structured questionnaire, Q-methodological study and semi-structured in-dept interview were used to uncover opinions on the determinants of (non-)compliance with TB treatment in the Eastern Cape. These methods will be outlined, consecutively.

#### **3.1 Structured questionnaire**

A structured questionnaire was used in which questions were asked to the compliers and defaulters regarding the objective factors; *demographic, socio-economic, predisposing factors* and other knowledge related items. These factors, displayed in grey in the conceptual model (figure 2), were asked in a structured interview. The relationship with the head of the family, family income, income per capita, fuel, type of house, place of residence, caste/religion, occupation and occupation of the head of the family were excluded. These are more difficult to find and since this research investigates subjectivity, these items were excluded. Instead, employment status is used as *social economic factors*. Gender, age, employment status, household size, marital status, education and knowledge related items were included in the questionnaire.

#### **3.2 Q-methodology**

Q-methodology is a hybrid qualitative method-quantitative method that provides a scientific foundation for investigating subjectivity, i.e., research regarding peoples' attitudes, viewpoints, beliefs, feelings and opinions (Brown, 1980; 1993; Stephenson, 1935; Van Exel & de Graaf, 2005; [www.qmethod.org](http://www.qmethod.org)). In a Q-methodological study a group of people is presented with a sample of statements, called the Q-set. The respondents, called the P-set, are asked to rank-order these statements from their individual point of view, according to some preference, judgement or feeling about them. By Q-sorting, people give their subjective meaning to the statements and by doing so they reveal their subjective viewpoint or personal profile. Q-sorting is a distinct technique with its own strengths and weaknesses though it continues to be confused with other techniques, such as cluster analysis (Brown, 1980). Cluster analysis is a multivariate technique for grouping responses statistically. It differs from Q-sorting and Q-analysis in that it draws on traditional inferential statistical methodology rather than Q-methodology for its theoretical grounding. One implication is that cluster analysis aims at achieving representation through random sampling and large numbers. Its end result is homogenous groups of objects about which assumptions are made based on broad categorizations.

Standard statistical procedures to Q-sort data such as the interpreting data by comparing individual score with the average score for a group (normative measures) cannot be used with Q-methodology. In Q-analysis, correlation between individual rankings of statements is an indication of similar viewpoints. The results of a Q-methodological study can therefore only be used to describe a population of viewpoints and not a population of people. However, some also argue that this is relatively unimportant, especially when the number of items is large (Polit & Hungler, 1999).

Q-methodology offers researchers a powerful tool for systematically examining subjective data. The forced procedure of Q-sorting is the subject of criticism. Critics argue that through Q-sorting they tend to exclude information concerning how people would ordinarily distribute their opinions. Although there are some disadvantages in using Q-methodology, there are also a number of key advantages especially for researchers seeking to explore perceptions and attitudes (Karim, 2001). This research contains the determinants of compliance to a prescribed TB treatment. Attitudes and beliefs are important factors in the conceptual model. These subjective factors of the TB patients in the Eastern Cape need to be recognized and acknowledged. Q-methodology is a research method that especially looks at attitudes, beliefs and perspectives like finding the determinants of compliance and the level of influence of each of these determinants of TB patients in the Eastern Cape, which is why this research method is used.

This Q-methodological study addressed the more subjective factors from the conceptual model; *the reinforcing factors, enabling factors, health beliefs, barriers and supports*. The purpose of this Q-methodological study is to uncover the main operant subjectivities surrounding compliance and non-compliance with TB treatment, alongside demographic, socio-economic and predisposing factors. Performing a Q-methodological study involves the following steps: definition of the discourse; development of the Q-sample; selection of the P-set; Q-sorting; and analysis and interpretation (Van Exel & de Graaf, 2005).

- **Definition of the discourse**

The discourse contains all the relevant aspects of the TB (non-)compliance discourse, which are discussed in chapter 2.

- **Development of the Q-sample**

The Q-set/statements (table 1) addressed the *reinforcing factors, enabling factors, health beliefs, barriers and supports* from the conceptual model (figure 2).

**Table 1 Q-set/statements**

<ul style="list-style-type: none"><li>• <i>Reinforcing factors</i><ol style="list-style-type: none"><li>1. Community health worker's support and interest in me</li><li>2. Home visits by the community health worker</li><li>3. Other people's opinion of TB treatment</li><li>4. My family's opinion of TB</li><li>5. Media attention for the consequences of TB</li></ol></li><li>• <i>Enabling factors</i><ol style="list-style-type: none"><li>6. Receiving TB drugs free of charge</li><li>7. Delivery of TB drugs at my doorstep</li><li>8. The support and help from support groups</li><li>9. The support of a government disability grant which is paid for six months</li></ol></li><li>• <i>health beliefs</i><ol style="list-style-type: none"><li>10. I take my treatment because I really want to get healthy again.</li><li>11. The main thing is to improve my life situation, so I take my treatment</li><li>12. The chance that TB makes me sick</li><li>13. The chance of dying of TB</li><li>14. I think this treatment will really help me so I'm prepared to take the medicine</li><li>15. Having to think about TB and the drugs all the time is burdensome</li><li>16. Trust that I can take the drugs for the whole six months</li><li>17. My expectations of life after TB treatment</li></ol></li><li>• <i>barriers</i><ol style="list-style-type: none"><li>18. The public association of TB with HIV/AIDS</li><li>19. Fear of telling others that I have TB</li><li>20. The number of pills that I have to take</li><li>21. The treatment of an other disease (e.g. HIV/AIDS) is more important</li><li>22. Having to leave home</li><li>23. Travel time to the TB clinic</li><li>24. The rules and restrictions that come along with the therapy</li><li>25. Abstinence from smoking and drinking</li><li>26. waiting time in clinics</li><li>27. Money to buy fare for transport to the TB clinic</li><li>28. Loss of daily wages</li><li>29. Treatment by the staff</li></ol></li><li>• <i>Supports</i><ol style="list-style-type: none"><li>30. The communication with the community health worker</li><li>31. Presence of supportive person, who establishes routine in taking pills</li><li>32. Difficulties in keeping routine in taking the drugs</li></ol></li></ul>
---

The item "social an economic aid" from the conceptual model is divided into two statements; statement 8 (the support and help from support groups) and 9 (the support of a government disability grant which is paid for six months). Stigmatization is also divided into two statements; "the public association of TB with HIV/AIDS" and "fear of telling others that I have TB". The Q-set/statements were translated into Xhosa. The respondents could read the statements in English and Xhosa. A translator was present during the interviews with the patients.

- **Selection of the P-set**

Q-methodology is a small sample methodology. The aim is to have approximately as many respondents as statements. The focus is on in-depth analysis of small number of cases rather than superficial analysis of large number of cases. In Q-methodology, the population and the sample are not as rigidly defined as in quantitative research. The P-set is not random; it is a purposive sample. The P-set consisted of a group of TB patients in the Eastern Cape who complied with therapy, and a group who defaulted. The compliers were found at the clinics and hospital in the township of Grahamstown. In search of the non-compliers; community health workers and compliers were asked if they knew people who defaulted from treatment. In the Eastern Cape, patients who do not take their treatment are followed up, even after missing a day. If patients have missed 10 treatments in a row, they have to be retested. The course of (six-month) treatment has to start afresh if a patient misses one month of treatment. When a TB patient misses 10 treatments and has to be retested, this patient is considered a defaulter.

- **Q-sorting**

The Q-set was presented to the TB patient in the form of a pack of cards. These cards contained all the statements from the Q-set. Respondents were instructed to rank the statements using the conditions of instruction below and a score sheet.

The central question for Q-sorting/ranking the statements for the compliance group:

*“What is helping you to stick to your six-month TB treatment?”* Here are some things other people have told us have helped them. What has helped you?

The central question for Q-sorting/ranking the statements for the non-compliance group:

*“What made you stop the TB treatment?”* Here are some things that other people have told us, what were the main reasons for you?

The score sheet took the form of a quasi-normal distribution ranging from “least important” (-3) on the far left to “most important” (+3) on the far right (figure 3). An assumption is made regarding the respondents’ opinions. Expected was that their opinion is outspoken, but not too much. A procedure of Q-sorting was chosen were people can distribute their opinions using a “2, 3, 6, 10, 6, 3, 2” distribution. This rather safe distribution asks for less salient statements, which is chosen to prevent that respondents have to be more outspoken on the matter than they really are.

**Figure 3 score sheet**

least important						most important
<b>-3</b>	<b>-2</b>	<b>-1</b>	<b>0</b>	<b>+1</b>	<b>+2</b>	<b>+3</b>

During the interview, the participant was asked to read through all of the statements carefully, in order to get an impression of the type and range of opinions at issue before ranking them. The respondent was instructed to begin with a rough sorting while reading, by dividing the statements into three piles: statements which the participant generally agreed with, those statements that he or she disagreed with and those about which the participant was neutral, undecided, or that did not apply to her or his situation. After the participant had sorted the statements into the three described piles, he or she was asked to rank order the statements according to the point of view regarding the determinants of TB compliance and to place them in the provided score sheet. After the Q-sorting, the in-dept interview began. The participant was invited to elaborate on her/his point of view, especially with respect to the most salient statements; those placed at both extreme ends of the continuum on the score sheet. This additional information is helpful for the interpretation of factors and a better understanding of the results (Van Exel & de Graaf, 2005).

- **Analysis and interpretation**

First, the correlation matrix of all Q-sorts is calculated. This represents the level of (dis)agreement between the individual sorts, that is, the degree of (dis)similarity in points of view between the individual Q-sorters. Next, this correlation matrix is subject to factor analysis. Factor analytic techniques are used to identify patterns of shared meanings between respondents. The objective is to identify the number of natural groupings of Q-sorts by virtue of being similar or dissimilar to one another, that is, to examine how many basically different Q-sorts are in evidence (Brown 1980; 1993). People with similar views on the topic will share the same factor. Respondents' degree of association with each factor is represented by their correlation with that factor or factor loadings. If two participants both have high correlation on a specific factor, their arrangement of card was similar.

To arrive at a final factor analysis, the original set of factors is rotated using varimax rotation. By rotating the factors, the opinions are examined from different angles. It does not affect the consistency in sentiment throughout individual Q-sorts or the relationships between Q-sorts; it only shifts the perspective from which they are observed. Each resulting final factor represents a group of individual points of view that are highly correlated with each other and uncorrelated with others.

The final step before describing and interpreting the factors is the calculation of factor scores and difference scores. A statement's factor score is the normalised weighted average statement score (Z-score) of respondents that define that factor. Based on their Z-scores, statements can be attributed to the original quasi-normal distribution, resulting in a composite (or idealised) Q-sort for each factor. The composite Q-sort of a factor represents how a hypothetical respondent with a 100% loading on that factor would have ordered all the statements of the Q-set.

### **3.3 Semi-structured in-dept interview**

Semi-structured interviews were held with community health workers and the P-set. After the respondents from the compliance group are finished with their Q-sort, in-dept interviews are held to uncover their perspectives on non-compliance. In-dept interviewing is a powerful tool for understanding the participant's perspectives of live, experiences, or situations expressed in their own words. Health behaviour such as compliance with therapy, with its complex determinants is therefore best understood in a face-to-face encounter between the researcher and the TB patients as in in-dept interviews. These in-dept interviews are guided by a semi-structured questionnaire. Compliers have to determine and explain which of the Q-set the five most important reasons for non-compliance are. The same goes for the non-compliers; after performing the Q-sort on non-compliance, they have to mention what they think that the five most important reasons for compliance are. In addition, the community

health workers had to mention which of the statements are the five most important reasons for non-compliance and adherence to TB treatment among TB patients in the Eastern Cape. To find information about the level of defaulting among TB patients in the Eastern Cape the community health workers were asked the default level at their clinic.

### **3.4 Reliability and validity**

Methodological triangulation involves the use of multiple qualitative and/or quantitative methods. In this descriptive study, different research methods are used to uncover the determinants of compliance and non-compliance to TB treatment in the Eastern Cape. If the conclusions from each of the methods are the same, then validity is established.

The reliability of Q-methodology has been established by various means. One of these is the test-retest study. Studies have shown that when the same instrument is applied to an individual at two points of time, the resultant correlation coefficient is .80 or higher.

Q-methodology is based on an individual respondent's viewpoint and not the researcher's viewpoint, each of the responses is taken as valid and as a valuable source of information in the study. Because there is no external criterion for a person's point of view, the issue of validity of Q-sorts does not apply (Brown, 1980).

## 4 Results

The data were gathered in Grahamstown the Eastern Cape. People from the Rhodes University, Temba Hospital (for TB/HIV), Primary Health Care Office, clinics for standard treatment, the clinic for more complex treatment and the Ministry of Health Department were interviewed. The group of compliers were interviewed at the clinics or in the hospital and the defaulters at their homes in the township of Grahamstown. During this research, 34 TB patients who defaulted from treatment, 33 compliers and 14 community health workers were interviewed. This chapter presents the results from the structured questionnaire, the Q-methodological study and the semi-structured in-dept interviews.

### 4.1 Structured questionnaire

The more objective factors; *demographic*, *socio-economic* and *predisposing factors* of the patients were asked in a face-to-face, in-dept interview. First, the results of these factors are presented.

#### 4.1.1 Demographic factors and social economic factors

The number of male and female respondents among the non-compliance and compliance group was more or less the same. The total level of employment was 25.4%; two (5,9%) in the non-compliance group and fifteen (45,5%) in the compliance group. Nine percent has had no education in their lives. Fifty-two percent of the respondents were single and the average household size for both groups was nine, with a range from five up to 15 (table 2). All the respondents lived in the informal urban region; the township of Grahamstown. For more detailed information see appendix 1 and 2.

**Table 2 Demographic and social economic factors**

		Compliance group (n=33)	non-compliance group (n=34)
<b>Gender</b>	Male	16	16
	Female	17	18
<b>Age</b>	20-25	2	3
	25-30	7	5
	30-35	9	11
	35-40	7	5
	40-45	5	8
	45-50	3	2
<b>Employment status</b>	Employed	15	2
	Unemployed	18	32
<b>Household size</b>	5-7	7	4
	7-9	8	9
	9-11	8	12
	11-13	4	6
	13-15	5	2
	15-17	1	1
<b>Marital status</b>	Single	18	18
	Married	15	16
<b>Education</b>	Yes	31	30
	No	2	4



#### **4.1.2 Predisposing factors**

The results from the Focus Groups and the in-dept interviews show that the respondents know the TB symptoms. They mention a lot of coughing, lost of appetite, coughing up blood and weight loss. They also are aware of the fact that TB is curable and that the people who don't get cured are only the ones that defaulted from treatment. The respondents believe that everybody has TB, but that only when the immune system is failing a person develops TB. As causes of TB, the patients in this research mention; not wearing warm clothes, catching a lot of cold, standing to long in the rain, eating unhealthy food, alcohol abuse, smoking and staying in damp places where there is a lot of dirty water. Some of the respondents mention bacilli and germs as the cause of TB and the fact that you can catch it if another person with TB coughs in your face or spits on the ground. Some of the respondents believe that sharing food and drinks with the same dishes spreads TB. To prevent this from happening some of them wash their dishes with bleach. They are aware that people who do not take their medicine are contagious and spread TB quickly, so most of them advise and stimulate each other to take the prescribed pills.

Most of the patients said that you could only cure from TB with the medicine provided by the clinics, only a few older patients still believed that both the medicine from the clinics as well as a traditional healer could cure TB. In the old days TB was considers a Xhosa sickness. When somebody coughed up blood, people believed this person was kicked by an *impundulu*, which is a bird with an evil spirit. People in that time associated coughing up blood with witchcraft, nowadays people are aware of the fact that TB causes these symptoms. They knew this because in the last few years there has been much information on this topic on television, radio, on billboards in the township, schools, in papers and at the clinics. The respondents say that in the old days, people had no knowledge of TB. However, many of the respondents believe that when diagnosed with TB, short after you will also have HIV/AIDS. Many of them think TB develops into HIV/AIDS.

#### **4.2 Q-method results**

PQMethod (Scmolck, 2002), a dedicated Q-package was used for analysis. The centroid method using judgemental rotation was used to derive the factors. The results were validated by examining statistically derived solutions using varimax rotation.

Results from the group of TB patients in the Eastern Cape who complied with therapy and the group who defaulted from treatment will be presented.

##### **4.2.1 Compliance group**

After examining a range of factor solutions and rotations, a one-factor solution emerged and factor loadings are shown in Table 3.

**Table 3 Factor loadings matrix (compliance group)**

Sorts	Factor 1	Sorts	Factor 1
1	0.7093	18	0.6687
2	0.6502	19	0.7310
3	0.4096	20	0.6263
4	0.6392	21	0.7223
5	0.7595	22	0.6514
6	0.6416	23	0.8011
7	0.7905	24	0.8061
8	0.7402	25	0.7694
9	0.7762	26	0.8166
10	0.7409	27	0.8098
11	0.7787	28	0.8116
12	0.7272	29	0.6717
13	0.8410	30	0.6220
14	0.7334	31	0.7007
15	0.7328	32	0.7830
16	0.8466	33	0.7433
17	0.6600		

With 32 statements and  $p < 0,001$ , the correlation coefficient between a respondent's Q-sort and a factor must be equal to or higher than .58 for the respondent to be a defining variable for that factor. Factor analysis revealed one distinct perspective on the determinants of compliance in eyes of TB patients who comply with treatment in the Eastern Cape. Of the 33 Q-sorts, there was one "null" case (Q-sort 3); a Q-sort that does not load significantly on the factor found.

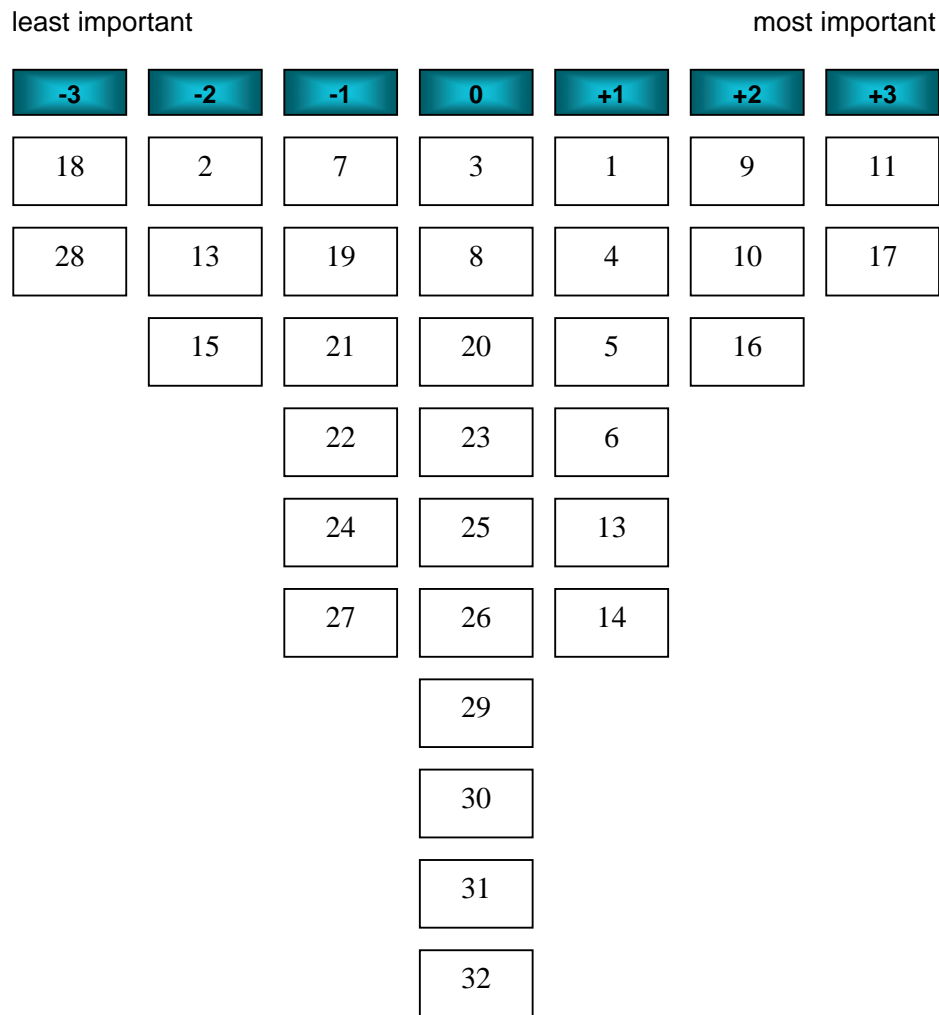
A statement's factor score is the normalised weighted average statement score (Z-score) of respondents that define that factor. The perspective of the compliers on the most important determinants of compliance with TB treatment provides a clear picture. They share the view that statements 11, 17, 10, 9, 16 and 14, respectively are the most important determinants of compliance to TB treatment in the Eastern Cape. The Z-scores (Table 4) for these statements are high and there is a clear gap between statements 14 and 12. The respondents were less unified regarding the least important determinants of compliance. Their perspective on the least important determinants based on the Z-scores is less clear-cut.

**Table 4 Normalized factor scores (compliance group)**

<b>Statement</b>	<b>Z-score</b>
(11) The main thing is to improve my life situation, so I take my treatment ( <i>motivation</i> )	1.877
(17) My expectations of life after TB treatment ( <i>cost-benefit analysis</i> )	1.799
(10) I take my treatment because I really want to get healthy again. ( <i>health motivation</i> )	1.734
(9) The support of a government disability grant which is paid for six months	1.727
(16) Trust that I can take the drugs for the whole six months ( <i>self efficacy</i> )	1.531
(14) I think this treatment will really help me so I'm prepared to take the medicine ( <i>perceived benefits</i> )	1.328
(12) The chance that TB makes me sick ( <i>perceived susceptibility</i> )	0.809
(4) My family's opinion of TB	0.767
(5) Media attention for the consequences of TB	0.674
(1) Community health worker's support and interest in me	0.597
(6) Receiving TB drugs free of charge	0.579
(30) Difficulties in keeping routine in taking the drugs	0.177
(3) Other people's opinion of TB treatment	0.011
(29) Treatment by the staff	-0.009
(23) Travel time to the TB clinic	-0.217
(31) Presence of supportive person, who establishes routine in taking pills	-0.282
(26) waiting time in clinics	-0.456
(8) The support and help from support groups	-0.540
(32) Difficulties in keeping routine in taking the drugs	-0.572
(20) The number of pills that I have to take	-0.599
(25) Abstinence from smoking and drinking	-0.651
(19) Fear of telling others that I have TB	-0.688
(22) having to leave home	-0.703
(27) Money to buy fare for transport to the TB clinic	-0.711
(24) The rules and restriction that come along with the therapy	-0.779
(7) Delivery of TB drugs at my doorstep	-0.910
(21) The treatment of an other disease (e.g. HIV/AIDS) is more important	-0.991
(13) The chance of dying of TB ( <i>perceived severity</i> )	-1.006
(15) Having to think about TB and the drugs all the time is burdensome ( <i>perceived costs</i> )	-1.012
(2) Home visits by the community health worker	-1.065
(18) The public association of TB with HIV/AIDS	-1.152
(28) Loss of daily wages	-1.264

Based on their Z-scores, statements are attributed to the original quasi-normal distribution, resulting in a composite (or idealised) Q-sort. The composite Q-sort (figure 4) of a factor represents how a hypothetical respondent with a 100% loading on this factor would have ordered all the statements of the Q-set.

**Figure 4 composite Q-sort of the compliance group**



Looking at the more salient statements (placed in the  $\pm 3$  and  $\pm 2$  positions); motivation (statements 10 and 11) and the future (statement 17) are very important concepts in the factor found. This is reflected in respondents' words: *"I don't like feeling sick. The pills from the clinic make me healthy, so I take them"*; *"TB made me really sick. After I took the pills, I felt better again. When I take my pills for a few months, I am cured from TB. That is why I am going to finish my treatment"*; *"I don't want to spread the disease to my family. If I take my medicine I will be cured from TB and will no longer be contagious, which is why I take my medicine"*. Health is considered an important factor of life and a way to improve and secure future prospects and life situation: *"I want to get a job soon; therefore I need to be healthy"*. Issues of self-efficacy are also important in this account, evident in statement 16. Respondents from this group are confident in fulfilling their treatment. Most of them never missed a day of treatment. They go to the clinic daily without somebody reminding them, they are very independent and capable to motivate and stimulate themselves to comply with

their TB treatment: *“my boss does not like his employees to be sick, so I go to the clinic every day to collect my pills”*; *“I do not want to stay sick for too long, because I don’t want to loose my job. Last year somebody got fired because of TB that is why I go to the clinic every day to collect my pills”*. The support of a government disability grant, which is paid for six months (9), is a clear account, especially for the unemployed compliers: *“now that I have my own money I can buy food again. Because of the money, my neighbours and my family respect me”*; *“the grant made me feel less troubled. I could totally focus on getting health again.”*

Statements 18 and 28 are identified as least important determinants of compliance followed by 2, 13 and 15. The level of unemployment in the compliance group is 55%. Statement 28 is therefore not applicable for them. Statements 18 and 15 stand in the way of compliance. They determine non-compliance more and are therefore considered least important regarding compliance with TB treatment. Home visits by the community health worker almost never happened in the compliance group. Respondents placed this statement on the far left side of the score sheet not because they think of it as least important, but because it did not apply to them. Most respondents believe that compliance with TB treatment will cure TB and chances of dying are minimized. Therefore, statement 13 is considered least important.

#### 4.2.2 Non-compliance group

After examining factor solutions and rotations, a one-factor solution emerged (table 5).

**Table 5 Factor loadings matrix (non-compliance group)**

Sorts	Factor 1	Sorts	Factor 1	Sorts	Factor 1
1	0.7152	13	0.6755	25	0.8381
2	0.8043	14	0.6913	26	0.7808
3	0.7785	15	0.7774	27	0.7660
4	0.8680	16	0.7414	28	0.8003
5	0.8272	17	0.6324	29	0.7408
6	0.8123	18	0.6999	30	0.6987
7	0.7460	19	0.7112	31	0.7905
8	0.7757	20	0.7900	32	0.8198
9	0.8329	21	0.6500	33	0.8026
10	0.8715	22	0.5800	34	0.7540
11	0.6868	23	0.7825		
12	0.8060	24	0.7962		

With 32 statements and  $p < 0,001$ , the correlation coefficient between a respondent’s Q-sort and a factor must be equal to or higher than .58 for the respondent to be a defining variable for that factor. Factor analysis revealed one distinct perspective on the determinants of

compliance in eyes of TB patients who comply with treatment in the Eastern Cape, the 34 Q-sorts all load significantly to the factor.

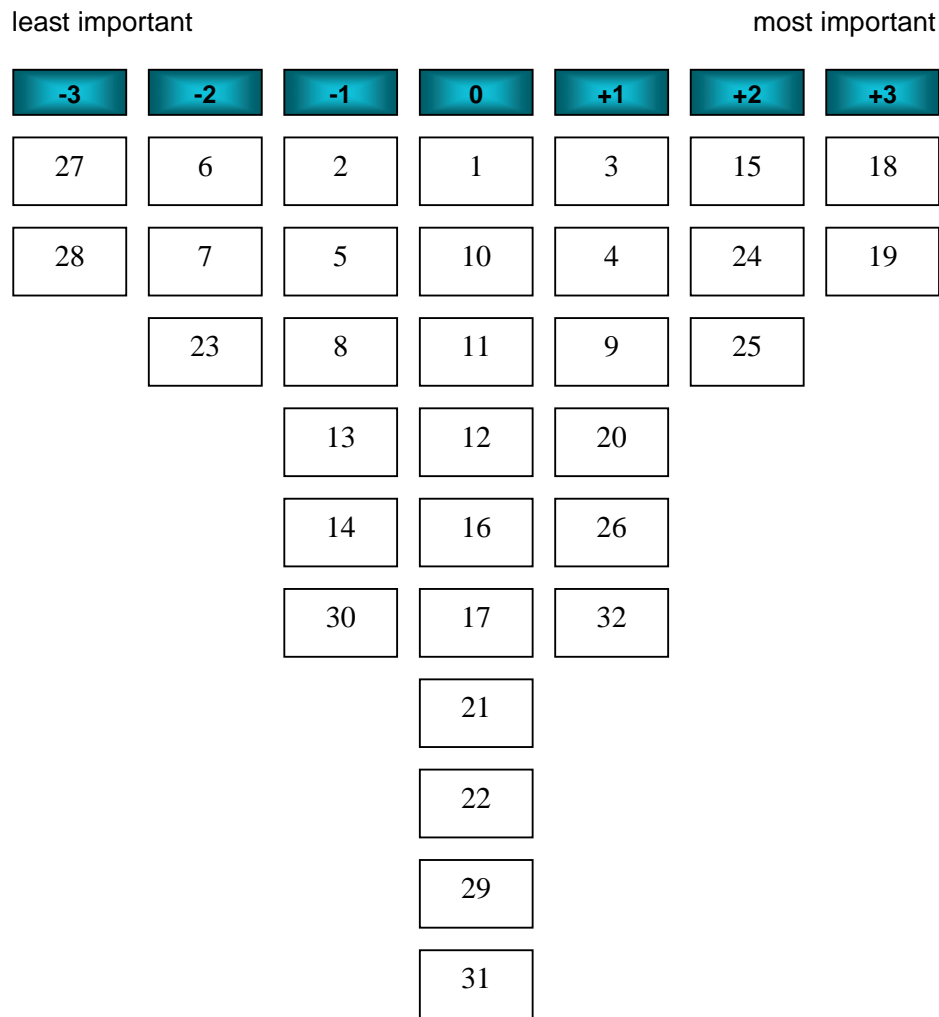
A statement's factor score is the normalised weighted average statement score (Z-score) of respondents that define that factor. The perspective of the defaulters on the most important determinants of non-compliance with TB treatment provides a clear picture. Respectively, statements 18, 19, 15, 25, 24, 4, 20 and 3 are identified as most important determinants of non-compliance to TB treatment in the Eastern Cape among the non-compliers. The Z-scores (Table 6) for these statements are high and there is a gap between statements 3 and 32. The respondents are less clear on the least important determinants on non-compliance. There is no clear gap in the Z-scores. Again, there seemed to be a less clear-cut opinion on the least important determinants.

**Table 6 Normalized factor scores (non-compliance group)**

Statement	Z-score
(18) The public association of TB with HIV/AIDS	1.782
(19) Fear of telling others that I have TB	1.512
(15) Having to think about TB and the drugs all the time is burdensome ( <i>perceived costs</i> )	1.460
(25) Abstinence from smoking and drinking	1.442
(24) The rules and restriction that come along with the therapy	1.401
(4) My family's opinion of TB	1.375
(20) The number of pills that I have to take	1.311
(3) Other people's opinion of TB treatment	1.195
(32) Difficulties in keeping routine in taking the drugs	0.859
(26) waiting time in clinics	0.468
(9) The support of a government disability grant which is paid for six months	0.415
(22) having to leave home	0.135
(11) The main thing is to improve my life situation, so I take my treatment ( <i>motivation</i> )	0.022
(10) I take my treatment because I really want to get healthy again. ( <i>health motivation</i> )	-0.075
(12) The chance that TB makes me sick ( <i>perceived susceptibility</i> )	-0.136
(17) My expectations of life after TB treatment ( <i>cost-benefit analysis</i> )	-0.186
(29) Treatment by the staff	-0.337
(21) The treatment of an other disease (e.g. HIV/AIDS) is more important	-0.351
(1) Community health worker's support and interest in me	-0.523
(16) Trust that I can take the drugs for the whole six months ( <i>self efficacy</i> )	-0.578
(31) Presence of supportive person, who establishes routine in taking pills	-0.595
(13) The chance of dying of TB ( <i>perceived severity</i> )	-0.600
(2) Home visits by the community health worker	-0.605
(5) Media attention for the consequences of TB	-0.676
(14) I think this treatment will really help me so I'm prepared to take the medicine ( <i>perceived benefits</i> )	-0.749
(8) The support and help from support groups	-0.790
(30) Difficulties in keeping routine in taking the drugs	-0.824
(23) Travel time to the TB clinic	-0.852
(7) Delivery of TB drugs at my doorstep	-1.018
(6) Receiving TB drugs free of charge	-1.030
(27) Money to buy fare for transport to the TB clinic	-1.516
(28) Loss of daily wages	-1.937

Based on their Z-scores, statements are attributed to the original quasi-normal distribution, resulting in a composite (or idealised) Q-sort (figure 5).

**Figure 5 composite Q-sort of the non-compliance group**



Looking at the statements placed at both extreme ends of the continuum on the score sheet (placed in the  $\pm 3$  and  $\pm 2$  positions); “the public association of TB with HIV/AIDS” (18) and “fear of telling others that I have TB” (19) are considered as most important determinants of non-compliance by the defaulters. Stigma is an important concept in this factor: “*people saw me at the clinic and thought I had HIV, so I stopped going*”; “*after I told my family I had TB, they didn’t want to see me anymore. I explained to them that treatment would cure me from TB, but they were afraid that I soon would also have HIV, so it does not matter to them even if I am cured from TB*”. The costs and barriers of TB treatment also have great impact on non-compliance to TB treatment, evident by statements 15, 24 and 25. This is reflected in the respondents’ words: “*after weeks of following the rules I wanted to have fun again, so I stopped the treatment*”; “*it was difficult for me to remember the rules of the treatment. I often forgot to go to the clinic for my medicine*”. The TB patients who stayed at Temba Hospital also mentioned being bored had a negative impact on compliance. They wished that there

were more activities in the hospital for them to attend to: *“if only I had something to do, to keep my mind of things”*; *“my hospital stay felt like being in prison, I wanted to go out and enjoy life again”*; *“after weeks of just sitting around and doing nothing all day made me want to leave the hospital.”*

Statements 27 and 28 are identified as least important determinants of compliance followed by 6, 7 and 23. Only two respondents in the non-compliance group are employed, which is why statement 28 mostly did not apply. There are six clinics in the township of Grahamstown; so travel time to the clinic (23) is short and therefore not considered a problem. Because travel time is short, people can walk to the clinics and do not have to pay for transportation (27). When respondents elaborated on putting statement 6 on the extreme left, it became clear that they took getting the drugs free of charge for granted. They said that if they did have to pay for the medicine it would complicate compliance for sure. Statements 7 and 8 are placed on the far left side of the score sheet not because they think of it as least important, but because it did not apply to them.

### **4.3 Results from the semi-structured in-dept interviews**

Community health workers, compliers and defaulters were interviewed to uncover opinions on the determinants of (non-)compliance. The community health workers were also asked the level of default at the clinic where they work. First, these results are presented.

#### **4.3.1 Reported level of default**

TB is a major public health problem in South Africa, made worse by poor adherence to and frequent interruption of treatment. The exact level of default is unknown. The level of default mentioned by community health workers from the different clinics and the hospital varies within a range from 0-35%. The town clinic mentions a default level of 0%. They only have employed TB patients and according to the community health workers working there; their employment status is the reason that these patients are motivated enough to fulfill the required six months treatment. Only sometimes, their patients miss a day, but even that almost never happens. The Temba Hospital reports the highest level of default. Their patients are all unemployed and according to the community health workers besides TB, they all have HIV/AIDS. In the rest of the clinics, the level of default is about 25-30%. The exact amount is not registered and therefore not known, this number is only an estimation made by the people working their. The given percentage from the different community health workers within the same clinic also varies.



### 4.3.2 Determinants of non-compliance

Community health workers and compliers were asked to give their perspective on non-compliance with TB treatment. After reading the Q-set, they had to mention the five most important determinants for non-compliance (table 7).

**Table 7 determinants of non-compliance**

Statement	Community health workers (n = 14)	Compliers (n = 33)	Total
(25) Abstinence from smoking and drinking	13	28	41
(24) The rules and restrictions that come along with the therapy	13	21	33
(11) The main thing is to improve my life situation, so I take my treatment (motivation)	8	24	32
(10) I take my treatment because I really want to get healthy again (health motivation)	5	25	30
(15) Having to think about TB is burdensome	9	20	29
(18) The public association of TB with HIV/AIDS	12	16	28
(19) The fear of telling other about TB	7	19	26
(9) The support of a government disability grant	4	17	21

The respondents from the compliance group describe alcohol (25) as main determinant of non-compliance: *“they just don’t want to deal with their problems; they rather drink their troubles away”; “because of their drinking habits they often miss treatment”*. The community health workers also mention a link between alcohol and non-compliance: *“when people are in the fourth or fifth month of treatment, they feel a lot healthier again and some start their drinking habits. Soon after that, they get sick and have to start treatment afresh”*. Only the community health workers from the town clinic did not. The fact that people are not allowed to drink and/or smoke, are not able to eat what they want and the factor of having to take a handful of pills every day makes them feel troubled as if they have to put their lives on hold (24). People often stop with their treatment because they want to enjoy their life again instead of complying with the treatment and following the rules and restrictions: *“people often have problems following the rules, they especially don’t want to give up their drinking habits”; “some complain about not being able to eat and drink whatever they want, they rather stay sick and have the freedom to do whatever they want”*. Motivation (10) is described as an important determinant for non-compliance: *“they are just not motivated enough to get healthy, they don’t think it is worth to change their lifestyle for and they especially do not want*

*to give up drinking alcohol*'. The compliers mention a strong association between *health motivation* (10) and non-compliance: *"they just don't care about their health"*. Burdensome (15) is identified as an important factor. This is reflected in community health workers' words: *"the defaulter just don't want to deal with the disease and rather be sick and walk away from the problems, because of the burdens and the rules and restrictions that come with the treatment"*. Beside the rules, restriction and burden of the treatment, the community health workers believe that the public association of TB with HIV/AIDS (18) is also an important determinant of default: *"people do not know the difference between these two diseases and associate the one with the other"*. This is contributed to the fact that a person with AIDS most of the time gets TB infected. There also seems to be a fear of telling others your TB status (19). According to the people interviewed, a TB patient automatically drops in status; *"there is less respect for people with TB in the community, people think that a person with TB also has or soon will have HIV/AIDS"*; *"my husband stopped going to the clinic because his friends saw him and started to ask him questions about it. He was afraid they would reject him, so he decided not to go anymore"*. The disability grant (9), which is paid for as long as a person has TB and is on treatment, seems to negatively influence compliance. In order to collect the grant, a person must be TB diagnosed and has to take the prescribed medicine; otherwise, a doctor can stop the grant. The compliers and some of the community health workers at Temba Hospital mention this as an important determinant of non-compliance with TB treatment because it extends the time that they receive the grant: *"there are people who take their medicine from the clinics, but who in reality do not take their pills. They hide the pills in their mouth and spit them out as soon as there are outside the clinic"*.

#### **4.3.3 Determinants of compliance**

Community health workers and defaulters were asked their opinion on compliance with TB treatment. After reading the Q-set, they had to mention the five most important determinants for compliance (table 8).

**Table 8 determinants of compliance**

Statement	Community health workers (n = 14)	Defaulters (n = 34)	Total
(16) Trust that I can take the drugs for the whole six months	14	31	45
(10) I take my treatment because I really want to get healthy again (health motivation)	12	29	41
(11) The main thing is to improve my life situation, so I take my treatment (motivation)	7	28	35
(17) My expectations of life after TB treatment (cost-benefit analysis)	11	21	32
(31) Presence of an important person who establishes routine in taking pills	-	31	31
(14) I think this treatment will help me, so I'm prepared to take my medicine	7	17	24
(30) The communication with the community health worker	13	8	21
(5) Media attention	6	-	6

Strong association is identified between self-efficacy (16) and compliance. Association expressed in respondents' words: *"the people who finish their treatment are very confident. They are strong and have more trust in their own ability to finish treatment"*. Besides being strong and believing in their own abilities, the people who comply with therapy for the whole six months are the patients that are motivated to get healthy again (10): *"the compliers consider health very important and therefore they are able to fulfil the treatment"*. The community health workers say that the compliers are especially motivated to take their medicine and get healthy (11) so that they cannot spread the disease to their family: *"they know that if they default from treatment, they will become contagious again and will spread the TB more easily to the people they love"*. An association is described between statement 17 and compliance with TB treatment: *"the compliers look at the future and see a reason to fight for. This has a positive effect on their ability to comply with TB treatment"*; *"the people with a job have a reason to fight for. I will never have a job because I did not go to school and can only speak Xhosa. For me nothing will really ever change, so I choose to enjoy my life instead of going to the hospital again"*. Defaulters identify a link between having no prospects in life and non-compliance. The group of non-compliers also say that a supportive person who reminds them on taking the pills on a regular basis helped them (31): *"I often forgot going to the clinic to collect my pills. In the beginning my wife then reminded me, which helped. After a few months however, she got mad at me and said she was tired of thinking about it all the time and that I had to do it myself. Maybe I would have finished my treatment if she helped me the entire time of the treatment."* The compliers have more faith in the medicine from the clinics than from a traditional healer (14): *"the medicine from the clinics*

*can only cure TB; medicine from the traditional healer cannot, they are only for Xhosa diseases*". Most of the community health workers identify the communication between patient and community health worker (30) as a decisive determinant of compliance, which none of the defaulters did. The community health workers also mention that the disease knowledge of the people in the township had improved greatly the last few years. People receive information about TB in schools, on billboard in the township, at the clinics, on the TV, in the papers and radio. Nowadays it is common knowledge that there is a cure for TB: *"people are more aware of the TB symptoms and believe that the medicine from the clinics will cure them and the medicine from the traditional healers will not"*.

## 5 Discussion

The level of default mentioned by community health workers from the different clinics and the hospital varies within a range from 0-35%. The aim of the WHO for preventable unfavorable treatment outcomes (default and transfer out combined) is a level of less than 10% in all high burden countries and regions like the Eastern Cape (WHO, 2006).

This Q-methodological study revealed one distinct perspective among the compliers and one among the defaulters. The (dis-)association from the Q-method results with the conceptual model, the literature (chapter 2) and the results from the semi-structured in-dept interviews will now be discussed.

From the *demographic factors* and *social economic factors*, a strong negative association is found between the factor of unemployment and compliance. During the in-dept interviews in search of the underlying processes as mentioned in Simon's theory of bounded rationality (1959) regarding the motivation differences, the reason of motivation problems described by the defaulters is linked to unemployment. During the interviews people said that unemployment leads to feelings of useless and failure, caused by the inability to provide food and other necessities for oneself and/or their children and failure to be a respectful member of the community. The literature supports these findings; patient's economic situation, financial difficulties and income level have great effect on compliance behaviour (Johansson et al., 1999, Barnhoorn & Adriaanse, 1992). The employment percentage in the compliance group is 45%. Only two of the respondents in the non-compliance group have a job. The unemployed people have almost zero chance in ever getting a job in their lives. Beside the problem of unemployment and the fact that there are no real prospects, living in a township, having to deal with TB and/or other diseases, death and stigmatization; a lot of people drink in order to forget their troubles. Looking at the theory of bounded rationality, the problems these people have to face are much bigger than their cognitive capabilities. Limited understanding of their problems and not knowing how and/or being able to deal with these problems; is linked to non-compliance with TB treatment.

In search of the community health worker's opinion on compliance, statement 5 "media attention for the consequences of TB" is mentioned as a *reinforcing factor* for compliance with TB treatment. The community health workers believe that since the rise of information given in the township, the people are better informed. People now know the signs, symptoms and causes of TB and immediately go to the clinics instead of waiting for too long. Nowadays most people immediately go to the clinic instead of turning to a traditional healer first, which has a positive influence on case finding. It common knowledge now that only the medicines from the clinic can cure people from TB and medicines from the traditional healers cannot.

These are important winnings, in which improved media attention played an important role according to the community health workers.

The results of the structured interviews regarding the *predisposing factors* show that the respondents know the TB symptoms. These findings are compliant with the results from the Focus Groups and the interviews held with the community health workers. TB patients mention that they can only cure from TB when they fulfil TB treatment with the medicines provided at the clinics. These results disassociate with the findings in chapter 2. The respondents in this study do not describe TB as a dangerous disease that only affects the poor people. Respondents in this research are aware that TB is spread through germs and not because of unhygienic behaviour or dirty people eating bad food. They also describe that people who do not take their medicine are contagious and spread TB quickly. Most of them advise and stimulate each other to take the prescribed pills and consider TB as a curable disease.

From the *enabling factors*, only statement 9 “the support of a government disability grant, which is paid for six months” is described as an important determinant of compliance. However, it seems to be a perverse incentive; it determines non-compliance as well as compliance. The compliers and community health workers say that there are people that abuse the grant and deliberately do not take the pills they collect at the clinics. This will prolong the time that they receive the disability grant. In order to receive the grant a person must be diagnosed with TB and has to take the prescribed medicine. This last demand however is impossible to check. During the interviews, the compliers told that they know people who hide the pills under their tongue and later through them away. The compliers described the disability grant as an important determinant of compliance. They say that it helps them in their independence to buy food and other necessities and that they feel less rejected by the community. This has a positive effect on their confidence, motivation, self-efficacy and compliance behaviour. They describe having regained respect from family and friends because of the grant.

Q-method results from the compliance group and the results from the semi-structured in-depth interviews held with community health workers and defaulters, show that the *health beliefs* (10, 11, 14, 16 and 17) are identified as most important determinants of compliance. Having good coping skills, intrinsic motivation, looking at the long-term benefits and concentrate on expectations of life after TB treatment, are positively linked to adherence with TB treatment.

Looking at the results from the Q-analysis in search of most important determinants of non-compliance and the conceptual model used in this research; *barriers* are strongly linked to non-compliance. Statements “the public association of TB with HIV/AIDS” (18) and “fear of telling others that I have TB” (19) are considered as most important determinants of non-compliance. Followed by “having to think about TB and the drugs all the time is burdensome” (15) and the *barriers* 24 (the rules and restriction that come along with the therapy) and 25 (abstinence from smoking and drinking). The results from the semi-structured in-dept interviews to uncover opinions on the determinants of non-compliance, supports these findings.

Stigma appears to have a serious effect on the incidence, experience and management of diseases and it is considered a significant cause of default from treatment (Bond, Chase & Aggleton, 2002; Chandra, Deepthivarma & Manjula, 2003; Muyinda, Seeley, Pickering & Barton, 1997). The stigma around TB causes rejection of TB patients by the community. People look at the non-compliers as people who just do not want to deal with the disease and do not want to change their lifestyle, especially their drinking habits. According to the compliers and the community health workers, the defaulters care less about their health and many blame them for being infected with TB, default from treatment, unemployment and putting society at risk of infection of TB. People with and/or cured from TB are considered to be weak and are less respected. Beside the fact that people with TB or cured from TB are less respected, whom the community tends to reject, there is also the burden of fear and stigma around HIV/AIDS. The fact that the community believes that TB can turn into HIV (18) and that people have problems distinguishing them, causes double stigmatized TB patients. People with TB have to live with the stigma and fear for TB and the stigma and fear for HIV. The fact that people believe TB develops into HIV, results in blaming TB patients not just for putting society at risk of infection with TB, but also with HIV/AIDS.

Rejection and finger pointing by the community reduces senses of pride, dignity and respect, which in turn causes feelings of depression. Depressive feelings together with stigmatisation often results in avoidance coping mechanisms (Deacon et al., 2005). Therefore, unemployment together with stigmatization is associated with increased non-compliance with TB treatment. Stigma however does not only affect the unemployed population. In this research, only two employed patients defaulted from treatment. As five most important reasons for non-compliance with TB treatment, they both mention statements “other’s people opinion of TB treatment” (3), “my family’s opinion of TB treatment” (4), “having to think about TB all the time is burdensome” (15), “the public association of TB with HIV/AIDS” (18) and “fear of telling others that I have TB” (19). This shows the importance and impact of stigma even among the employed population. In these interviews, they both said that their family, neighbours and friends rejected them and looked down upon them. The employed TB

patients are motivated and want to take their treatment to get healthy again. However, the negative attitudes from their family, neighbours, colleagues and friends towards TB and TB patients; makes them want to hide their disease. Out of fear that others find out their health status they choose to default from treatment.

Beside the *barriers* from the conceptual model, the defaulters and compliers who stayed at the hospital mention that boredom has a negative impact on compliance. They express their wish for more activities in the hospital for them to which they can attend. They think it would help them to keep their mind of the problems. The defaulters said that the main reason for their escape from the hospital was that they got nothing to do for months. They mention that activities would have a positive impact on their compliance behaviour.

The defaulters describe a positive association between the *supports* and compliance. They often need another person to support and motivate them in taking the prescribed medicine. They mostly see the burdens, rules and restrictions that come with TB treatment. Decisive determinants of non-compliance are the *barriers* and the *health belief* “perceived costs” of the TB treatment. At times when they did comply with TB treatment, they say that other people provided the support and helped them to focus on the benefits of the treatment. As soon as this support became less, the “cost-benefit analysis” resulted in favour of default.

The people in the compliance group are able to motivate, stimulate and support themselves. They depend less on the *supporting factors* and are capable to fulfil the treatment under self-supervision. In this research intrinsic motivation and the coping skills are stronger determinants of compliance than using an extrinsic motivator like with direct observation. Direct observation of TB patients taking their drugs is supposed to improve treatment outcome, compliance with, and completion of treatment. Zwarenstein, Schoeman, Vundule, Lombard & Tatley (1998) found during their research that treatment for TB was more successful among self-supervised patients. Retreatment patients had significantly more successful treatment outcomes if self supervised than on direct observation.

In this research, the patients from the town clinic are self-supervised and the adherence level is 100%. The patients and community health workers there say that direct observation is more a determinant of non-compliance. When a community health worker comes to the homes of the patients, the neighbours will notice them. The stigma around TB and the association of TB with HIV/AIDS make people feel ashamed and embarrassed for their disease and they do not want their neighbours finding out. They prefer to non-disclose their TB status, which promotes defaulting from treatment.

The people in the non-compliance group mention the *support* statement: 31 “presence of an important person who establishes routine in taking pills”, as an important determinant of



compliance with treatment. They also say that this only works for the first period of the treatment and that the supportive person after a while gets tired and bored with the supporting role. None of the community health workers mentions this statement as a determinant of compliance. They mention statement 16 “trust that I can take the drugs for the whole six months (self efficacy)” as a decisive factor for compliance with treatment, which in turn none of the non-compliers did.

## 6 Reflection on the used conceptual model and methods

The five most important determinants of compliance found in the literature are also found in this research, in which the conceptual model was used. A strong association is found between the *health beliefs* (10, 11, 14, 16 and 17) and compliance with TB treatment. Looking at the results in search of most important determinants of non-compliance and the conceptual model used in this research; *barriers* are strongly linked to non-compliance. Statements “the public association of TB with HIV/AIDS” (18) and “fear of telling others that I have TB” (19) are considered as most important determinants of non-compliance. Followed by “having to think about TB and the drugs all the time is burdensome” (15) and the *barriers* 24 (the rules and restriction that come along with the therapy) and 25 (abstinence from smoking and drinking). There is a difference found in the *predisposing factors*. TB knowledge on the symptoms and treatment of TB among the respondents has improved. However, many think TB will ultimately develop into HIV/AIDS. Since the integration of TB into the primary health care, there is an improvement in access of care. The *barriers* “travel time to the TB clinic” (23) and “money to buy fare for transport to the TB clinic” (27) are less of a problem in Grahamstown. There are six TB clinics and there is a hospital in the township.

Behaviour change approaches such as the HBM are limited to the individual cognitive health behaviour. This relative simple, linear relationship between individual knowledge and action does not take into account the variation among the political, socio-economic, and cultural contexts that prevail in the Eastern Cape. In search of the underlying processes, the higher level of unemployment is identified to link with motivation problems and therefore non-compliance to TB treatment. The expectations of life after TB for employed people are better than the situation they are in now. This is likely the reason why the people in the compliance group have a long-term view instead of just looking at the burdens. The prospects for the people in the non-compliance group are not likely to improve, which is associated with compliance problems. In developing countries, compliance with antituberculosis chemotherapy treatment poses specific problems because of the epidemiological and socio-economic context in which it occurs (Ashry, Ahmed, Aida, Zahira & Sallem, 1997). This research assumed a complex net of determinants of compliance and that behaviour is person specific. Compliance with TB treatment often is not the only problem people have to deal with. During the interviews, some respondents mentioned having to deal with several problems. Sometimes other problems become more important and have to be dealt with first.

The conceptual model used in this research made it possible to uncover the patient's perspective on the determinants of compliance and non-compliance with treatment among TB patients in the Eastern Cape. The conceptual model not alone uncovers the

determinants, but also looks at their interactions. By focusing on the attitudes and beliefs of individuals, a better insight and understanding of compliance behaviour among TB patients in the Eastern Cape is obtained. The conceptual model helps to understand, explain and predict the different factors that influence health behaviour and is considered a useful tool in search of the determinants of (non-)compliance.

One of the great side effects of conducting the Q-method is that respondents spontaneously indicated to have enjoyed participating in the study, even though the interviews sometimes lasted over 2 hours. Patients who stayed at the hospital especially expressed enjoying their participation. They said they were looking forward to my coming there. Respondents described having fun reading the cards and sorting them in the provided score sheet. Q-sorting perhaps requires greater involvement than standard survey analysis, but apparently does so in a very pleasant and comprehensible manner. Beside the fact that respondents seem to enjoy participation, they also mention that they are more aware of their own thoughts and behaviour after the interview. For these reasons, the Q-methodology is considered a useful research method to examine peoples' attitudes, beliefs and perspectives on compliance behaviour among TB patients in the Eastern Cape.

## **7 Conclusion and recommendations**

In order for TB treatment to be effective, it is important to access the factors that influence compliance with treatment. The research question during this study is:

*What is the patient's perspective on the determinants of compliance and non-compliance with treatment among TB patients in the Eastern Cape?* To answer this question several research problems are addressed and methodological triangulation is used. Validity is established by the fact that the results from the semi-structured in-dept interviews to uncover opinions on the determinants of (non-)compliance, supports the findings of the Q-methodological study.

Research problem 1: what information about the level of defaulting among TB patients in the Eastern Cape is available? The community health workers describe a default level between 25 and 35%. Only the town clinic has a different reported default level. The community health workers there say that the default level is 0%. The exact level of default is unknown, more research is necessary to get a better indication of the level of default. What is clear however is that the level of default at the clinics in the township of Grahamstown is much higher than 10%, which is the aim set by the WHO for the Eastern Cape.

Research problem 2: what determinants of compliance with TB treatment are found in the literature? After reviewing the literature, "the relationship between the patient and community health workers", "economic situation", "social isolation and stigmatization", "social support" and "knowledge" are mentioned by researchers as the most important determinants of compliance to TB treatment. For examining compliance behaviour, the determinants of compliance and their interactions are conceptualized and depicted in a TB Compliance model. After reviewing the literature and the transcripts from the Focus Groups held in Grahamstown this model is modified to the local context, leading to the conceptual model used in this research. Results from the Focus Groups show a positive link between "other people's opinion of TB treatment" and compliance. Respondents also mention that "media" has improved TB knowledge in the Eastern Cape, which has a positive effect on compliance with TB treatment. Patients mention experiencing difficulties with the "number of pills they have to take", which has a negative impact on compliance behaviour. A negative association is also described between compliance and "abstinence from smoking and drinking", "waiting time in clinics" and "following the rules and restriction that come along with the therapy".

Research problem 3: which of the determinants found in the literature causes compliance among TB patients in the Eastern Cape and which influences compliance the most? The conceptual model (p. 19) contains the determinants of (non-)compliance found in the

literature and Focus Groups. Compliers identify statements “I take my treatment because I really want to get healthy again” (10), “the main thing is to improve my life situation so I take my treatment (11), my expectations of life after TB treatment (17) “trust that I can take the drugs for the whole six months” (16) and “the support of a government disability grant, which is paid for six months” (9) as most important determinants of compliance. The results from the semi-structured in-dept interviews support these findings.

Research problem 4: which of these determinants causes non-compliance and which influences non-compliance the most? The conceptual model (p. 19) contains the determinants of (non-)compliance found in the literature and Focus Groups. Q-method results show high association between non-compliance and statements “the public association of TB with HIV/AIDS” (18), “fear of telling others that I have TB” (19), “having to think about TB and the drugs all the time is burdensome” (15), “the rules and restriction that come along with the therapy” (24) and “abstinence from smoking and drinking” (25). Stigma is an important concept in this factor. The costs and barriers of TB treatment also have great impact on non-compliance to TB treatment. Results from the semi-structured in-dept interviews support these findings.

The defaulters and compliers from the hospital mention that boredom promotes non-compliance. They express their wish for more activities in the hospital for them to which they can attend. The defaulters said that the main reason for their escape from the hospital was that they got nothing to do for months. They mention that activities at the hospital would have a positive impact on their compliance behaviour.

Research problem 5: what needs to change in order to improve compliance among TB patients in the Eastern Cape? After reviewing the literature it came to light that in many developing countries people believe, TB is an incurable and dangerous disease, which affects the poor people. TB was associated with unhygienic habits and TB patients were seen as dirty people who eat bad food. Therefore, TB was considered a disgrace, which consequently causes shame and blame and people did not want to even look at, walk by, eat with or work with people with this disease. For these reasons, TB was considered a “social” disease. This study shows that TB patient knowledge has greatly improved. The *predisposing factors* and knowledge related items from the conceptual model are more or less the same for as well the compliers as the defaulters. Respondents mention having more faith in the medicines and knowledge of community health workers than in the traditional healers and are aware of the fact that TB can be cured. TB is described as a disease of the lungs, caused by germs and bacilli. These are important winnings in the fight against TB. In this research no association is found between TB and poverty, unhygienic habits and/or dirty

people who eat bad food. However, people with and/or cured from TB are considered to be weak and are less respected. A trip to the clinic and/or home visit from a DOT may bring the disease to light, which causes rejection and stigmatization of TB patients. Many people also believe that TB will develop into HIV/AIDS. The fact that the community believes that TB turns into HIV and that people have problems distinguishing them causes double stigmatized TB patients. Therefore, TB is still considered a “social” disease, but for different reasons.

The consequences of TB as a “social” disease and the stigma TB patients have to face needs to decrease. The media should focus on the fact that a person with TB that complies with treatment is in fact a strong person and that a person cured from TB even stronger. Special attention should be given to the fact that people believe TB results into HIV/AIDS. Media should focus on the differences and on the fact that TB cannot develop into HIV. This will contribute to decrease the double stigmatization and rejection of a person with TB. Rejection and stigmatizing of TB patients that consequently causes shame and blame, only promotes patients to default from treatment.

Community health workers must be aware of the role of cultural characteristics as determinants of compliance to treatment. Community health workers should act to destigmatize and avoid any attitudes that may affirm stigma, especially the double stigma of TB with HIV/AIDS. More time and better support must be given to the community health workers, so that they are able to put the patient in the center instead of providing task orientated nursing. A good patient-physician relationship can positively influence adherence.

This research shows that the disability grant is an important determinant of compliance. Respondents say they regain respect from their family, friends and neighbours because of the grant. They also feel less rejected and therefore feel more confident and motivated to complete their treatment. Therefore, it is important that the TB patients on treatment will continue to get the disability grant. Since this seems a perverse determinant, more research is necessary regarding the way in which it is given. Perhaps compliance could improve if the incentive changes into a cured person and not a sick one on medication. Recommended is to look into the effects on compliance if the disability grant is somewhat lowered and when a person after six months is cured from TB, they receive a bonus.

To improve adherence; there should be more daily activities and better prospects. This research shows that compliers tend to have a long-term view and are capable to fulfill the treatment under self-supervision. Community health workers need to distinguish this group from the patients that have drinking problems and/or no real prospects. Mostly, they are not motivated enough to finish treatment, bored and therefore need to be motivated. Here lays an important task for the community health workers. To improve adherence, it is necessary

to follow a concordance model. This means shared decision making about medicine and treatment between a community health worker and a patient, based on partnership and fully valuing the patient's expertise and beliefs. Community health workers need to be innovative and creative in providing care in such a way that they stimulate and motivate patients. It is important to not only motivate and support patient regarding their treatment, but in their whole lives. The complete social context must be taken into account.

It is important to provide more time for the community health workers, so they have more time on their hands to motivate and stimulate the patients. The defaulters describe a need for daily activities. The patients who stayed at the hospital identify boredom as the main determinant of non-compliance. They say that more activities in the hospital would have a positive effect on their compliance behaviour. The government and/or municipalities should provide recreation and leisure facilities; sporting and arts/craft activities in the clinics. The unemployed people who are motivated and capable to guide these activities can work there as a volunteer. Daily activities of the unemployed members of the township community, something to keep them occupied in order to keep their mind of the problems they have to face, is linked to compliance. Community health workers must recognize that their role is not simply treatment observation, but also motivating patient in adherence. Community health workers must pay special attention to the specific needs of the individual patient to improve treatment adherence. This is the only way to regain feelings of pride, dignity and respect of the people in the community. Patient centered care is a necessary condition to improve compliance among patients and therefore the outcomes of TB treatment in the Eastern Cape.

Because adherence is context driven and employment has a strong association with compliance; it is recommended to improve the education of the children. When education is improved, chances of getting a job also improve. In this research, an association is found between employment or the chance of getting a job in the future and feelings of pride, dignity and respect. When the next generation has better prospects, this will contribute to a higher level of adherence with TB treatment.

## References

Ashry, G., Ahmed, M.A.M., Aida, A.R.S., Zahira, M.G., & Sallem, S. (1997). Compliance with antituberculosis drugs among tuberculosis patients in Alexandria, Egypt. *Eastern Mediterranean Health Journal*, 3, 244-250.

Auer, C., Sarol, Jr.J., Tanner, m., & Weiss, M. (2000). Health seeking and perceived causes of tuberculosis among patients in Manilla, Phillipines. *Tropical Medical International Health*, 5, 648-656.

Barnhoorn, F. (1994). Waarom tbc-patiënten geen medische hulp zoeken. *Medische Antropologie*, 6, (2):242-261.

Barnhoorn, F., & Adriaanse, H. (1992). In search of factors responsible for noncompliance among tuberculosis patients in Wardha Distract India. *Social Science and Medicine*, 34, (3):291-306.

Black, B., & Bruce, M.E. (1998). Treatment in tuberculosis: The essential role of social work. *Social work in Health Care*, 26, (3):51-68.

Bond, V., Chase, E., & Aggleton, P. (2002). Stigma, HIV/AIDS and prevention of mother-to-child transmission in Zambia. *Evaluation and program planning*, 25, 347-356.

Brown, S.R. (1980). *Political subjectivity: Applications of Q-methodology in political science*; Yale University Press

Brown, S.R. (1993). A primer on Q-methodology. *Operant Subjectivity*, 16, (3/4):91-138

Chandra, P., Deepthivarma, S., & Manjula, V. (2003). Disclosure of HIV infection in South India: Patterns, reasons and reactions. *AIDS Care – Psychological and Socio-Medical Aspects of AIDS/HIV*, 15, (2):207-215.

Comolet, T.M., Rakotomalala, R., & Rajaonariora, H. (1998). Factors determining compliance with tuberculosis treatment in an urban environment, Tamatave, Madagascar. *Tubercle and Lung Disease*, 2, 891-897.



Conner, M., & Norman, P. (2005). *Predicting health behaviour: research and practice with social cognition models*. Berkshire: Open University Press.

De Vallière, S., & Barker, R.D. (2006). Poor performance status is associated with early death in patients with pulmonary tuberculosis. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 100, (7):681-686.

De Villiers, S. (1991). Tuberculosis in an anthropologic perspective. *South African Journal of Ethnology*, 14, (3):69-72.

Deacon, H., Stephney, I., & Prosalendis, S. (2005). *Understanding HIV/AIDS stigma. A theoretical and methodological analysis*. Capetown: HSRC Press.

Dodor, E. A., & Afenyadu, G. Y. (2005). Factors associated with tuberculosis treatment default and completion at the Effia-Nkwanta Regional Hospital in Ghana. *Elsevier*, 99, 827-832.

Escott, S., & Walley, J. (2005). Listening to those on the frontline: Lessons for community-based tuberculosis programmes from a qualitative study in Swaziland. *Social Science and Medicine*, 61, 1701-1710.

Van Exel, N.J.A., & de Graaf, G. (2005). *Q-methodology: A sneak preview*. Retrieved march 2006; <http://www.jobvanexel.nl/> and <http://www.qmethod.org/>

Hochbaum, G.M. (1958). Public Participation in Medical Screening Programs: A Socio-Psychological Study. *Public Health Service Publication*, 572.

Hanoch, Y. (2002). "Neither an angel or an ant": Emotion as an aid to bounded rationality. *Journal of Economic Psychology*, 23, 1-23.

Johansson, E., Diwan, K.V., Huong, N.D., & Alberg, B.M. (1996). Staff and patient attitude to tuberculosis and compliance with treatment: an exploratory study in a district in Vietnam. *Tubercle and Lung Disease*, 77, 178-183.

Johansson, E., Long, N.H., Diwan, V.K., & Winkvist, A. (1999). Attitude to compliance with tuberculosis treatment among women and men in Vietnam. *Tubercle and Lung Disease*, 3, 862-868.

Liefooghe, R., Michiels, N., Habib, S., Moran M.B., & Muynck, A. (1995). Perception and social consequences of tuberculosis : a focus group study of tuberculosis patients in Ialkot, Pakistan. *Social Science and Medicine*, 4, (12):1685-1692.

Karim, K. (2001). Q methodology-advantages and disadvantages of this research method. *Journal articles*, 15, (4).

Mishra, P., Hansen, E.H., Sabroe, S., & Kafle, K.K. (2005). Adherence is associated with the quality of professional-patient interaction in Directly Observed Treatment Short-course, DOTS. *Patient Education and Counseling*, 63, (1-2): 29-37.

Mullen, P.D., Hersey, J.C., & Iverson, D.C. (1987). Health behavior models compared. *Social Science and Medicine*, 11, 973-981.

Murray, C., De Jonghe, E., Chum, H.J., Nyangulu, D.S., Salomao, A. & Styblo, K. (1991). Cost-effectiveness of chemotherapy for pulmonary tuberculosis in three sub-saharan countries, *Lancet*, 338, 1305-1308.

Muyinda, H., Seeley, J., Pickering, H., & Barton, T. (1997). Social aspects of AIDS-related stigma in rural Uganda. *Health Place*, 3, (3):143-147.

Norman, P., Abraham, C., & Conner, M. (2000). *Understanding and changing health behaviour; from health beliefs to self-regulation*. Amsterdam: Harwood academic publishers.

Polit, D.F., Hungler, B.P. (1999) Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24, (2):105-112.

Rosenstock, I.M. (1966). Why people use health services. *Milbank Memorial Fund Quarterly*, 44, 94-124.

Rosenstock, I.M. (1974). Historical origins of the health belief model, *Health Education Monographs*, 2, 1-8.

San Sebastian, M., & Bothamley, G.H. (2000). Tuberculosis preventive therapy: perspective from a multi ethnic community. *Respiratory Medicine*, 94, 648-653.

Schmolck, P. PQMethod version 2.11, 2002.

Simon, H.A. (1959). Theories of decision making in economic and behavioural science. *American economic review*, 49, 253-283.

Simon, H.A. (1967). Motivational and emotional control of rational choice. *Psychological review*, 74, 29-39.

Solomon, M., De Jong, W., & Jodrie, T.A. (1988). Improving drug regimen adherence among patients with sexually transmitted disease. *Journal of compliance in Health Care*, 3, 41-56.

Stephenson, W. (1935). Correlating persons instead of tests. *Character and Personality*, 4, 17-24

Sudre, P., ten Dam, G., & Kochi, A. (1992). Tuberculosis: a global overview of the situation today. *Bulletin of the World Health Organization*, 70, 149-159.

Tamura, H. (2005). Behavioural models for complex decision analysis. *European journal of operational research*, 166, 655-665.

Van der Walt, H.M., & Swartz, L. (2002). Task orientated nursing in a tuberculosis control programme in South Africa: where does it come from and what keeps it going? *Social Science and Medicine*, 54, 1001-1009.

Walzl, G., Beyers, N., & Helden, p. (2005). TB: a partnership for the benefit of research and community. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 99, 15-19.

Westaway, M.S. (1989). Knowledge, beliefs and feeling about tuberculosis. *Health Education Research*, 4, (2):205-211.

WHO (2004). A guide to monitor and evaluation for collaborative TB/HIV activities. Retrieved march 2006; [http://www.who.int/hiv/pub/tb/en/guidetomonitoringevaluationtb\\_hiv.pdf](http://www.who.int/hiv/pub/tb/en/guidetomonitoringevaluationtb_hiv.pdf)

WHO (2004). Report of a "lessons Learnt" Workshop on the six ProTEST Pilot Projects in Malawi, South Africa and Zambia. Retrieved march 2006; [http://whqlibdoc.who.int/hq/2004/WHO\\_HTM\\_TB\\_2004.336.pdf](http://whqlibdoc.who.int/hq/2004/WHO_HTM_TB_2004.336.pdf)

WHO (2005). Global Tuberculosis Control – Surveillance, Planning, Financing. Retrieved September 2006;

[http://www.who.int/tb/publications/global\\_report/2006/pdf/full\\_report\\_correctedversion.pdf](http://www.who.int/tb/publications/global_report/2006/pdf/full_report_correctedversion.pdf)

WHO, (2006). Factsheet Tuberculosis. Retrieved September 2006;

[http://www.who.int/mediacentre/factsheets/fs104/en/;](http://www.who.int/mediacentre/factsheets/fs104/en/)

[http://www.who.int/tb/publications/2006/tb\\_factsheet\\_2006\\_1\\_en.pdf](http://www.who.int/tb/publications/2006/tb_factsheet_2006_1_en.pdf)

WHO, (2006). Expected results. Retrieved September 2006;

<http://www.afro.who.int/tb/expectedresults.html>

Zwarenstein, M., Schoeman, J.H., Vundule, C., Lombard, C.J., & Tatley, M. (1998). Randomised controlled trial of self-supervised and directly observed treatment of tuberculosis. *Lancet*, 352, 1340-1343.

## Appendix 1

### Demographic and social economic factors of the non-compliance group

Patient	Gender	Age	Employment	Household size	Marital status	Education
1	male	29	unemployed	7	single	Yes
2	male	32	unemployed	13	married	Yes
3	male	24	unemployed	12	married	Yes
4	female	27	unemployed	12	single	Yes
5	female	30	unemployed	15	single	No
6	male	31	unemployed	5	single	Yes
7	female	31	unemployed	8	married	Yes
8	female	29	unemployed	8	single	Yes
9	female	40	employed	7	married	Yes
10	male	42	unemployed	6	married	Yes
11	male	44	unemployed	6	married	Yes
12	female	35	unemployed	9	married	Yes
13	female	29	unemployed	10	single	Yes
14	female	30	unemployed	9	married	Yes
15	male	22	unemployed	10	single	No
16	male	46	unemployed	8	single	Yes
17	female	41	unemployed	12	married	No
18	male	34	unemployed	11	single	Yes
19	female	33	unemployed	10	married	Yes
20	male	31	unemployed	11	married	Yes
21	female	41	unemployed	5	single	Yes
22	female	40	unemployed	14	single	Yes
23	male	37	unemployed	11	single	Yes
24	male	36	employed	9	married	Yes
25	male	30	unemployed	9	single	Yes
26	female	31	unemployed	9	married	Yes
27	male	32	unemployed	8	single	Yes
28	female	27	unemployed	9	married	No
29	female	39	unemployed	10	single	Yes
30	female	23	unemployed	7	single	Yes
31	male	41	unemployed	8	married	Yes
32	male	45	unemployed	9	single	Yes
33	female	36	unemployed	9	married	Yes
34	female	44	unemployed	8	single	Yes

## Appendix 2

### Demographic and social economic factors of the Compliance group

Patient	Gender	Age	Employment	Household size	Marital status	Education
1	female	23	unemployed	11	single	Yes
2	female	29	unemployed	7	single	Yes
3	female	31	unemployed	14	married	No
4	male	45	employed	7	single	Yes
5	male	26	employed	6	married	Yes
6	female	33	unemployed	7	married	Yes
7	female	28	unemployed	5	married	Yes
8	female	48	employed	10	single	Yes
9	male	41	employed	9	married	Yes
10	male	21	unemployed	14	single	Yes
11	female	39	unemployed	15	married	Yes
12	male	40	unemployed	11	single	Yes
13	female	37	unemployed	12	single	Yes
14	male	30	unemployed	13	married	Yes
15	female	44	employed	9	single	Yes
16	male	25	employed	8	married	Yes
17	female	32	unemployed	10	married	Yes
18	male	35	employed	9	married	Yes
19	male	35	employed	9	single	Yes
20	male	41	unemployed	9	married	Yes
21	male	27	employed	11	married	Yes
22	female	34	unemployed	13	single	Yes
23	female	30	unemployed	10	single	Yes
24	female	36	employed	13	single	Yes
25	female	29	unemployed	7	married	No
26	male	30	employed	5	single	Yes
27	male	47	unemployed	6	single	Yes
28	female	42	employed	7	single	Yes
29	female	31	unemployed	6	single	Yes
30	female	33	employed	7	married	Yes
31	male	28	unemployed	8	married	Yes
32	male	35	employed	6	single	Yes
33	male	38	employed	6	single	Yes