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FACULTY OF COMMUNITY AND HEALTH SCIENCES

A mini thesis submitted in partial fulfilment of the requirements for the degree of Masters in Public Health in the Faculty of Community and Health Sciences, University of the Western Cape.

TITLE: An exploration of the reasons for defaulting amongst Tuberculosis patients on the Community Based Directly-Observed Treatment Programme in the Siyanda district, Northern Cape Province.

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Adherence to treatment

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DOTS Strategy

Primary Health Care facility

Qualitative study

Northern Cape Province

ABSTRACT

Background: Tuberculosis (TB) poses a major public health challenge in South Africa and in the Northern Cape Province. The province has the third highest in TB incidence rate in the country. Poor adherence to TB treatment impacts negatively on treatment outcomes. Siyanda district in the Northern Cape Province has the second highest number of TB defaulters in the province despite the fact that 79.9% of these patients are on Community Based Direct Observation of Treatment (CBDOT).

Aim: To explore the reasons for defaulting of TB patients from TB treatment in the CBDOT Programme in the Siyanda district, Northern Cape Province

Study design: This was a qualitative exploratory study**.**

Study population and sampling: Two TB nurses with varying years of experience in the TB Control Programme serving as key informants were selected from the participating facilities in the study area. Ten TB defaulters who were on the CBDOT programme were selected from the Electronic TB Register. Two focus group discussions (FGDs) comprising of purposively selected DOT Supporters (five in one group and six in the other) from different NGOs in the community were selected for maximum variation.

Data collection: Key informant interviews were conducted with the TB nurses. Records of all defaulters in the study population were reviewed including clinic progress notes and patient TB treatment cards. In-depth interviews were conducted with the TB patients. FGDs were conducted with DOT supporters.

Analysis: Analysis commenced simultaneously with collection of data. This enabled the researcher to continuously review and reflect on the data collected. Thematic content analysis was done. Categories emerged through the inductive process of the data analysis. Notes that were kept during

data collection, reflections, audiotapes and transcripts were used to support the thick description of the findings.

Results: The participants generally appreciated the programme and mostly had a good relationship with the DOT supporters. However, the quality of care exacerbated by inadequate health services such as lack of adherence counselling training of health professionals, low levels of education amongst TB defaulters, were found to be major contributory factors to TB defaulting. The patients interrupted treatment several times before defaulting, were not counselled during the interruption phase and understood TB messages differently. TB defaulters in the Siyanda District face socio economic challenges which include alcohol abuse, a major historic ill in the district and the grape farming community in the region. The impact of the disability grant on TB treatment adherence remains anecdotal and requires further research as TB defaulters did not admit to defaulting so that they could continue benefiting from the disability grant although these statements were refuted by the DOT supporters and key informants. The attitude of employers and fear of losing employment were also contributing factors.

Conclusion and recommendations: It has become evident that TB in the Siyanda District is a public health issue. The predominantly rural, impoverished and transient community that moves to the farms to seek employment requires a CBDOT programme that will address pertinent challenges in the district to achieve a positive reduction in the TB defaulter rate. It will require collaboration with stakeholders including farmers, to address the challenges posed by the disease. Improved staff allocation, staff capacity development and community education are also recommended to improve quality of care.

DECLARATION

I declare that *the exploration of the reasons for defaulting amongst Tuberculosis patients on the Community Based Direct Directly-Observed Treatment Programme in the Siyanda district, Northern Cape Province* is my own work, that it has not been submitted for any degree or examination in any other University, and that all the sources I have used or quoted have been indicated and acknowledged by complete references.

Phyllis Baitsiwe November 2009

Signature: ----------

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Last but not least, to my husband, my two daughters for the continuous support and encouragement.

Acronyms

AIDS	Acquired Immune Deficiency Syndrome
DOT	direct observation of treatment
DOTS	direct observation of treatment short-course
CBDOT	Community based direct observation of treatment
HBC	Home Based Care
MDR TB	Multi-Drug Resistant Tuberculosis
PHC	Primary Health Care
PTB	Pulmonary Tuberculosis
PTC	Patient Treatment Card
TB	Tuberculosis
TDG	Temporary Disability Grant
WHO	World Health Organization
XDR TB	Extreme Drug Resistant Tuberculosis

List of terms

CHW	Community health worker: members of the communities where they work, should be selected by the communities, should be answerable to the communities for their activities, should be supported by the health system but not necessarily a part of its organization, and have shorter training than professional workers (WHO, 2007b)
LHW	Lay Health Worker: Consumers, who are not certified health care professionals, may be trained to promote health and provide health care services (Lewin et al, 2005).
MDR TB	Tuberculosis disease where there is in vitro resistance to both isoniazid and rifampicin, with or without resistance to other anti- tuberculosis drugs (DOH, 2009).
Smear positive TB cases	the presence of at least one acid fast bacilli (AFB+) in at least one sputum sample (DOH, 2009)
TB cure rate	Percentage of new smear positive PTB cases cured at first attempt (DOH, 2009)
TB defaulter rate	Percentage of smear positive pulmonary TB patients that interrupted TB treatment for two months or more (DOH, 2009)
TB interrupter	TB patients who interrupt TB treatment for less than two months (DOH, 2009)

TB Incidence rate	Tuberculosis incidence is the estimated number of new tuberculosis (TB) cases arising in one year per 100,000 population. All forms of TB are included, as are cases in people with HIV (DOH, 2009).
XDR TB	MDR-TB and in vitro resistance to any of the fluoroquinolones plus one or more of the injectable second-line anti-TB drugs, ie. kanamycin, amikacin or capreomycin (DOH, 2009).

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CHAPTER 1

INTRODUCTION

1.1 Background

This chapter includes the introduction, background and the setting within which the study was conducted. This is followed by the problem statement and concludes with the researcher's own experience in the field.

Tuberculosis (TB) remains the most common cause of death in adults in less developed countries. TB is said to kill nearly two million people globally annually primarily from the poorest communities in developing countries. The World Health Organization (WHO) estimates that 9.27 million new TB cases were diagnosed in 2007 (139 per 100 000 population) marking an increase from 9.24 million cases in 2006 (140 per 100 000 population). Forty four percent of the cases in 2007 were reported to be new smear positive (WHO, 2009).

It was at the forty-fourth World Health Assembly in 1991 that TB was recognized as a major public health problem globally and it was resolved that 70% case detection and 85% cure rate of new smear positive cases should be achieved globally by 2000. Subsequently, the use of the direct observation of treatment short-course (DOTS) strategy, recognised as a global strategy to fight TB increased from hundred and two countries in 1997 to 180 countries in 2007 (WHO, 2007). Forty one African countries were implementing the strategy by 1998 (WHO, 2006b). Considerable progress has been made globally since then

and the treatment success rate for new smear positive TB cases reached the target of 85% in 2006 (WHO, 2009). The treatment success in areas implementing DOTS strategy globally increased from thirty three countries in 2005-2006 to thirty six in 2007 (WHO, 2009).

South Africa has been rated as one of the 22 high burden countries that contribute approximately 80% of the total global burden of all TB cases. South Africa has the 5th highest TB incidence in the world with 0.46 million cases reported in 2007 (WHO, 2009). The TB incidence rate for the country has increased from 269 per 100 000 population in 1996 to 720 per 100 000 population in 2006 (Department of Health (DOH), 2007). The defaulter rate remains high although a slight reduction has been marked from 10.4% in 2005 to 9.1% in 2006, creating a barrier to achieving the targets set for TB treatment cure rate outcomes (WHO, 2009).On the other hand, the cure rate had increased over five years from 49.7% in 2001 to 63% in 2006 (DOH, 2007).

The Northern Cape Province reported the second highest defaulter rate in the country at 13.1% during 2005 and this was an increase from 11% in 2004 (DOH, 2007). This trend was not consistent with the national figures which showed stability at 10% during both 2004 and 2005 (DOH, 2007). However, the proportion of new smear-positive TB cases that successfully completed treatment, whether with bacteriologic evidence of success or without (success rate) in the country had increased from 65.8% in 2004 to 71.4% in 2005. The cure rate had increased from 38.3% to 50.1% during the same period (DOH, 2007).

Similar to global trends, there is an increase in proportion of new smear positive cases at both National and Provincial level. A constant improvement has been marked in National TB cure rate over the 5 years. See Table 1.

Table 1: Comparison of case finding amongst new smear positive cases and TB cure rate between Northern Cape and South Africa, 2001-2005

Year	New smear positive PTB cases per 100 000 population		TB Cure rate	
	Northern Cape	South Africa	Northern Cape	South Africa
2001	279	188	58.7%	49.7%
2002	339	217	62.6%	50%
2003	414	251	64.6%	50.9%
2004	387	253	38.3%	50.8%
2005	395	267	50.1%	57.7%

Source: DOH, 2007

The Northern Cape had reported an alarming increase in the number of new smear positive PTB cases per 100 000 population between 2001 and 2005 and similar trends were marked in the country. This could however be attributed to improved case finding strategies (Fourie, 2006). A consistent improvement has been marked in the country-wide TB cure from 49.7% in 2001 to 57.7% in 2005, whilst the cure rate in the Northern Cape reduced from 58.7% to 50.1% during the same period (DOH, 2007).

The DOTS strategy was implemented in the Northern Cape in 1997 to improve the management of TB patients in the province.

The Northern Cape (Northern Cape Department of Health, 2009) similar to the National TB Control is targeting to:

- Detect at least 70% of new sputum smear-positive TB cases
- Cure at least 85% of these cases by 2014
- Reduce TB prevalence and death rates by 50% relative to 1990 levels.
- Reduce the TB defaulter rate which was 13.1% in 2005 to 5.8% in 2011

1.2 Study setting

The study was conducted in the Siyanda district, Northern Cape Province. The district is primarily rural, with small pockets of communities living far from each other and has a population of 209889 people (Census, 2001). The district is divided into six local municipalities with the largest local municipality having a population of 73 786 people (//Khara Hais) and the smallest local municipality with a population of 6 850 people (Mier).

Table 2: Age distribution

Age	Population %
<19 years	41.4
20-59 years	50.9
>60 years	7.7

Source: 2001 census

Fifty one percent of the inhabitants of the district are in the age group 20-59 years old with those above 60 years being in the minority. The district has slightly more females (51.21%) than males (48.79%). The coloured community are in the majority at 63.71% (census, 2001).

The district unemployment rate was reported at 27% during 2004 which could be related to the inconsistency of the agricultural sector (Siyanda District Integrated Development Plan (SDIDP), 2007). According to the last socio-economic survey in 2000, approximately 60% of the inhabitants have a monthly household income of between R0-R800 (SDIDP, 2007). The economy in the district is largely dominated by mining and agriculture, the latter comprising of commercial grape farming, livestock and game farming (SDIDP, 2007). The majority of the workforce is made up of seasonal farm workers recruited from rural and peri-urban areas in the Siyanda and John Taolo Gaetsewe Districts in the Northern Cape and

from the North West Province. These workers flood the farming areas during September to December each year and relocate to other farms in the district during the season guided by the availability of work. Poverty linked to high unemployment rate, illiteracy, alcohol abuse and insufficient housing provision are the greatest social problems impacting directly on the incidence and prevalence of TB (Gelmanova et al, 2007; Gross and Blumel, 2008; Santos, Vendramini, Oliveira, and Villa, 2007).

The abuse of alcohol in the Siyanda district, similar in many wine farming districts, is rooted in the "dop" system. This system, introduced during colonial rule, was the rationing of alcohol in lieu of payment to farm workers in the grape farming industry. This system is no longer legal in South Africa although in a study done by Parker (2004), the mayor of !Kheis Municipality indicated that the system is still common in this part of the country. Consequently, alcohol abuse in the district is one of the major challenges facing health services leading to a cycle of poverty and dependency (London, 1999).

1.2.1 TB control programme

The responsibility to manage the TB programme is shared between the National, Provincial and District Departments of Health and in some instances the local municipalities with clear responsibilities at all levels (DOH, 2007). TB Programme implementation is integrated into all Primary Health Care (PHC) programmes including TB and HIV collaborative activities. Due to the high burden of HIV, it is important to develop systems for joint planning and execution of activities between the TB and HIV and AIDS programme (WHO, 2008a).

Amongst others, the provincial and district health management are responsible for co-ordinating the programme implementation, supervision and provision of training. To address

the factors contributing to the burden of TB, it is important to strengthen the public-private–partnerships because failure to involve other care providers may result in amongst others improper management of TB patients (WHO, 2006a).

Siyanda district has thirty nine PHC facilities and thirteen mobile clinics all providing TB services. Due to the vastness of the district, availability of health services to remote areas and farms are provided through mobile clinics that visit some farms on a weekly or monthly basis. In the Siyanda district, PHC facilities diagnose and initiate treatment of TB patients. Patients who are diagnosed at hospital level are commenced on treatment there and then are referred to PHC facilities for further management. The district has no designated facility to admit drug-sensitive TB patients but should there be a need for admission, TB patients are admitted to the general wards where beds are available. TB patients on treatment are given a return date for collection of medication and sputum collection at two, three or five months. However, most clinics in the district have no system of tracing if the patients had returned for the appointment on a specific day. This discovery may only be made early in the interruption period or when it is too late and the patient is already a defaulter.

The TB Control programme has a formalized referral system that is meant for the benefit of a highly mobile community like in the Siyanda District. This accessibility to TB services allows TB patients to obtain TB drugs and continue with their treatment anywhere in the district including at the farms where mobile clinics visit certain points at specified periods. The added advantage of this is that accessibility to TB care should prevent TB treatment interruption and defaulting. However, some TB patients move throughout the district in the pursuit of work and therefore do not use the system effectively. TB patients are informed that they can use the patient treatment card or GW20/15 (often referred to as the green card)

anywhere in the country. However, some patients leave without notifying the TB clinic and therefore have no medication or referral which compromises their treatment.

1.2.2 CBDOT Programme

To ease the burden of frequent clinic attendance, long queues and long travelling distances to clinics, the National TB Control Program and Northern Cape Province introduced the CBDOT programme as part of the Home and Community Based Care programme. The CBDOT programme forms part of the community health workers (CHW) programme funded through the HIV and AIDS conditional grant from the Department of Health and the Department of Social Development. The programme is implemented by Non Government Organizations (NGOs) who recruit volunteers known as CHWs or DOT supporters from the community. Sixty five percent of TB patients in the Northern Cape are on the CBDOT programme (NCDOH, 2008).

Once the patient has a negative smear microscopy at two or three months and has been commenced on continuation phase, they are referred to the CBDOT programme. During 2007, the DOT supporters collected the TB treatment for their patients from the clinic and kept it with them for the patients to be supported at the DOT supporter's home. The policy has since changed and the supporter together with the TB patient collect the treatment from the clinic on a weekly basis but the patient keeps it and the DOT supporter goes to the patient's house. Some DOT supporters use their own discretion and still keep the treatment of some patients. The patients are given their weekend dosages to self-administer. However, the effectiveness of CBDOT has become questionable because despite the introduction of this programme, TB patients on the programme are still reported to default from treatment.

1.2.3 DOT Supporters

The training of CHWs is conducted by a consultant agency sourced by the HIV and AIDS programme and the refresher course on TB for the DOT supporters is still conducted by an NGO called TB FREE. In addition to conducting home visits to support TB patients on treatment, DOT supporters (as part of the Home and Community Based Care programme) are trained and expected to provide preventive care to healthy people through community education programmes; comprehensive care to people at risk or frail older persons; people with moderate to severe functional disabilities, people recovering from illness; in need of assistance e.g. post deliveries or after specific treatment; palliative care to the terminally ill persons; persons living with HIV and AIDS or any other debilitating disease (DOH, 2005). They support up to eight patients per day and at least six of the patients are expected to be TB patients on CBDOT.

The district has two hundred and twenty nine CHW from the one thousand three hundred available within the province who are mostly concentrated in the major towns (NCDOH, 2009). Each supporter receives a stipend of R1000 per month. The TB sisters at the clinics provide ongoing support to the DOT supporters in the form of weekly or monthly meetings conducted with the purpose of addressing challenges experienced in community–based service provision. It is at these meetings where performance reports are presented and new policy decisions are discussed.

TB patients on farms have to wait for a mobile clinic that visits points at certain farms weekly or monthly. There are no DOT supporters designated for the farming areas therefore even though migrant TB patients have their treatment, the DOT support services are not available in the area for monitoring the patients. In addition, an inadequate number of DOT

supporters is available. The appointments and expansion of the DOT support programme is based on availability of funds from the HIV and AIDS conditional grant. The allocation of DOT supporters per district is based on the population and health profile of the district. The supporters are currently paid a stipend; it is therefore a challenge to expand the programme with only paying stipends to volunteers.

1.2.4 Financial and Nutritional Support

High unemployment, high poverty levels and increased HIV and TB cases in this district is bound to increase the demand for social assistance. Indigent patients diagnosed with TB benefit through initiatives such as the temporary disability grant which is issued by the South African Social Security System. When patients contract TB they become eligible to apply for the temporary disability grant administered by South African Social Security Agency (Department of Social Development, 2008). Some TB patients have exceeded the stipulated maximum grant period of 12 months although interrupted and many have re-applied on several occasions during the prolonged period of treatment. Information of the number of TB patients on the disability grant in the district is not readily available.

In addition, TB patients with a body mass index of less than 18.5 and those infected with HIV benefit from the food security programme of the Department of Health in the form of nutritional supplements and food support. The Department of Social Development in the province also runs a food security programme for the TB indigent households and TB patients in some instances are able to benefit from both programmes as there are no cross-references between the two departments. Patients receive food supplements and monthly or three monthly food parcels. With these benefits afforded the TB indigent, fuelled by the high unemployment rate, there is a perceived need of TB patients to remain on the grant,

this raises the question whether the temporary disability grant for the indigent is an unintended incentive.

1.3 Problem statement

Once TB is diagnosed, TB patients are informed about the disease and treatment duration by the clinic staff; in some facilities TB patients sign a contract as a commitment to complete their treatment. Regular TB awareness campaigns in the form of door to door visits led by the Member of the Executive Council (MEC) together with health officials, DOT supporters and Khomanani volunteers are conducted. With these efforts the treatment completion rate for 2007 was 70.4% (NCDOH, 2009). However, despite the implementation of the CBDOT programme, the number of TB cases diagnosed in Siyanda district had increased from 1750 in 2006 to 2179 in 2008. The district cure rate had decreased from 64.1% in 2006 to 59.9% in 2007. The TB defaulter rate increased from 8.6% to 10.4% during the same period (NCDOH, 2008). The province has a limited number of lay counsellors trained on adherence counselling, limited number of social workers and psychologists and no rehabilitation facility for patients with substance abuse. The district is however utilizing the services of the environmental health officer and health promotion officer to conduct adherence counselling on the patients that are interrupting treatment or have already defaulted. There is a need to explore why the defaulter rate is increasing despite all the interventions that are apparently in place.

In an attempt to strengthen the relationship between the Department of Health and the farming sector, the TB co-ordinator in the district, has initiated discussions to improve access to TB services on the farms and to also further expand the involvement of all other stakeholders such as the farmers union Department of Labour and Department of

Agriculture in the district in the control and management of TB. This study aimed therefore to explore the reasons of patients for defaulting from TB treatment in the CBDOT Programme in the Siyanda district. It is expected that the discussions will provide strategies that will inform interventions to reduce the defaulter rate amongst TB patients in the CBDOT programme.

1.4 Researcher's own experience

The researcher is the provincial manager for the TB Control Programme. Her scope of work includes co-ordinating and managing the implementation of the DOTS programme and Drug resistant TB (MDR and XDR TB). In addition she co-ordinates and oversees the implementation of the TB infection control guidelines and ensure the development of provincial policies and implementation of national policies. As a co-ordinator, she has to ensure that TB services are rendered by qualified and competent health professionals which necessitates targeted TB training of health professionals within and outside the public health sector.

Her experience in the programme spans over 5 years and she has had the opportunity to interact with TB professionals and experts from different sectors. TB, a public health problem, needs to be addressed as a public health challenge seeking involvement of other stakeholders. There has been a limited involvement of other stakeholders in the control of TB thus far. The TB programme both at provincial and district level has started engaging other sectors including correctional services, farming, mining and education in an effort to control TB. The researcher is of the opinion that the community structures and forums like churches, ward councils, recreations and sporting activities where many people congregate are not utilized to the maximum to address the TB problem. It is her opinion that before

2004 the programme was not afforded the necessary status and resource allocation it required, which might have led to the year on year poor performance of the programme.

The responsibilities of the co-ordinator include training and providing support to health professionals. A high turnover of health professionals especially nurses and doctors has made the interventions of the province in capacity development appear futile. Although I understand the challenges posed by staff shortage at facility level, the rotation of nurses from one programme to another within health facilities poses a challenge in continuity of care and accountability by health care workers. With such staffing levels, targets by the province to improve TB services are not achievable.

CHWs provide DOT support and other community services to HIV positive patients but the researcher is of the opinion that optimum value is added to the TB Control Programme by the presence of the CHWs where they are available and where there is adequate monitoring and reporting systems in place. The programme is concentrated in the urban and peri-urban areas. The rural areas where TB patients have to travel long distances to the clinics have no services of CHWs and the roll-out of the programme is slow to the needy areas.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

In this chapter, an overview will be given on the magnitude of TB, TB and HIV globally, country-wide and in the Northern Cape Province, control mechanisms in place and the TB treatment regime in South Africa. The policies guiding TB Control Programme globally will be unpacked and those include the DOTS strategy and the Stop TB Strategy. At the end of the chapter, the factors influencing adherence to TB treatment will be discussed with lessons learned from other parts of the world.

2.2 Tuberculosis Overview

TB remains one of the main challenges and the single largest infectious cause of death in the world. An increase has been marked in the number of cases diagnosed with TB. 9.27million new cases had been diagnosed globally in 2007 which is an increase from 9.24million new cases in 2006 (WHO, 2009). WHO reports that during 2008, about 1.3 million deaths occurred globally only among patients that were HIV negative. However, the scourge of HIV and AIDS has been reported to fuel the spread TB. Approximately 1.3 million amongst the 9.27 million cases of TB have been diagnosed with HIV and 456 000 deaths have been reported to have occurred amongst TB patients who were HIV positive globally (WHO, 2009).

TB is a bacterial disease usually affecting the lungs (pulmonary TB). Other parts of the body can also be affected, for example, lymph nodes, kidneys, bones and joints (extra-pulmonary

TB). There are five closely related mycobacteria responsible for TB with the most common form being Mycobacterium Tuberculosis. TB is infectious and usually spreads from person-to-person through the air by droplet nuclei that are produced when a person with untreated pulmonary or laryngeal TB coughs, sneezes or sings. They may also be produced by aerosol-producing investigations such as sputum induction, bronchoscopy and through manipulation of lesions or processing of tissue or secretions in the laboratory. The most infectious cases are those with smear positive pulmonary TB, particularly those with lung cavities. Many people are said to have latent TB that has yet to develop obvious symptoms (DOH, 2007). TB transmission in most instances occurs in dark, damp spaces and overcrowded places where droplet nuclei can stay airborne for a long time. Close contact and prolonged exposure increases the risk of transmission (DOH, 2009).

The most common symptoms of TB include persistent cough for more than two weeks, unexplained weight loss, sputum production, which may occasionally be blood-stained, fever for more than two weeks, night sweats, loss of appetite, a general feeling of malaise, shortness of breath and chest pain (DOH, 2009). TB diagnosis is confirmed in patients suspected of having TB through the collection of two sputum specimens on consecutive days for TB smear microscopy and in the HIV positive patients, a third specimen is collected for smear and culture. The patient's HIV status influences the diagnostic algorithm which currently poses a challenge in timeous diagnosis of smear negative HIV positive patients which often results in high TB mortality due to the delay (DOH, 2009).

In South Africa, two positive smears are indicative of TB. Should one smear be negative, a third specimen is collected for microscopy and culture in cases of new patient and if one is positive, TB is diagnosed. However in a HIV positive person, one positive smear indicates

diagnosis of TB. Active TB in HIV positive patients is ruled out through screening for TB symptoms. TB cultures have been reported to yield better outcome in screening than TB smears and therefore more reliable in diagnosing TB in HIV positive people (DOH, 2009).

In the Siyanda district, similar to many districts in the province, poor adherence to the algorithm for diagnosis of Pulmonary TB (PTB) has been reported. TB suspects with an inability to produce sputum are diagnosed though X-rays (NCDOH, 2008). The South African TB Programme has over the years improved the algorithms for diagnosis and management of TB through consultation and obtaining expert opinion of provincial TB programme managers, medical doctors, academics from universities and utilization of TB research outcomes. Failure to adhere to the algorithms often result in misdiagnosis of patients and unnecessary treatment of patients and this was evident in the finding made in Kwazulu Natal (1998) where 4% of TB patients were unnecessarily treated and 9% were misdiagnosed (Reid, Newman, Wilkinson, Squire, Sturm and Gilks, 1998). Monitoring of patient response to TB treatment, which is one of the key indicators of programme performance, occurs at two and five months for new cases and three and seven months for re-treatment cases. TB and HIV co-infection monitoring forms part of the monitoring of programme performance.

2.3 Tuberculosis and HIV

The HIV epidemic has been reported to have fuelled the increase in the proportion of people diagnosed with TB placing a strain on limited resources. TB on the other hand is said to be the leading cause of death amongst HIV positive people. During 2007, 14.8% of the 9.27 million new TB cases globally were HIV positive. Although the number of people with TB diagnosed with HIV appears to have doubled, WHO reports that this could be attributed to improved TB data management (WHO, 2008b).

HIV infection leads to a reduction in the immune system resulting in the inability of the body to prevent the spread of the bacilli from localized granulomas and putting the HIV positive patients at a higher risk of rapid progression from latent TB infection to active TB disease (WHO, 2008). HIV is also said to increase the risk of TB disease reactivation and re-infection **(**Datiko, Yassin, Chekol, Kabeto, 2008). WHO (2009) reports that the risk of HIV positive people developing TB has increased from 6% to 20.6% and is said to be pronounced in those countries with a high HIV prevalence rate. This projection is higher in South Africa where 50% to 60% of HIV positive people with immuno-suppression are at risk of contracting TB (DOH, 2009). It is therefore imperative that TB prevention and control is successfully implemented.

2.4 Tuberculosis control

Lower TB treatment success rate have been reported in Africa in comparison to other regions and this is attributable to higher proportion of deaths and interestingly to a lesser extent to treatment defaulting (WHO, 2009). The adoption of the DOTS strategy revived the efforts to tackle TB effectively and was aimed at contributing towards achievement of the TB related Millennium Development Goal (MDG) of combating HIV/AIDS, malaria, and other diseases. South Africa similar to the Stop TB Partnership, a global organization aimed at eradicating TB through forming partnerships with international organizations and countries, has endorsed two targets linked to the MDGs. The two targets are to detect at least 70% of new sputum smear-positive TB cases and cure at least 85% of these cases and reduce TB prevalence and death rates by 50% relative to 1990 levels by 2015 (WHO, 2006b).

Non-adherence to TB treatment makes it difficult to control the spread of the disease, to reach the target for treatment success and to reduce the TB incidence rate. Non-adherence

might result in the development of drug-resistant TB which is more expensive to treat (Wares, Singh, Acharya and Dangi, 2003). The South African TB Control Programme aims to reduce the TB defaulter rate from 10.4% as was the case in 2005 to 4% by 2011, whilst the Northern Cape intends to reduce it from 13.1% to 5.8% in 2011. Different methods are being used in the province to directly observe patients while on treatment which include:

- Facility-based supervision (take treatment at the clinic)
- Workplace DOT (take treatment at work under supervision of a treatment supporter who could be an occupational health nurse, supervisor or colleague)
- Family-oriented and CBDOT provided by volunteers in the community (DOH, 2009).

TB patients are put on a six or eight months standard short- course in a fixed dose combination consisting of isoniazid, rifampicin, pyrazinamide, and ethambutol for two months, then isoniazid and rifampicin alone for a further four months. In addition re-treatment cases receive a fifth drug namely streptomycin for the first two months of the intensive phase which lasts for three months. (DOH, 2009). TB becomes non-infectious when a patient has been on treatment for about two weeks. The patient is considered cured and discharged at six months when they "have negative smears at 5 months and had negative smears on at least one previous occasion at least 30 days prior" (DOH, 2009: 40). The guidelines are clear on the management of TB treatment interruption. However, poor programme management including inappropriate patient diagnosis, management, poor patient monitoring could result in failure to achieve MDGs and targets set by WHO (DOH, 2007). The implementation of intervention strategies to reduce the default rate has not

yielded satisfactory results and more attention to social and economic causal factors is recommended by WHO (WHO, 2005).

The WHO recommends that a TB patient be supported through the entire duration of treatment. Health facilities with limited human resources and increased number of TB patients have failed to effectively manage the cases that presented at the facilities. Facility based support has been reported to not be accessible to all patients at all times. Many countries like South Africa (DOH, 2009), Tanzania (Lwila et al, 2003) and Pakistan (Walley et al, 2001) are implementing a range of treatment support models including CBDOT for TB patients. This service is provided by volunteers from the community or by family members. When properly managed, the programme provided at community level has the potential to have positive TB outcomes by ensuring that TB patients adhere to their medication (Kironde and Banjunirwe, 2002).

2.5 DOTS strategy

Subsequent to the forty-fourth World Health Assembly in 1991, where TB was declared a global emergency there was a global adoption of the DOTS strategy as a policy package for the control of TB by WHO during the early 1990s (Maher, Chaulet, Spinaci and Harries, 1997; WHO, 1999). The DOTS strategy is a combination of technical and managerial interventions and is regarded as the most effective strategy to address TB challenges. All avenues are explored to effectively tackle the disease by addressing all risk factors that make individuals susceptible to TB infection. The strategy has five principles: political commitment with increased and sustained financing; case detection through quality-assured

bacteriology; standardized treatment with supervision and patient support; uninterrupted supply of drugs and recording and reporting.

2.5.1 Political commitment with increased and sustained financing

Political commitment revolves around prioritizing TB. Additional resources will be needed and this will require political commitment to mobilize resource within government and outside by liaising with all partners in the fight against TB. Political commitment has been seen to go further to include civil society and TB advocacy groups. For example in SA where amongst others Treatment Action Campaign (TAC) has been seen to play a prominent role in influencing policy change for HIV and TB in South Africa by holding government accountable to service delivery resulting in improved access to services for people living with HIV and AIDS (TAC, undated).

2.5.2 Case detection through quality-assured bacteriology

The National TB Control guidelines for South Africa (DOH, 2009) recommended sputum smear microscopy and culture and drug susceptibility testing (DST) as the method of TB case detection. For this to be realised, a laboratory network with culture and DST services is required and attention is also required for case detection amongst HIV infected people and other high-risk groups. The Northern Cape Province has one laboratory facility that conducts cultures and DST which poses a challenge with regards to access to services and turn- around times (NCDOH, 2009). New interventions have been suggested to improve case detection and achieve WHO targets. Widdus (2003) reports that there are more than 50 public-private partnerships that operates globally with the purpose of improving access to

health care by providing the means to fight diseases like TB and malnutrition related to poverty.

2.5.3 Standardized treatment, with supervision and patient support

The important factor in management and control of TB is the appropriate provision of standardised treatment to all categories of adult and paediatric patients. Supervision of TB patients when taking treatment may be undertaken at facility, home, in the community or at work (WHO, 2006b).

2.5.4 Uninterrupted supply of drugs

An effective drug supply and management system with reliable drug procurement and distribution systems need to be maintained. WHO (2006b) recommends that TB drugs should be supplied to patients at no cost.

2.5.5 Recording and reporting

The TB data gathered through a reliable recording and reporting system is utilized to plan, procure and distribution TB medication. A sound and reliable monitoring and evaluation system forms the basis for evaluation of programme performance and informs policies and decision making at management level. The TB Control Programme has standardised recording and reporting tools that allow for tracking of programme performance at the lowest level of health care. All health care providers are required to use the tools to improve reporting of cases (DOH, 2009).

2.6 Effectiveness of the CBDOT programme

The implementation of the DOTS strategy is viewed as being effective by the WHO since its adoption in the early 1980s. It has been established that the treatment success in areas implementing the DOTS programme globally since 1998 became evident in thirteen consecutive cohorts of new smear positive patients treated between 1994 and 2006. The programmes maintained an above 80% treatment success rate and the prevalence and mortality rates related to TB are decreasing (WHO, 2009). An important component of the DOTS strategy is the direct observation of treatment which is intended to address patients' non- compliance to treatment (Kironde and Kahirimbanyi, 2002). The WHO (2008a) recommends that supervision must be carried out in a context-specific and patient-sensitive manner, either at a health facility, in the workplace, in the community or at home; and is meant to ensure adherence on the part both of providers (in giving proper care and support) and of patients (in taking regular treatment). Researchers have found out that the models of support differ in certain areas. Lwila et al (2003) established in a study done in Tanzania that TB patients on the health facility support had to be supervised at the clinic during the two-month intensive phase and self supervised during the continuation phase. Patients on CBDOT were expected to collect their treatment from the clinic monthly throughout the duration of the treatment whilst patients on facility based DOT collected their treatment daily for the first two months . In comparing the outcomes in the two modalities, it was apparent that the cure rate between TB patients on facility-based DOT and community DOT yielded no significant difference confirming that it is not necessary for health care worker to supervise a patient because a trained CBDOT supporters that are supervised by health workers are just as efficient in caring for the TB patient as the health worker. Lwila et al (2003).

Similar conclusions were drawn from the studies conducted by Zwarenstein et al (2000) and Kironde and Kahirimbanyi (2002). (Zwarenstein et al, 2000) conducted a study in Elsies River, a suburb in Cape Town and compared TB treatment outcomes for patients on facility based DOT, self-supervision and CBDOT. TB patients on facility based DOT took treatment under direct observation of a nurse for five days a week for the first eight weeks during intensive phase and three times a week for the continuation phase. The patient on CBDOT had to go to the Lay Health Workers (LHW) who kept the medication. The study yielded similar results with no significant difference in treatment outcomes between facility based DOT and CBDOT model. Kironde and Kahirimbanyi (2002) established that CBDOT model and facility based DOT model offered under supervision of a nurse yield similar TB treatment outcomes for new TB cases but indicated that there was a significant difference in the treatment outcomes of re-treatment patients that were on CBDOT as compared to those on self therapy. All three studies have therefore confirmed that CBDOT is as effective as facility based offered by health care workers. CBDOT was therefore confirmed as being of better-quality mode of support amongst re-treatment cases than self- supervision. The findings imply that CBDOT is a workable and cost effective option, especially in high burden TB settings (Kironde and Kahirimbanyi, 2002) and low resource settings (Zwarenstein et al, 2000). Lwila et al (2003) was however quick to point out that CBDOT model should not replace facility based DOT and should rather be used to supplement other treatment modalities (Kironde and Kahirimbanyi, (2002).

2.7 The Stop TB Strategy

The Stop TB strategy initiated by WHO has been adopted by many countries including South Africa with the sole purpose of addressing the challenges and gaps to enable national programmes to achieve the MDGs (WHO, 2006b).

The six principles of the stop TB strategy include:

- Pursue high-quality DOTS expansion and enhancement which includes the five principles of the DOTS strategy.

  TB challenges can be addressed through the implementation of collaborative activities such for the prevention and control MDR TB. Intervention strategies should target high risk groups including prisoners and refugees.
- It is important to educate the community on TB
- The strengthening of the health system can be achieved through the mobilization of resources.
- The engagement of all care providers through Public–Public and Public–Private mix approaches that have been proven to be effective in increasing case detection and the management of TB patients (Arora, Lonnroth and Sarin, 2004).
- Operational research at programme management level should be encouraged and to enhance research on development of new TB drugs, vaccines and TB diagnostics. (WHO, 2006b).

Despite the various strategies and initiatives that have been put in place, there are still factors which influence adherence to TB treatment.

2.8 Factors influencing adherence to TB treatment

There are many factors contributing to poor adherence to TB treatment as is discussed below.

2.8.1 Patients' Understanding of Treatment

There are different factors that could influence the TB patient's understanding of his treatment. Some studies confirm that low literacy levels can be linked to non-adherence or is a significant risk to poor adherence. Wolf et al (2007) conducted a study on literacy, self-efficacy and HIV medication adherence and established that 31.4% of the non-adherent patients had marginal to low literacy skills. Hoa, Diwan, Co and Thorson (2004) established in a study in Vietnam that when the literate and illiterate TB patients were scored on TB knowledge, the illiterate patients had performed poorer than the literate. This finding is collaborated in another quantitative study conducted by Gopi, Vasantha, Muniyandi, Chandrasekaran, Balasubramanian and Narayanan (2007) in South India, where a higher percentage (39%) of patients were found to be non- adherent and illiterate in comparison to 30% of the literate non-adherent. On the contrary, Comolet, Rakotomalala and Rajaonarioa, 1998 found no significant difference in the literacy level between defaulters and adherent patients.

A direct association is reported between lower educational levels and poor health status (Ratzan, 2001). Illiteracy results in the inability of patients to understand information given to them by health professionals on the disease, instructions on their treatment and the duration of treatment and on the outcomes of failure to adhere to treatment. This could be attributed to diagnostic and treatment options that have become more complex (Ratzan, 2001). The literate patients in Vietnam study were found to comprehend and have adequate knowledge on TB and therefore adhere more to TB treatment than the illiterate highlighting the need for improved communication strategy targeting the illiterate (Hoa, Diwan, Co and Thorson, 2004). "Health literacy is the capacity to obtain, process and understand basic

health information and services needed to make appropriate health decisions" Selden *et al.*, (2000 as cited by Ratzan, 2001:211).

Individuals with limited health literacy come from all walks of life and the problem of limited health literacy is often greater among older adults, people with limited education and those with limited English proficiency. Patients' understanding of their conditions, treatment and purpose thereof is positively related to treatment adherence (Haynes, McDonald and Amit, 2002; Munro et al, 2007). There are striking gaps between the way health information is presented and the patients' ability to understand and act on it. The interpretation of disease, illness and wellness by patients may be different to what was given by the health professionals (Bam et al, 2006 and Gopi et al, 2007). "The patients' knowledge, attitudes and beliefs may however act as 'filter' for the information and services offered by health services" (Munro et al, 2007: 1241). Naidoo, Dick and Cooper, (2009) refers to the attribution theory to explain why causal attributions or a patient`s understanding or perception of the cause of the disease would contribute to them adhering to their treatment. In their study, patients had a belief that their disease was caused by certain external factors beyond their control, referred to as "out of their locus of control". They believed that there was nothing that they could do to improve their condition and had no control over their fate. Rotter (1975) refers to this group of people as having a high external locus of control.

Some studies report that patients appear to be better adherent to treatment during the intensive phase of treatment (Naidoo et al, 2009). When chemotherapy begins to take effect, TB patients stop taking their treatment because they are not well informed, the symptoms subsided (Munro et al, 2007) or they were feeling better (Estifanos and Lindtjørn, 2005). As demonstrated by Comolet, Rakotomalala and Rajaonarioa (1998), twenty six out of the

ninety five patients in a study conducted in Madagascar stopped taking treatment around the third month because they felt better and 12% were not aware of the normal duration of TB treatment. Bam et al (2006) had similar results in a study conducted in Nepal, where 35.5% of non-adherent TB patients defaulted because they were not told to take treatment regularly and 25.4% thought that they had been cured.

2.8.2 Attitude of TB patients

Kironde and Bajunirwe (2002) pointed out that the TB patients seem to have negative attitudes towards the DOT support system. In their study, there appeared to be a lack of confidence in the DOT supporters with the perception that they were not well-trained. Another factor identified was that the community was not properly informed during selection of DOT supporters. Complacency broadly defined as a feeling of pleasure or security often while unaware of potential danger has been cited as being common amongst TB patients and in some studies as a contributory factor to TB defaulting. Naidoo, Dick and Cooper (2009), conducted a study in the Western Cape Province, South Africa, and established that TB patients took their disease less seriously than they would HIV, which could possibly be attributed to their knowledge that TB is curable. Newly diagnosed TB patients might receive the news of their diagnosis with in a more positive light than they would a diagnosis of HIV. The prevalence of TB in the community might influence a response of that nature as they would probably know a lot of people diagnosed with TB in the community but who are fine (Naidoo, Dick and Cooper, 2009). On the other hand, TB patients in a study conducted in Thailand showed that TB patients' beliefs about whether TB can be cured influence their attitude towards their disease. Ninety five percent of patients in this study who reported to have had a good attitude towards TB treatment, were also compliant with their treatment (Lertmaharit, Kamol-Ratankul and Jittimanee, 2005).

It is therefore important that patients are well informed about the DOT strategy so that they can be fully aware of what to expect during treatment which would alleviate the negative attitudes experienced.

2.8.3 Previous interruption and defaulting

Previous defaulting and continuous interruption of treatment are amongst the common predictors for defaulting. In a study by Shargie and Lindtjørn (2007), two thirds of TB defaulters were known to have interrupted treatment during the intensive phase of their TB treatment. Almost 80% of the re-treatment patients that had defaulted or completed treatment missed one or two treatment doses during the intensive or continuation phase. Similar findings were made in a retrospective cases-control analysis of data conducted in Bangalore City with the objective of identifying socio-demographic and treatment risk factors that resulted in TB defaulting. The ineffective retrieval system was reported to be one of the contributory secondary factors leading to TB interrupters ultimately being defaulters (Vijay, Balasangameswara, Jagannatha and Kumar, 2003).

2.8.4 Organization of Health Services

Despite the availability TB diagnostics for 100 years and anti-TB drugs for the past 50 years, the spread of TB still has not been controlled. The WHO attributes this poor performance to, amongst other reasons, poorly organized services that fail to ensure detection and cure of TB patients. In the former soviet republic, the collapse of the health care system has resulted in increased TB incidence rate (WHO, 1999). The escalating TB challenges in South Africa are attributed to historical neglect of the TB programme and poor programme management (Fourie, 2006). There are several factors within the health services that can impact on adherence to TB treatment.

2.8.4.1 Accessibility and availability of treatment

In a qualitative study conducted by Portwig and Couper (2006), TB patients indicated that travelling to and from the clinic was one of the reasons why they defaulted from treatment. The CBDOT programme was therefore implemented to address this challenge. CBDOT favoured by TB patients on the CBDOT programme in Tanzania was found to be more accessible as patients did not have to go to the clinic daily to collect medication and it was flexible, allowing patients to continue with normal daily activities which were convenient to patients (Wandwalo et al, 2004). However, this is not always the case. In studies conducted by Zwarenstein et al (2000), Khan et al (2005) and Dick, Murray and Botha (2005), TB patients on CBDOT were expected to take drugs at their DOT supporters' homes and under their direct supervision which meant that they had to go to the DOT supporter's house which was not always convenient. In a Western Cape study, DOT supporters waited at their houses for TB patients to come daily for their treatment (Dick, Murray and Botha, 2005). In the Rawalpindi district, India, the CHW was expected to visit the patients at their homes but instead it was left up to the patient to visit the CHW (Khan et al, 2005). The patients resented this mode of support which in their opinion contributed to them defaulting from TB treatment. In many instances they were too sick to go to the CHW's home or they would not find the CHW at home, thus defeating the purpose of CBDOT.

WHO recommends that TB patients receive an adequate uninterrupted supply of TB treatment free of charge (WHO, 2006b). In a study conducted in Nepal, a patient amongst those that adhered to TB treatment cited free TB treatment as a factor that encouraged him to adhere to treatment. Although some patients reported TB drug shortage at some of the clinics, this did not discourage them from adhering to their treatment. (Wares et al, 2003).

2.8.4.2 Quality of care

One principle of Community Home Based Care is for CHW to promote and ensure quality of care, safety, commitment, cooperation and collaboration (DOH, 2005). However, the number of patients to be observed by each DOT supporter may impact on the outcome of the patients and the effectiveness of the method employed. DOT supporters provide in addition to treatment support to TB patients, care to HIV and AIDS patients, the frail and old, disabled and post delivery patients. Dick, Murray and Botha (2005:11) are of the opinion that DOT supporters should not become "home carers" for HIV and AIDS as this "blurs their role as TB treatment supporters" and would lead to inadequacy within the TB Control Program.

The method used to allocate a DOT supporter to a TB patient could impact on the adherence to treatment by the patient. In studies conducted by Zwarenstein et al (2000) in Cape Town and Wandwolo et al (2006) in Tanzania, TB patients were randomly allocated either to CBDOT or facility DOT. The patients on CBDOT program were supervised either by a family member or close relative who lived with the TB patient, a former TB patient or LHW in the case of the Cape Town study. The treatment outcomes of patients randomly assigned to CBDOT was found to be more effective than those patients that were given an option to choose a DOT supporter at the facility. This could be attributed to family member being encouraged to see one of their own being cured from the disease or previous TB patient being given an opportunity to support another patient through the period of taking their treatment.

The service provided by DOT supporters in some instances is viewed as being of poor quality in that functions including TB health education, case detection and patient referral (Dick, Murray and Botha, 2005) are not performed adequately. Instead DOT supporters were found only "policing" TB patients (Khan et al, 2005), resulting in TB patients not being knowledgeable about TB, which can contribute to poor adherence. This is confirmed by the findings in the randomized controlled study conducted in Tanzania where TB patients in the CBDOT programme were of the opinion that TB patients obtaining their treatment at the health facility were receiving regular health education whereas they were not (Wandwalo et al, 2004b). This could be attributed to CHWs lacking the skills to provide simple services even within their scope due to lack of training and intermittent supervision as was established in Tamil Nadu, India. In this case, the volunteers were unable to respond to drug related complaints raised by the patients and this has been cited as a contributory factor to poor treatment outcomes (Nirupa et al, 2005). This is consistent with the findings of the study done by Wares et al (2003) in Nepal where poor performance on the part of LHW resulted in TB defaulting. Adherent and non-adherent TB patients in the same study equally indicated good knowledge on TB and treatment duration although some non-adherent TB patients were found not to utilize the information gained from the CHWs to make sound health decisions by completing their treatment (Wares et al, 2003). Twenty one TB patients from each of the adherent and non-adherent groups indicated that they had not been informed about drug side effects which led to 34% of TB patients defaulting on treatment. Lack of information can be seen as an indication of poor quality.

2.8.5 Attitude of DOT supporters and health care workers

The right of patients to respect, dignity and privacy is upheld and protected in several international and local publications (WHO, 2001; WHO, 2006a; DPSA, 1996). The

relationship between a TB patient and the DOT supporter is important in ensuring adherence to treatment. Naidoo et al (2009) are of the opinion that good communication between the health care provider and a patient is able to predict adherence to TB treatment. Communication allows for people to raise and address concerns and to be treated with dignity. Upholding patient rights increases positive attitude towards one another and motivation to adhere to treatment (Naidoo, Dick and Cooper, 2009). Wares et al (2003) confirmed that health care workers' negative attitude, inept behaviour and aggression was the second most common reason for non-adherence in Nepal.

2.8.5.1 Support of the DOT supporters by health professionals

The attitude of the formal health workers toward the DOT supporters plays a prominent role towards the involvement of the community in the control of TB. Due to their lower literacy level, LHWs are often treated without respect by the health professionals who are of the opinion that they are more superior to the LHWs. In addition, health professionals lack the ability to optimally utilize the lay workers to the benefit of the health system (Kironde and Bajunirwe, 2002).

Another factor is the failure by the Department of Health to provide incentives for the supporters may result in disruption of service provision (Kironde and Bajunirwe, 2002). However, DOT supporters in the Northern Cape Province have over the past four years been paid a stipend of R1000.

2.8.6 Side effects of TB drugs

Different views are held by researchers on the impact of side effects on TB defaulting. Comolet, Rakotomalala and Rajaonarioa (1998) in a study done in Madagascar was unable to establish a correlation between drug side effects and treatment defaulting. The findings showed that TB drug side effects were common and in reasonably high proportion between the defaulters and controls. This finding is corroborated by a study done in India which demonstrated that patients who reported drug side effects and those who did not had similar treatment outcomes (Nirupa, et al, 2005).To the contrary, some researchers established that TB drug side effects and inadequate information on side-effects can lead to TB treatment default. In the findings of a systematic review done on forty four articles by Munro et al (2007) it was found that some TB patients reported to have stopped taking their treatment because they experienced side effects. These findings are further supported by Wares et al (2003) in a non- randomised, exploratory, semi- qualitative study in Tarai, Nepal using non-adherent and adherent TB patients. The researchers established that vomiting, stomach problems and itching were the most common side-effects stated by eleven out of thirty two non-adherent patients as contributing toward stopping TB treatment. Similar to the systematic review conducted by Munro et al (2007), it is also reported that some patients were not informed by the health care workers as to what to do when they experience side-effects (Wares et al, 2003). It is apparent that patients are still not properly counselled and supported through the treatment period (where they should have been told about the side effects and what to do about it) and the quality of patient counselling and education provided is questionable. Apart from the health services there are social factors that also influence adherence to TB treatment.

2.8.7 Social Factors

2.8.7.1 Substance abuse

Extreme poverty, poor support networks, unstable living circumstances, previous incarceration, alcohol and substance abuse and lack of high school education are cited as factors that can adversely influence TB treatment outcomes (Gross, R. and Blumel, 2008; Franke et al, 2008). Gelmanova et al (2007) established that substance abuse is the single major factor associated most strongly with non-adherence to TB drugs and defaulting in Tomsk, Russian Federation. Fourteen out of twenty one TB defaulters were found to be alcohol abusers upon initiation of treatment and three out eighteen were found to abuse alcohol after treatment had been initiated. Contrary to this finding, excessive alcohol use was not found to be statistically significant in contributing to TB treatment defaulting in a case-control study done in Tamatave, Madgascar (Comolet, Rakotomalala, and Rajaonarioa, 1998).

The Northern Cape Province ranked third highest at 8.9% amongst provinces with the highest level of hazardous drinking during 2005 and amongst pregnant women ranked the highest at 24.9% (Peltzer and Ramlagan, 2009). This could have serious repercussions for the control of TB in this province.

2.8.7.2 Migration of TB patient

The Stop TB strategy clearly recommends that it is essential to put in place intervention strategies to address the plight of the groups that are at risk and they include the migrant workers, slum dwellers, cross border populations and the homeless (WHO, 2006b). Movement of communities has become more pronounced due to many reasons and these

include unemployment, refugee migration, asylum seeking, cross border movements and homelessness. Unemployed people are at a greater risk of defaulting on TB treatment as they often have to migrate to areas where they can find employment (Hasker et al, 2008; Gelmanova et al, 2007). This is common amongst populations that are skilled and they migrate to certain areas that will offer them employment for short period of time. These workers are often not planning to stay permanently in the location of work. The living conditions are in most instances very poor, overcrowded and there is poor nutrition which puts them at a risk of contracting TB (Koebel and Daniels, 1997).

These conditions are also common in slum dwellers, the homeless, refugees and those moving across the border (Figueroa-Munoz and Ramon-Pardo, 2008). In these displaced population, poor access to the TB programme and TB treatment is common and therefore interrupted supply of TB drugs. TB patients may not stay long enough in one place to complete treatment (Ford, Sizaire and Mills, 2008)

The United States of America (USA) is said to have more than four million migrant farm workers in an industry that is viewed as the second most dangerous occupation due to poor living and working conditions and amongst others they have high incidence rate of TB (Morbidity and Mortality Weekly Report, 1992). Migrant workers are said to prioritize acute illness over preventive care and chronic diseases when they seek treatment. Cummings et al (1998) conducted a quantitative study in California in an attempt to determine the link between patient migration and DOT and established that 77% of patients who moved were actually on DOT. They further established that those patients who moved defaulted nearly

six times more than those who did not move. The reasons for defaulting treatment however were not clear.

TB patients have to take treatment for at least six months. This prolonged period might pose a challenge for migrant communities in completing the full treatment as some might move to a new location before completing treatment and experience fear of discrimination. The Cummings study finding is supported by a discovery made in Delhi, India where slum dwellers often changed their residence in pursued of better job opportunities therefore making it difficult to trace and treat them (Singh, et al, 2002). Due to the laws of some countries, TB patients are motivated to complete their treatment. Populations that migrate to the USA with latent TB are mandated by law to obtain a certification of preventive therapy which served as an encouragement for them to return to the clinic and complete their preventive treatment (Munro et al, 2007).

In treating Ethiopian nomads, Chiu (2005) highlighted adherence counselling as the most important component of any TB treatment because the course of treatment is so burdensome. Of all the patients that formed part of the individual counselling sessions and group education sessions in the study, 80% completed their treatment and only 10% defaulted.

2.8.7.3 Social and community support

Family support is one of the key factors in ensuring that a TB patient adheres to their treatment. TB patients that are supported by family and the DOT supporter are able to achieve good treatment outcomes (Thiam et al, 2009).

2.8.7.4 TB stigma

People with TB often suffer from labelling, stereotyping (Link and Phelan, 2001) social isolation, rejection and discrimination imposed by family members and the community. Kelly (1999, as cited by Naidoo et al, 2009) refers to this definite experience of stigma as "enacted stigma". Because of the high death rate amongst TB patients also infected with HIV, traditional healers in Zambia refer to TB as "Satan's disease". This has been reported to impact negatively on patients' health seeking behaviour, disclosure and adhering to TB treatment (Department of International Development, 2006). The disease stigma has become more pronounced in communities with high TB and HIV prevalence. Fear of being labelled as being HIV positive may be a decisive factor by TB patients not to inform family members that they have TB (Zolowere et al, 2008).

It has been reported that TB patients and their families are often rejected by their communities (Liefooghe et al, 1995; Baral, Karki and Newell, 2007) Rejection is also in some instances reported within a family. India has been reported to have incidents of a member of the family being shunned by other members because they have TB. Persons contracting TB are said to have diminished prospects of getting married and this therefore influences the decision of women and parents of girl-children to seek health care when TB is suspected or to take treatment under the CBDOT programme (Jaggarajamma et al, 2008). Fear of contracting the disease has been noted to drive family discrimination but on the other hand although to a lesser extent in the Nepal study TB patients have been seen to "self-stigmatize" either for fear of infecting family members, in attempt to avoid gossip or fear of discrimination (Baral, Karki and Newell, 2007). Some TB patients have been reported to be ashamed to attend social functions for fear of coughing amongst other people and some thought that friends and neighbours kept away from them because of the disease.

In a study done in Nepal, with 63% of the population infected still reports that stigmatization of patients by the community is common. Some TB patients during in-depth interviews reported that they were isolated by fellow patients in a hospital once it was known that they had TB (Lewis and Newell, 2009).

Few interventions, conventional in nature (ElIis et al, 1997) are designed to address the social and family support challenges (Munro et al, 2007). These interventions only target education and behaviour change on the part of the patient to enable them to adjust to the medical regime. Family and community can play an important role in motivating and counselling these patients and NGOs can be mobilized to establish support system in the community (Jaggarajamma, et al, 2008).

2.8.7.5 Employer support

TB patients have been reported not to disclose their disease to their employers because they did not wish the employers to know of their disease. Foreign born employees in the USA have shown an increase in the number of TB cases and are therefore subjected to TB testing before being employed. TB testing was carried in immigrants in East London, although some of those immigrants screened found it acceptable some thought it was discriminatory because their perception was that only immigrants were screened (Brewin, 2006).

As much as 63% of TB patients did not inform their colleagues that they had TB in a study done in India. The workers feared that once their employers knew that they had TB they would be laid-off work (Jaggarajamma et al, 2008). These perceptions have proven to be a common reason for non-disclosure amongst employed TB patients as supported by two

other research findings. The findings of the research studies reviewed by Munro et al (2007) were indicative of fear of losing one's job or being dismissed as one of the reasons for failure to disclose TB disease to the employers. These findings were further supported by TB patients interviewed in Vietnam who reported that because of the stigma linked with TB they feared losing their jobs if they informed their employer that they had TB. They also were not at liberty to request financial assistance from the employer to procure medication and this contributed to non-compliance to TB treatment (Johansson et al, 1996).

2.8.8 Financial support

TB defaulting is worsened by reasons such as failure to earn an income during visits to the clinic (Rubel and Gorra, 1992); or inability to work (Liefooghe, et al, 1995). The transient nature of seasonal workers and the long duration of TB treatment may result in poor adherence to TB treatment. Twenty nine percent of the patients in a South India study defaulted due to migration for occupational reasons and natives returning to their place (Jaggarajamma et al, 2007).

Failure of people to seek employment and provide for their families may result in them seeking social assistance. The social assistance regulations (2008) defines temporary disability grant (TDG) as "a disability that will continue for a period of not less than six months or for a continuous period of not more than twelve months as the case may be". TB patients in South Africa are eligible to a temporary disability grant (TDG) sometimes referred to as "perverse incentive" because patients are seen to be rewarded for contracting the disease and therefore resulting in failure amongst some of the defaulters to take "health enhancing medicines" (Steel, 2006). An increase in the uptake of TDG has been linked to an increase in the occurrence of chronic diseases including HIV and AIDS and TB. Due to

high levels of poverty, it has become apparent that there would be an increase in applications for the grant as more people have no income other than the grant (Steel, 2006). Similar perceptions were shared by patients interviewed in a Cape Town study that aimed at determining the socio-cultural understanding of TB among patients and household members. Although some respondents in that study indicated that social security support was a perverse incentive for TB patients to default on their treatment, none of those TB patients asked would admit to that (Ellis et al, 1997). However, Steel (2006) in a quantitative and qualitative study found no similar evidence in the developed countries like the USA and United Kingdom.

In this chapter an overview of TB was given followed by how TB is controlled and the factors influencing adherence to DOT. The purpose was to explore the international and local policies that influence the provision of TB services at all levels and the role played by service providers as well as the effectiveness of the health services and of CBDOT. It was further explored how family and social factors influenced adherence. TB patient's knowledge attitude and behaviour was also covered. The next chapter will deal with the aim, objectives of the study, description of the research design and the methods.

CHAPTER 3

METHODOLOGY

3.1 Introduction

This chapter outlines the aim and objectives of conducting this study and describes the methodology of this study including the rigour and limitations experienced of the study.

3.2 Aims and Objectives

3.2.1 Aim

The **aim** of the study was to explore the reasons for defaulting of TB patients from TB treatment in the CBDOT programme in the Siyanda district, Northern Cape Province.

3.2.2 The Objectives of the study were:

- To explore patient specific factors associated with TB treatment default amongst patients in the CBDOT programme.
- To explore health system specific factors associated with TB treatment default amongst patients in the CBDOT programme.
- To explore community, social and cultural factors associated with TB treatment defaulting among patients in the CBDOT programme.

3.3 Study Design

This was an exploratory qualitative study grounded in a phenomenological approach, conducted to explore and obtain in-depth understanding of the context and issues affecting adherence to TB treatment in the CBDOT programme (Morse, 1994).

Marett (2005) defines anthropology as a study of human beings everywhere throughout time. An anthropological approach was taken in an attempt to understand the relationship between cultural and social structures and how they impact on health (Krumeich et al, 2001). This method was chosen as it allowed for in-depth exploration of the knowledge and perceptions of all participants and sharing of rich information and experiences and it is useful in studying and understanding human behaviour and developing theories (Green and Thorogood, 2004). The researcher's background in TB increased her ability to identify with the actual experience of the participants and to have an extensive understanding of their world they live in Creswell (2003, as cited by Van Rooyen, Le Roux and Kotze, 2008).

3.4 Study population

The study population consisted of three categories in the study population. The first category was of TB nurses from the PHC facilities. The second category comprised of DOT supporters working on the CBDOT programme and who had worked with TB patients for at least one year. The third category was of TB defaulters above eighteen years who have been registered at one of the fourteen PHC facilities selected for the study in the Siyanda district between April 2007 and March 2008 was one category. They also had to be in the CBDOT programme and had stopped taking treatment for two or more months. The second category was of TB nurses from the PHC facilities. The third category was DOT supporters working on the CBDOT programme and who had worked with TB patients for at least one year. Children less than 18 years old were excluded as their failure to take treatment may be attributed to other reasons such as poor family commitment which would not have been applicable to adults who are the focus of this study.

3.5 Sampling

Purposive maximum variation sampling was done for key informants and focus group participants. To obtain maximum variation and to facilitate free discussion, participants were purposively selected based on their experience (Rice and Ezzy, 1999). Purposive criterion sampling was done for TB defaulters in order to obtain rich data (Rice and Ezzy, 1999). The vastness of the Siyanda district and the concentration of high numbers of defaulters in certain PHC facilities necessitated purposive selection from the local municipalities and PHC facilities. The Siyanda district TB outcomes report was drawn from the Electronic TB Register (ETR) per local municipality and two of the six local municipalities with the highest TB default rate were selected. The PHC facilities from the two local municipalities where the number of defaulters exceed ten patients were selected from the ETR. These amounted to fourteen facilities. The three categories of participants selected from the study population were as follows:

3.5.1 TB nurses

Two professional nurses were purposively identified as key informants from the Olifantshoek community health centre in the Kgatelopele Local Municipality and Lingelethu clinic in the //Khara Hais Local Municipality as they met the selection criteria of being the least experienced of one year and the most experienced nurses who had been trained on TB management.

3.5.2 DOT supporters

Two focus group discussions (FGDs) were conducted with five and six participants respectively. The intention was to have two groups of six supporters each but one DOT supporter declined to participate in the study with no reason given. The first FGD was

conducted with purposively selected and experienced DOT supporters solely from Kgatelopele local municipality. The second FGD was a mixture of DOT supporters from PHC facilities in the //Khara Hais local municipality which had the highest and !Kheis local municipality with the lowest TB defaulter rates. The DOT supporters were from different NGOs. The participants chosen were those least experienced and those more experienced in the TB Programme for the purpose of maximum variation. The DOT supporters were drawn from the two NGOs functioning in the district namely Northern Cape AIDS Forum and Christana. The selection was done with the assistance of TB nurses from the selected PHC facilities.

3.5.3 TB defaulters

Some key informants took the opportunity to identify TB defaulters that they thought should be included in the study, their reason being that some of them refused treatment and this study was viewed as a strategy to counsel patients and have them return to treatment. However, to ensure that information gathered was thorough and rich making the study truly purposive (Rice and Ezzy, 1999), the researcher chose the following inclusion criteria:

The participants should:

- have stopped taking TB treatment for 2 months or more
- be 18 years and above
- be registered at one of the 14 PHC facilities in the study in the Siyanda District between April 2007 and March 2008.
- be on CBDOT programme during the same period

Patient records were consulted to verify if the patient was on the CBDOT programme during their period of treatment and to obtain addresses to which they could be traced. Participants were purposively selected to include a range of ages and from both genders as well as

employment status to ensure that differing viewpoints were obtained. TB defaulters were interviewed until saturation was reached ending the interviews with ten defaulters.

3.6 Data collection

Apart from record reviews, key informant interviews, in-depth interviews and focus group discussions were conducted. The researcher acted as a facilitator during the FGDs and was the interviewer in the interviews. A tape recorder was used to audiotape all the data collection which were transcribed verbatim. The facilitator/interviewer took notes of all peculiar events during the interviews. The interviews were conducted in Afrikaans or English, at the request of the participants The researcher is fluent in both Afrikaans and English which was an advantage because this made the participants feel more at ease being able to converse in their own language (Rice and Ezzy, 2005). All sessions commenced with self introductions to establish rapport. The language of interview was agreed upon since most participants were Afrikaans speaking. The reception and atmosphere at all sessions were inviting and accepting.

3.6.1 Record review

Records of all defaulters in the study population were reviewed for patient treatment, follow-up notes and progress in order to select participants. An adherence profile was recorded for each participant. Gaps and recorded best practices on the community based programme, tracing of defaulters and communication between DOT supporters and clinic nurses were identified and a journal of the findings was kept.

3.6.2 Key- informant interviews

Two nurses were selected as key informants as it was anticipated that they would have different perspectives on TB depending on their experience in the TB programme. The first interview was conducted at Olifantshoek community health centre which is about 200km from Kimberley in the office of the key informant. The second interview was conducted in a counselling room at Lingelethu Clinic, Upington. There was much distraction at both venues as the interviews were conducted during clinic times. The interviews were conducted using a semi-structured interview guide (see Annexure A). The nurses trained on TB treatment guidelines and having had experience in managing TB patients were able to share their experiences in treating the patients.

3.6.3 Focus Group Discussion

The FGD allows for dialogue and therefore it is a technique that draws out rich information and it is during this process that participants have an opportunity to clarify and explore issues (Kitzinger, 1995). The advantages of FGDs are that it allows the platform for discussion of topics that might not normally be discussed openly and those that are reluctant to be interviewed can form part of the discussion group without fear of being discriminated against. Two FGDs were conducted with DOT supporters from two of the six local municipalities. Both venues were quiet, away from the hustle and bustle of the noisy area of the clinic and no disturbances were encountered. DOT supporters that participated in the first interview had their own transport to and from the interview locality whilst the DOT supporters that participated in the second FGD from Keimoes and Progress clinics were transported to and from their homes by the facilitator and this gave the participants time to know each other and for the interviewer to know them as individuals. A semi-structured FGD interview guide was used to conduct the FGDs (Annexure C). Participants in both groups were given refreshments

before the FGD which served as an ice breaker and was a token of appreciation. The FGDs were conducted in the participants` language of choice (Afrikaans or English). Participants were requested to give their personal experiences as DOT supporters as well as their perceptions on the effectiveness of the programme and reasons why TB patients defaulted. The FGDs attempted to describe the variety of challenges faced in CBDOT programme by DOT supporters from different facilities and NGOs and from different local municipalities, as well as documenting common elements. During the debriefing, participants shared their appreciation for being considered to participate in the study and regarded this encounter as an achievement. Information and best practices were shared amongst members of the second FGD. All FGDs and interviews were tape recorded and later transcribed verbatim.

3.6.4 In-depth interviews

In-depth interviews are described by Rice and Ezzy (1999) as focussed interviews, unstructured interviews, non-directive, open-ended or semi-structured interviews. It is during in-depth interviews that complex issues can be dealt with. In-depth interviews were conducted with identified TB defaulters on CBDOT programme primarily in consultation rooms that were in most cases poorly ventilated with lots of distractions as the interviews were done during clinic times. In one case, the interview was conducted under a tree outside a participant's house with continuous interruptions from parents and household members who were under the influence of alcohol. The participant appeared to be under the influence as well, although she denied it. The DOT supporters responsible for the identified TB patients were asked by the interviewer to trace and brief them prior to the interviews. Some participants had to be picked-up from their homes by the researcher and on some occasions they were nowhere to be found resulting in interviews being postponed and ultimately

cancelled. The researcher used this opportunity to observe the living conditions of the defaulters which reflected poverty including some uninhabitable homes.

A semi-structured in-depth interview guide (Annexure B) was developed which served to illicit reasons for defaulting from TB patients. The interviewer assumed a non-judgemental attitude and did not allow prior knowledge gained from the clinic sister about the participants to influence the interview process (Moustakis, 2004 as cited by Naidoo et al, 2009). An open dialogue was kept allowing participant and interviewer to reflect on their interpretations and gain common understanding (Rice and Ezzy, 2005). After completion of each in-depth interview, debriefing was conducted after the tape recorder was switched off so that the interviewer could share with the participant her interpretation and gave the participant the opportunity to check and clarify issues (Kvale, 1996 as cited by Naidoo et al, 2009). Each interview lasted between 45 -90 minutes.

3.7 Data Analysis

Analysis commenced simultaneously with collection of data. This enabled the researcher to continuously review and reflect on the data collected, identify gaps and highlights and further address these, generate meaning and ensured that issues emerging were incorporated into the data collection process on subsequent interviews. Thematic content analysis was done which included familiarization process of listening to the tapes and studying notes with the purpose of developing key ideas; a thematic framework was identified. The objectives provided the basic set of overarching organized categories which was the initial step in an attempt to derive meaning from responses of participants and to see what themes and concepts were generated. In addition, through the inductive process as data was analysed, some categories emerged. This process was followed by indexing of data, rearranging the data and lastly mapping and

interpretation. Notes that were kept during data collection, reflections, audiotapes and transcripts were used to provide thick description of the findings (Pope, Ziebland and Mays, 2000).

3.8 Rigour

Various measures to ensure rigour were employed during the study. Purposive sampling was done through the identification of TB patients that defaulted on treatment. Although the assistance of the clinic sister was solicited, other patients were also selected by the researcher so that information gathered was varied which ensured richness of the data collected (Rice and Ezzy, 1999). By not only relying on the choice of the clinic sister, selection bias which is broadly defined as deliberate selection of cases which can be a serious issue in qualitative research especially when extreme cases are selected was averted (Pope, Ziebland and Mays, 2000).

Triangulation of data sources was achieved by collecting information from the different sources i.e. from defaulters, TB nurses at the clinics and the CBDOT supporters to identify patterns of convergence which assisted in developing an overall interpretation (Pope and Mays, 1995). There was also methods triangulation through the different methods of data collection i.e. key informant interviews, in-depth interviews and FGDs.

Credibility was achieved through adoption of a non-judgemental and neutral approach in phrasing questions to the participants which made them feel at ease and therefore more prone to speak openly. The audiotapes were transcribed verbatim by an independent person to ensure that no information was lost adding to the credibility of the study. At the end of each

interview and FGD, key points were summarised and verified with participants on issues that had been discussed to verify information and clear up any misunderstanding.

A detailed account has been given of the context, selection of participants, the process of data collection and analysis to create an audit trail. Direct quotes have been included in the text to substantiate interpretations. Thick, rich information that is detailed renders the research credible as it allows the reader of the report to experience the events as was experienced by the researcher (Creswell and Miller, 2000). This transparency will allow any reader of the research report to judge whether the interpretation submitted is adequately supported by the data and that results can be applied to similar settings (Creswell and Miller, 2000). To ensure credibility of the study, the responsibility of establishing rigour was shifted from the interviewer/facilitator to the participants through member checking (Creswell and Miller, 2000). The interviewer took the transcriptions and interpretations derived from the interviews back to the FGDs and key informants to review them and confirm their accuracy. The FGDs and key informants offered objective comments and reflection of the discussions and the TB defaulters on the other hand would not be able to provide the same quality of criticism due to low education level and possibility of being subjective.

Reflexivity was enhanced by the researcher keeping a personal journal throughout the research process on her thoughts, state of mind and feelings so as to create self- awareness on her position. A debriefing took place with the supervisor telephonically to reflect on the research conducted.

3.9 Ethical Consideration

Written ethical approval was obtained from University of the Western Cape Ethics Committee and thereafter from the Northern Cape Provincial Health Research Committee. Permission was obtained from the district management to examine TB clinic records. Participants were informed that their names would not be used in the reports that will be generated. Careful measures were employed to treat the patients' records with confidentiality. Information collected from participants was placed in a locked-up file and no other person except the researcher can gain access to the records (Polit and Hungler, 1993). The purpose of the research was explained to all participants and they were made aware that they were participating in the study on a voluntary basis. A letter written in English and translated into Afrikaans explaining the research study, requesting participation and assuring confidentiality was handed to the patient and was explained to the patient verbally. Informed written consent was obtained from all the participants. Permission was also obtained from the participants to tape record the interviews.

Participants were informed that should they decide not to participate or change their mind later, they were welcome to withdraw at any time without any negative impact to themselves or their treatment. They were also reassured that the study would not interfere with their treatment in any way. No participant was paid for participating in the study and therefore there was no incentive to want to take part in the study which might have created bias if there was.

3.10 Limitations

The facilities with high TB defaulter rates selected are primarily from the peri-urban areas and therefore the findings will therefore not be applicable to the rural area in the same district. The limitation of qualitative research is that results cannot usually be used to make statements

about the wider community, that is, they can indicate a range of views and opinions, but not their distribution (Green and Thorogood, 2004). In FGDs participants often agree with responses from fellow group members and so caution was taken during interpretation of the results. Confidentiality may have been compromised by the presence of other participants. The researcher did everything in her power to put them at ease and win their confidence by being non-judgemental and convincing them of confidentiality and telling them about the importance of confidentiality. Pseudonyms were created for each participant. Another limitation in FGDs is that an unskilled interviewer might be unable to engage reluctant participants. To overcome this challenge, the interviewer drew all participants into the discussion when she noticed lack of participation from some in the group (Kitzinger, 1995).

The risk of recall bias, which is an inherent problem of retrospective study designs, was taken into account. A concern existed whether the respondents would remember events leading to them defaulting on treatment and when they stopped taking treatment. To address this, the study period was limited to one year prior to the study which also afforded the researcher the opportunity to intervene by convincing the defaulters to return to the programme (Katzenellenbogen, Joubert and Karim, 1997). For those defaulters who were unable to accurately recall their treatment history and when they stopped taking their treatment, verification of the self-reported data was done through proxy sources e.g. the use of patient clinic records. This assisted in verifying information given by the patient and in some instances assisting the patients in recalling information on their history of TB treatment (Hassan, 2006).

CHAPTER 4

RESULTS

4.1 Introduction

This chapter gives an overview of the socio-demographic status of the participants and gives the participants' responses during interviews with key informants, focus group discussions with DOT supporters and in-depth interviews with TB defaulters. The results have been organised into: patient related factors; social, community and economic factors; health system factors. The primary source of information was from tape recordings and a journal kept during the interviews.

4.2 Background quantitative socio demographic information

Table 3: Socio demographic data of all participants in the study

Characteristic		**Key Informants n=2**	**DOT supporters n=11**	**TB defaulters on CBDOT program, n=10**	
				New	**Re-treatment**
Ages:					
	18-19	0	0	0	**1**
	20-29	0	3	0	**8**
	30-39	1	0	0	**0**
	40-49	0	6	0	**0**
	50-59	1	2	0	**1**
	60 and above	0	0	0	**0**
Sex:					
	Males	0	1	0	**8**
	Females	2	10	0	**2**
Education					
	no formal	0	0	0	**0**
	basic elementary	0	11	0	**2**
	above elementary	2	0	0	**8**
Occupation					
	unemployed	0	0	0	**10**
	student	0	0	0	**0**
	pensioner	0	0	0	**0**
	employed	2	11	0	**0**
On disability grant		**0**	**0**	**0**	**6**

The two key informants were females and were registered nurses trained on TB management although one has been trained on TB adherence counselling. The two key informants worked in the TB clinic for one year and more than five years respectively, but in addition, they also provided PHC services. Only one male formed part of the FGDs. The DOT supporters have been classified as employed because they work up to eight hours per day and receive a stipend. All DOT supporters had a basic elementary education level.

Most of the TB defaulters were in the 20-29 age group and most (80%) were males. The sex of the defaulters was influenced by the availability of defaulters at the clinics selected. Other factors that also contributed to the higher proportion of males in the study were that more males (67.3%) than females (32.7%) sought TB treatment and that a higher proportion of males (68.9%) than females (35.1%) were found to default on TB treatment. Some defaulters whose names were selected from the register could not be traced and reasons given by the TB sisters and DOT supporters are listed in table 3. Eighty percent of the defaulters had above elementary education level (above grade nine). All participants were unemployed at the time of the interviews but were reporting on previous experiences as casual or contract workers and six of them were on the temporary disability grant during the period of default. Two of the defaulters indicated that they have never applied for the grant. All defaulters interviewed had defaulted treatment before and some of them had not resumed treatment at the time of the interview.

Table 4: Reasons for disappearance of TB defaulters on CBDOT that could not be traced

Cause	Defaulters not traced n (%)
Moved to the farms or elsewhere	13 (39.3)
Address incomplete or wrong	9 (27.2)
Died	11 (33.3)
Total	**33 (100%)**

4.3 Qualitative interview findings

4.3.1 Patient related factors influencing adherence to TB treatment

Many individual personal factors in this study appear to have influenced adherence to TB treatment.

4.3.1.1 Education level

None of the defaulters interviewed went to school beyond grade nine and some of them stopped at grade six and seven. Many of them are young people, ages ranging between 24-27 years and this was highlighted by both key informants:

They are just normal patients on DOT and they didn't go to school or they only left a lower standard

4.3.1.2 Alcohol use

Substance abuse seems to have played a major role in this study. The DOT supporters unanimously agreed that substance abuse is a major factor associated most strongly with non-compliance to TB drugs and defaulting:

He drinks every day, now tell me what is the problem?... alcohol! Alcohol! Alcohol! That is the biggest problem that we have here in Upington with our TB patients.

Alcohol is a problem, you can go and talk to him at the shebeen [pub], we talk so sternly with the patients...

These findings were supported by the key informants:

> *Patients go to drink [*alcohol*] at 7 o'clock in the morning and the patient is already not at home, the DOT supporter goes there every day to the patient but doesn't find the patient at home…now the problem is the patient is already addicted for a long time and when they come on TB treatment it takes time for them to stop drinking*

This was further supported by statements made by one defaulter who said that he drank a lot and was irritated by the unscheduled visits of the DOT supporter because he wanted to go and drink alcohol. It appears as if the TB defaulters prioritized alcohol intake over their TB treatment:

> *No, I drank a lot at that time, after drinking then I have a hangover then I feel that I am not going to the clinic*
>
> *No if I drink like that then I don't drink the tablets because alcohol and tablets don't agree with each other*

Another TB defaulter confirmed the statement:

> *On other days when I drink (alcohol) I don't drink my tablets and on other days when I don't drink (alcohol) then I drink my tablets*

From the information presented, it seemed as if some TB defaulters felt isolated if they could not drink alcohol with their friends.

> *When I drink with my friend then I don't want to take treatment because in my group I am the only one who takes TB treatment...I also want to enjoy... to enjoy with them.*

When asked whether counselling provided by lay counsellors to TB patients on alcohol abuse and smoking was adequate, this did not seem to be the case as one key informant responded:

> *I think if they can send them to a rehabilitation centre for treatment things of that nature, mm it's not easy nowadays to get somebody in a rehabilitation centre.*

4.3.1.3 Use of other medication and other health services

The use of other medication or health services does not seem to negatively influence TB patients' adherence on CBDOT program in this study. Most of the TB defaulters have not consulted private doctors or traditional healers with regards to TB. In fact one defaulter said that he consulted a private practitioner and said that he was incorrectly diagnosed with asthma and was only told at the clinic that he had TB.

4.3.1.4 Previous treatment interruption

There appears to be a link between previous treatment interruption and defaulting. Some TB patients that ended up defaulting had shown a history of interrupting treatment on several occasions prior to defaulting:

I drink them [TB tablets] on some Mondays, on some Mondays I don't come out. (This meant the patient had not gone for treatment)

4.3.1.5 TB drug side effects

TB drug side effects seemed not to have influenced TB treatment defaulting. Even though some TB defaulters were not informed about possible side effects, when they experienced those, they continued with the treatment:

No I don't stress about them [side effects]

4.3.1.6 Complacency

It was the perception of DOT supporters that TB defaulters were complacent about TB because they seemed to be more afraid of HIV than TB and therefore adhered more to the HIV treatment:

They have a thing ... they have a word that they use that 'I am not afraid of TB because TB can be cured'

4.3.2 Social, Community and Economic Factors

The association between TB and poverty is amplified by overcrowding, poorly ventilated housing, malnutrition, smoking, stress, social deprivation and poor social capital. Poor

living conditions and overcrowding in refugee settlements similar to informal settlements in the Siyanda district are said to increase the risk of TB (Figueroa-Munoz and Ramon-Pardo, 2008).

For TB patients to adhere and complete the prolonged course of treatment, they require the support of the family, their community and employers. Some might be unproductive for a certain period during their treatment, have no income to sustain themselves and their families and will therefore need financial support. Although most of the TB defaulters were poor and could not afford a balanced meal daily, they benefited from the social services food security project. When asked whether he had adequate and well balanced food during the time of treatment, one TB defaulter responded:

> *"Yes, I had, the welfare* [Department of Social Services] *also came to delivered food parcels"*

4.3.2.1 Financial support

TB patients qualify for a TDG for a period of not less than six months and not more than twelve months. Once the patients have been diagnosed with TB and commenced treatment, some of the patients voluntarily apply for the TDG and continue to receive the grant until it expires at the end of twelve months, irrespective of whether the TB patient adheres to treatment or not. There is currently no mechanism in place to link grant recipients to TB treatment adherence and the patient would therefore continue receiving the grant even though they had stopped taking their TB treatment. The Social Assistance Act (2004) does not state how often a person can apply for the grant. Some TB defaulters in the study with a history of interrupting and defaulting on TB treatment have been disability grant

beneficiaries on more than one occasion. After the grant has been stopped, many reported to have resumed their treatment and re-applied for the grant.

DOT supporters indicated that TB defaulters were informed about TB and some TB defaulters on the disability grant stopped taking their treatment at a certain time during their treatment course because they wanted to continue benefiting from the disability grant:

> *They drink those* [TB tablets] *for six months. When they get to two months, this month they dodge, ask me why?... because if you dodge this month, it means that when we get to six months, the fifth month sputum, then it will still be positive and it means that they can still get paid.*

With the guaranteed continued pay-out of the grant, one DOT supporter was of the opinion that TB defaulters misused the disability grant:

> *He gets that pay but on that day… the following day he has got nothing left of that pay and that tells me that he still doesn't care for his health*

The perception of the DOT supporters was confirmed by this TB defaulter:

> *The other reason is that I got the pay* [disability grant] *then I took a DVD for myself, you see? Then the pay was stopped, I couldn't pay it off and the people came to take it, now it is again at the shop*

It became difficult to prove the latter as no defaulter admitted that disability grant was not an incentive to taking TB treatment. When asked whether the disability grant in anyway might have impacted on him defaulting, one TB patient said:

> *No, I have now decided that I must complete the treatment otherwise I don't know what will happen to me*

When asked how the abuse of the grant could be stopped, a DOT supporter said:

Look, when the patient received the grant, he misuses it and he doesn't buy what he is supposed to buy. Maybe the nearest HBC authority ... then the HBC to look, then the HBC ensures that everything is done in the correct manner but then the HBC [needs to] *works with welfare* [the Department of Social Development].

Not all defaulters on CBDOT program have been on the grant during the treatment period and some defaulters have actually decided not to re-apply after the grant had expired:

4.3.2.2 Community and family support

TB patients are most likely to adhere to treatment and be cured if they are supported and cared for by their families (Thiam et al, 2009). One TB defaulter was of the opinion that if a person wants to garner support from family members and the community, it is important to communicate openly about illness:

No look here, if you say a thing openly...do you understand? Then they accept you... do you understand? And I didn't hide it from them, do you understand? Yes.

For families to have an understanding of the disease and be able to support the TB defaulters, it is imperative for them to be informed about the disease and be involved in their care. Some defaulters did not inform their families that they were on treatment or that they were actually defaulting on their treatment. One TB defaulter indicated that his brother did not know that he was not taking his treatment. He didn't think that his parents knew that he was on TB treatment. Another defaulter thought that his brother was under the impression that that he had completed his treatment course.

Portwig and Couper (2006) believe that a supportive infrastructure is important in ensuring that the TB patient completes treatment. However, one defaulter in this study could not complete her treatment due to appalling living conditions at her home and inability to inform her family about the disease and the challenges she experienced in completing her treatment. Communication breakdown, erosion of the family infrastructure and poor relationship with her father and the step mother manifested as a result of alcohol abuse and therefore poor support for her. Another TB defaulter also put the blame on alcohol abuse for the poor support he had from his mother. The mother shouted at him when she was drunk and called him names:

> *That I am a TB sufferer and so on and so…she shouts up in the street so that everyone must hear*

When asked how he felt about that, the defaulter said:

> *I feel very bad, heart- broken…sometimes I feel that...that the Lord can take me*

One DOT supporter highlighted stigma that was evident in one family:

> *She had issues that the people took her child; they discriminated against her because she has TB. In her family it's a big thing to have TB and all that*

One key informant confirmed that some defaulters had no support from their families and said that this was evident when the DOT supporters visited some of the defaulters and reported that the family had no interest in the patients' treatment.

However, not all TB defaulters felt that they were not supported:

> *I can say that they motivate me and say that I must leave alcohol and do this....*

An overwhelming majority of DOT supporters confirmed that families were supportive.

One reason for lack of family support was perceived to be lack of education. Although there was lack of interest by some families as indicated by the key informant, some DOT supporters said that they educated the patient and the family. The defaulters had conflicting views on whether the families were educated on TB by the supporters or not.

One defaulter confirmed that the families are educated:

> *She talks to me but they* [family] *also listen.*

On the other hand, one defaulter negated the statement and said that the DOT supporter did not talk to his family about TB even though this was part of the DOT supporter's responsibilities as alluded to by the key informant.

TB awareness campaigns educating families and communities about TB will improve support to infected family and community members. Some TB defaulters are of the opinion that some community members are not informed about TB resulting in lack of support from the community or family members by being shunned. However others have indicated that the community members that are informed about TB disease were better at accepting and supporting their neighbours infected with TB and motivating them to take their treatment than those that are not educated on TB:

> *No they support me; they insist that I drink my tablets and they ask me if I have eaten and so on.*

4.3.2.3 Employer support

An overwhelming number of TB defaulters did not inform their employers that they had TB; this was a response from one of the defaulters whether he informed his employer that he had TB:

> *No, they didn't know, let me say this... we are many young people and older people and there are others that are sick. We just fall in and work and nobody knows that we are sick*

Because of lack of pre-employment screening of workers, sick and potentially infectious TB patients share the same working space with healthy patients and this could exacerbate the transmission of TB.

There were a number of reasons given by the TB defaulters for not informing their employers that they have TB. One TB defaulter said that the reason why he did not inform the employer was because of the negative attitude of the employer. He was therefore afraid that being a temporary worker he would not be employed again. This was confirmed by another defaulter:

> *If you tell him, do you understand...he refuses you because he only thinks of the stretch* (the consequences)*…the thing that later stretches to him, do you understand.*

This perception was confirmed by another defaulter who quoted his employer when the TB defaulter informed him only when they were 200km away that he has TB:

> *"If I knew that you had TB I would have chosen someone else"*

This was further illustrated by the perception of a defaulter:

> *They will because they can't let an unhealthy man work amongst the others.*

More reasons were given by the defaulters for not informing their employers that they had TB. One defaulter was frustrated when his employer wanted him to complete his treatment first before returning to work:

I did take It [treatment]... *I took it for a little while, and then I left everything* [work and treatment]

One defaulter added that another reason for not informing the employer was the fact that the he did not feel ill on coming to work.

I actually felt that I drink my tablets, I didn't feel sick, now here in the middle of work I feel no-man, the chest is starting again to become sore, then I just drink the pain tablets

Although many of the defaulters had the perception of lack support from their employers, many DOT supporters were of the opinion that the farmers cared a lot about the health of their workers. The DOT supporters inform employers about TB and the consequences of TB defaulting and the importance of adhering to TB treatment

4.3.2.4 Migration of TB defaulters

Patient migration was stated as one of the major reasons for treatment defaulting amongst patients on CBDOT. Many people in this area have experience in the grape farming sector and would therefore move to the farms where there is work. On some occasions these trips are unplanned. One key informant explained the method used by the farmers to recruit farm workers:

But what happens in the location is that people are just gathered and they are on this truck and they go and they come to say that I am going to Siyanda or Keimoes

Because one defaulter did not know that he was to leave to go and work at the farms, he did not inform the clinic sister and therefore did not have adequate treatment. The same defaulter did not want to attend the clinic where he had moved to and preferred to come to the clinic where he had originally received the treatment:

I just felt I don't want to go to that clinic; I wanted to come here and have my treatment here.

However one defaulter indicated that she did inform the clinic sister when she went but the clinic sister refused to give her the treatment:

I asked sister [name of clinic sister omitted] *to give me tablets for the month, she didn't see a chance to give me then I left everything… when I see that I don't feel well then I come back again, because I know that I can't get well without the tablets...I wouldn't have defaulted if she had given me my tablets*

For some defaulters when they learnt about their departure only over the weekend it was easy to inform the DOT supporter because the supporter stayed in the same neighbourhood. Even though the clinic was closed, the DOT supporters used their initiative to obtain adequate treatment supply for the patient that was leaving:

I go to my colleagues and we put tablets together, do you understand ... because here is your green card...we sometimes take too many tablets

Yes, we as DOTS supporters, we have enough for our patients...If one doesn't have----- then we give to each, do you see [some supporters agreed].

The Patient Treatment Card or GW20/15 often referred to as the "green card" can be used anywhere in the country by the patients to continue with their treatment (Department of Health, 2009). The DOT supporters informed the defaulters about the value of the "green card":

"That green card is your passport at any clinic, even if you don't have a transfer letter you can...that green card is your passport, you can produce it and say I drink these tablets, any clinic will help you if you have that card."

One DOT supporter reported that some defaulters did not utilize the “green card” to obtain the TB medication:

> *At the end of the day he didn’t get the tablets, he didn’t make any means to... to... to...go to that clinic to say that I am coming from Lingelethu clinic*

4.3.3 Health system related factors

4.3.3.1 Quality of care

An opportunity for TB patients to choose a DOT supporter is said to be associated with improved treatment outcomes (Thiam et al, 2009). Where the TB defaulters in this study were given the opportunity, the choice in most instances was limited as few supporters were from their own neighbourhood. However, in certain instances some TB defaulters reported that they were not given an opportunity to choose a DOT supporter. Some defaulters including those defaulters that were not given an opportunity to choose a DOT supporter indicated that they were satisfied with the DOT supporter allocated to them. In all cases, the defaulters and the DOT supporters were introduced to each other by the clinic sister.

Although the choice of DOT supporter is said to enable the supporter and the TB patient to determine the terms and mode of supervision that is the most suitable to the daily activities of both (Thiam et al, 2009), some TB defaulters reported inconsistency in the visiting time of the supporters:

> *... she comes at anytime; she doesn’t have* [specific] *time when she comes*

Although the DOT supporters were expected to support TB patients daily except over the weekend, at least two defaulters reported that they were not visited regularly by the DOT

supporters. TB patients were expected to collect their medication from the clinic on a weekly basis accompanied by a DOT supporter. However, they reported that the only time they were visited by a DOT supporter was when they failed to honour their appointment with the purpose of finding out why they did not turn up at the clinic

DOT supporters reported that prior to 2008, they used to collect the tablets on behalf of the TB patients and kept it with them which meant that the patient had to go to them to take the treatment. However this was problematic for some TB defaulters:

> *...sometimes I can't even walk properly, and then I am really sick. The sisters don't want to understand, I can't walk... I can't!*

Although the policy changed and the TB patients had to keep their own medication, the DOT supporters still kept the tablets of some defaulters:

> *If I feel that it is a responsible patient, I give him his tablets but only for the weekend but the irresponsible one come to me to drink his tablets; I don't give him his tablets* (DOT supporter)

The statement was confirmed by another DOT supporter who had an "irresponsible" patient. In some instances the defaulters took medication at the DOT supporter's home; an agreement that was reached between the supporter and the defaulters. If the defaulter is too sick the DOT supporter goes to the defaulter's home.

There were instances when some defaulters did not meet their DOT supporter as was arranged. At times they ended up meeting in the streets or at the pubs and the DOT supporter administered the medication where they met. In these instances, the DOT supporters displayed a paternalistic attitude when addressing the TB defaulters:

I have decided even if he is under the influence of alcohol, she must get hers tablets... I found her at the 'shebeen'[it is a previously illegal drinking house particular to South Africa and sometimes referred to as a pub] *with a glass of beer in her hand and I said to her, "open your little mouth, you run away from me the whole day, these tablets you are going to drink!"*

The same paternalistic approach was evident in statement made by another DOT supporter when she addressed a TB defaulter:

"Look here, these are your lungs, you must...If you don't complete your treatment, I will take you, we will take the police, we will come and we will take you above the clinic and will take you to Gordonia Hospital".

This practice of DOT support was confirmed by the statement made by one key informant:

…like she [the DOT supporter] *gets hold of him tonight then she says to him, 'you didn't drink your tablets' then she gives him the tablets even though they belong to another patient.*

Although one the key informant indicated that she was aware of this practice, she also said that she cautioned the DOT supporters when addressing the TB patients:

"Don't shout at them in front of their friend, that is what I teach the DOT supporters. You never say it because you embarrass the patient and he will sit at home and never come again".

4.3.3.2 Adherence counselling

One key informant reported that in some clinics where they are available, adherence counsellors from the HIV and AIDS programme were utilized to counsel TB patients. Some

DOT supporters did adherence counselling and one key informant was satisfied with the quality of counselling:

I used to sit-in with them to hear are they giving the right type of information

One key informant reported that usually the TB sister counselled the TB patients with regard to their medication and TB support. However, the other key informants indicated that adherence counselling is not done:

As a sister I am not trained on counselling only refer if there is a problem to another counsellor at VCT because they have adherence counselling, they are overworked and cannot see all patients, it could be the reason for defaulting

4.3.3.3 Access to TB services

To ensure access to TB services throughout the country, the TB program has a formal referral system in place. The defaulters had to inform the clinic sister about their intended move so that they could be formally referred to another clinic. The effective use of the referral system was debated by the DOT supporters and it was mentioned that some defaulters did not know the name of the farm that they were travelling to and therefore the clinic sister was unable to properly refer them. One DOT supporter reported that in some instances the defaulters left without additional medication and received the treatment whilst working at the farm:

... the 'road sister' came and the sister gave him a month's tablets

In some instances the defaulters did not receive the treatment whilst at the farms and realised that the clinic does not come as often as they thought:

Ha-ah, it comes like... once a in a while, maybe once in a month, later on it doesn't come again

4.3.3.4 Education of TB patients

The DOT supporters and one key informant reported that the TB defaulters were well informed about their treatment as they signed a contract at the beginning of the treatment to say that they understood what was explained to them and that they would adhere to their treatment for the duration of the treatment. However, the second key informant indicated that inadequate staffing could have contributed to lack of knowledge of TB by the defaulters:

> *...there is no time because of staff shortage, this can happen when the sister does TB only.*

Some TB defaulters had a clear understanding of TB:

> *Becoming thinner, my condition becoming worse and loss of appetite, then I know that it is TB*

However, some TB defaulters did not have the correct information about the causes of TB:

> *... I had too much alcohol in my body, now it affects my lungs, that's why inside I have scars on my lungs*

The DOT supporters reported that some TB defaulters stopped taking treatment when chemotherapy took effect showing that they were not well informed:

> *...then you go over to the continuation phase, then you decide that you are becoming beautiful when you were weak and you came to the clinic and you were* +++[tested positive]*... ok now the results are negative then you decide on your own you don't want to drink the tablets anymore.*

4.3.3.5 Training and understanding responsibilities of the DOT supporters

- **Training of DOT supporters**

Few of the DOT supporters were trained on comprehensive care that includes amongst others TB, HIV and AIDS which capacitates them to render comprehensive care. Those not trained have learned from experience and have learned from the others.

- **Understanding of responsibilities of DOT supporters**

Both key informants indicated that DOT supporters saw up to eight patients and provided comprehensive care, which included antiretroviral therapy to patients and care for bedridden and TB patients. One key informant reported that the DOT supporters in addition had to assess the living conditions of the patients and address any social problems that might be there. They also had to educate the patients and family about the medication and did contact tracing.

However, the DOT supporters seem to mainly do the treatment supervision and education:

> *We observe him* [TB patient] *when he swallows them* [tablets] *to make sure that he really drank*

> *We went out to the community, door to door, here at this area we put five people together and we talk...*

> *We counsel them*

> *I spoke to him about alcohol abuse and substance abuse*

Some TB defaulters understood the responsibilities of the DOT supporters to give treatment and see to it that they adhere to the treatment:

> *They help people with the tablets, those people that cannot come and drink here*

... it is their work that they were supposed to do, do you understand? To go to the patients and ask them "how are you doing, is this treatment still fine?" that is their work.

Other TB defaulters saw the DOT supporters work as going beyond treatment supervision:

They ensure that you become strong; they ensure that ... They look after you that you drink your tablets and you eat:

In the opinion of the key informants, DOT supporters were known and appreciated by the community.

You know I even see at the funerals, when they thank people, they would say a certain home based carer supported us during this period

The sentiments shared by the key informants were confirmed by the DOT supporters:

Look, sometimes you talk to a client then it looks like he doesn't want to understand, then we go as a group, that's what we do. The men clean the yard, the women start with the house, and others start to cook. We teach them to eat health, how to be healthy, you want everything to be tidy

In some instances the DOT supporters made an extra effort to look for defaulters and to administer the treatment when the defaulters did not honour the appointment.

4.3.3.6 Relationship between TB defaulters and health officials

Some TB defaulters reported that they had a good relationship with health care providers both at facility and community level. Some DOT supporters felt although they were appreciated and respected by some TB patients, while some supporters felt that they were too lenient on the TB defaulters and the defaulters therefore took advantage. On the hand the

description by some DOT supporters of the TB defaulters did not confirm the above statement. Some DOT supporters expressed their frustration in dealing with TB defaulters:

They are not easy to deal with

He has become a nuisance

He said "later" to me but what will I do in the case that he doesn't want to stop drinking,

One DOT supporter reported on the challenge she encountered in tracing TB defaulters and administering the medication:

He always tries funny tricks to get away then you have to run after him to give him his medication.

The same DOT supporter felt that the police should become involved in coercing TB defaulters to take treatment and she reported on her actual experience in getting support of the police:

I had a problem with a patient, I would dial 10111 [South African Police Emergency telephone number] *then they come and they are so afraid when they hear that you call the police*

4.3.3.7 Support to DOT supporters by the clinic staff

All DOT supporters reported that they had good support from TB clinic sisters. There were regular meetings between the supporters and the TB sisters from the clinic and minutes of the proceedings were kept. The meetings offered a platform to discuss the challenges the supporters encountered, they received feedback from the TB clinic sister emanating from

meetings and training the clinic sister attended. Some meetings were held weekly and some every two weeks. This is how one key informant described the purpose of the meetings:

> *We have what we call ventilation meetings just to give them time or that opportunity to open up , you see, just so that they can relax because sometimes they have got their own problems*

One DOT supporter paid tribute to a TB clinic sister in Upington:

> *She helps ... a lot, if maybe you say to her that you have a problem, she will make time and she will walk with us until there, that's how she is*

The results in this chapter was based on TB defaulters, key informants and DOT supporters' perspective obtained during the interviews on why TB patients on CBDOT programme defaulted on treatment. It is clear from these results that a number of interrelated factors involving societal, personal and health service factors impact on the TB patient's ability to adhere to treatment. The following chapter forms a discussion around the results of the study.

CHAPTER 5

DISCUSSION

5.1 Introduction

This chapter will be a discussion of the findings of the study. An interrelationship common between social, economic, health- related and personality factors forms part of the discussion. The discussion will highlight the themes emerging under socio-economic factors to include alcohol abuse, unemployment, need to seek employment, lack of income, link to possible abuse of disability grant and how these impact on TB treatment adherence. The discussion will further draw attention to the health system in the area. TB defaulters attitude toward treatment, their lack knowledge of TB and behaviour has come up as some personal factors contributing to poor treatment adherence.

5.2 Social and Economic Factors

5.2.1 Implications of adherence on employment

The socio-economic status of the TB defaulters in this study reflects those of the district with an unemployment rate of 25,7% during 2008 (Stats SA, 2008). High unemployment rate amongst TB defaulters similar to this study has been cited as a major risk factor for defaulting amongst TB patients. In a study done in Tomsk, Russia (Gelmanova et al, 2007), twenty five out of the thirty eight non-adherent TB patients were unemployed. In the study, unemployment and therefore the need to seek employment similarly contributed toward defaulting. It has been established that unemployed TB defaulters left their homes for long periods to seek employment on farms where employment is offered and ended up not continuing with their treatment. Similarly, in Uzbekistan, Central Asia, 16% of patients defaulted due to migration in search of employment (Hasker et al, 2008). Many people in the

Siyanda district lack the skills to match the labour demand required to secure them permanent and sustainable employment that would improve their socio-economic status. This was confirmed by low literacy level, limited social support and poor living conditions evident in this study which not only negatively influences TB adherence but also places a socio-economic strain on the indigent population (SDIDP, 2007). TB patients that were not employed in the study did not benefit from any financial incentive for adhering to TB treatment. Hasker et al (2008) recommended intervention strategies in similar poor socio economic settings to promote and encourage adherence and at the same time addressing the harsh socio-economic challenges faced by the TB patients.

TB defaulting is worsened by reasons such as failure to earn an income during visits to the clinic (Rubel and Gorra, 1992); or inability to work (Liefooghe, et al, 1995). In the latter study, patients were said to run the risk of losing their jobs if it was known that they had TB. Similarly, some TB defaulters in the current study reported fear of informing their employer that they had TB because they were afraid that being a temporary worker they would not be employed again. TB is therefore seen to potentially exacerbate the unemployment rate in that once diagnosed with the disease, it becomes difficult to be employed. Due to the nature of the disease TB patients remain infectious for at least two weeks and are expected to present to health facilities in some instances daily for treatment or occasionally for sputum collection. To some employers this is viewed as taking workers away from point of work and therefore reducing productivity. In some instances other workers have to be trained which can be costly to an employer. This attitude by employers who are output driven can be interpreted as uncaring and insensitive. This might influence the decision of a worker whether to disclose to an employer or not. TB defaulters in the current study would not be

seen taking TB treatment for fear of being laid-off or not being employed again once the employer established that they had TB.

Many of the defaulters are farm workers not trained in any field and farming is their only trade and source of income. Workers were faced with a difficult choice of either seeking health by having their disease treated or disclosing their disease and risking job loss and poverty which will compromise their income and ability to provide for their families. In her address to business leaders in 2006, the then Minister of Health Ms Manto- Tshabalala-Msimang indicated that “a TB patient can lose an average of three-four months of work time, which translates to between 20-30 percent of the patient's annual income lost” (Department of Health, 2006b). Some workers in this study chose not to take their medication nor inform the supervisor about their disease, a confirmation of commitment to their job or a means to survival. The outcome of this study is consistent with a Western Cape study where patients also did not inform their employers about their disease for fear of losing their jobs (Naidoo, Dick and Cooper, 2009).

TB is seen to interrupt the workflow when workers have to constantly be taken for DOT and screening, it lowers productivity and raises both direct cost related to treatment and care and indirect costs such as the replacement and retraining of workers (TB alert, 2009). On the other hand employers have a legal obligation to provide and maintain, as far as is reasonably practicable a safe and risk free working environment for his employees (Occupational Health and Safety Act 85 of 1993). The farmers in this study might have had to make a judgement call to protect the rest of the workers against TB. DOT supporters in this study have however indicated that the farmers care for their employees. There appears to be a mismatch between the TB defaulter’s fears of negative response from the employer to a disclosure of TB and

the perceived reality by the DOT supporters of employer support. This opens up a potential avenue for interventions targeting discrimination associated with TB in the farming community.

5.2.2 Migration and its effects on health service provision

High poverty levels, limited skills and a need to provide for families as bread winners similar to the findings of study conducted by Munro et al (2007) resulted in the migration of many experienced grape farm workers during seasonal periods, from one farm to another working in the only industry where they are employable. Many of these trips are unplanned and work prospects take precedence over completing treatment even at the farms where they are employed. Due to lack of adherence counselling, an important component in treating TB amongst nomads as recommended by Chiu (2005), some TB defaulters in the current study left without their treatment and did not continue with treatment when they reached the farms. Accessibility of health care to migratory communities poses a challenge as is demonstrated by Chiu (2005) who found that the health care services were only available in towns along the main road for the nomads living in Ethiopia. Similarly, in the current study the PHC system in some areas of the district made it difficult for the patients to continue treatment as some farms were not reached by the mobile clinic, some only once a week or monthly. The current PHC system in some parts of the district does not mirror the social and economic reforms, growing momentum of migration and would therefore require improvement in addressing PHC service supply gaps. One of the four groups of PHC reform to revitalize PHC, as identified by the WHO Director General (WHO, 2008c) is to re-organize health services around the needs and expectations of the users to make them more responsive to the ever changing demands of the world. Although the Siyanda district has made an effort to bring care closer to people through the mobile clinic services and utilization of NGOs to provide DOT, an improvement in the PHC access will ensure that migratory TB patients are

able to access TB services anywhere in the district during the treatment period (WHO, 2008b).

On the other hand, failure to inform the clinic sister of their departure to the farms did not afford the referring facility an opportunity to establish accessibility of TB services on farms that patients were visiting. The implementation of the referral system, which according to WHO should ensure that people receive best possible care was on some occasions made difficult by the fact that some defaulters did not know the farms that they were visiting. The use of the PTC or GW 20/15 in these instances was therefore rendered obsolete and this was confirmed when some defaulters reported that they could not use their PTC to get TB treatment because the mobile clinic did not arrive at the farms where they were working. Similarly, in a different setting in Tashkent, Uzbekistan a substantial proportion of TB defaulters were lost to follow-up between hospital and PHC and this was attributed to a poor referral system (Hasker et al, 2008). The efforts to revitalize PHC through implementation of mobile health services as recommended by Kautzky and Tollman (*2*008) have proven to be inadequate to address challenges faced by migrant workers. However for those patients that left on unplanned trips, DOT supporters have on some occasions taken the initiative and given the defaulters medication belonging to other patients from their surplus.

5.2.3 Dependence on temporary disability grant

The effects of unemployment and lack of stable income is bound to increase the demand for social assistance and this trend is evident globally with more and more people seeking disability grants (Steel, 2006). The findings in this study indicate that most defaulters were on the grant during the period of defaulting. A pattern of defaulting and re-application for

the grant emerged and this appeared to be deliberate and premeditated in some instances. The social assistance regulations (2008) do not indicate the number of times a recipient can re-apply for the grant and this allows the TB defaulters to stay on the system and receive financial assistance for long period of time. This gap in the policy appears to have encouraged TB patients to default on treatment so that they can continue benefiting from the grant.

The TAC (2008) argues that the current practice of government to withdraw the TDG as soon as a person becomes healthy will result in temporary recovery and this system fails to act as an incentive for people to maintain good health. The labour movement in South Africa including Congress of South African Trade Union in 1998 made a call for the introduction of Basic Income Grant (BIG) for poor South African as part of the comprehensive social security grant. BIG would be available to all who are unable to earn an income whether a person is ill or not and this move would reduce the perceived need by TB patients to stay ill in order to receive some income (Barchiesi, 1995).

Two arguments manifest in this discussion: whether the TB patients discontinue their treatment citing lack of information about TB treatment duration or whether the TB patients do not want to be cured of the disease in order to remain on the grant. TB patients are only eligible to the grant whilst they have TB and are on treatment. During this study it was established that in some instances the discontinuation of treatment occurred at the same period that the disability grant lapsed. In many instances re-application for the grant occurred immediately after resumption of treatment suggesting a possible understanding by the patient that compliance to continuous treatment would yield successful treatment

outcomes, and therefore the cured TB patients will not be eligible for the disability grant. This in addition suggests creative adjustment, TB defaulters change their circumstances by not conforming to TB treatment directives with the purpose of addressing their financial needs (Steel, 2006). In this study, the supporters and key informants indicated that informed TB patients might still default because they want to remain on the disability grant suggest the need for further exploration and future study Although anecdotal evidence suggests that TDG for TB is being a "perverse incentive" interpreted as an applicant has to be sick to qualify for a TDG and this is supposedly viewed a reward for being sick, Steel (2006) cautions that such evidence should be treated with prudence.

Because of the lack of income in many households in this study, the disability grant might be viewed by TB patients as the only guaranteed and adequate income just enough to meet the daily needs of their families. This finding is corroborated by the findings of Naidoo, Dick and Cooper (2009) that due to high unemployment rate, most of the defaulters are unable to sustain themselves and their families and the grant is therefore viewed as a type of income. TB defaulters in the current study were found to use the grant to purchase household equipment which they could not afford once the grant was terminated. This type of practice feeds the cycle of dependency and non-adherence to TB treatment and highlights the abuse of the grant by the TB patients. In the Western Cape where TB patients from severely deprived households living in overcrowded, poorly ventilated homes and with low income confirmed that although they wanted to be cured and understood the importance of completing their treatment they would default on the treatment so that they could remain on the disability grant (Ellis et al, 1997).

5.2.4 Poverty and its impact on food supply

TB patients are encouraged to eat food with TB medication to reduce the side effects (Wares et al, 2003). Poverty often linked to food insecurity renders TB patients vulnerable to ill-health and poor treatment outcomes (WHO, 2005). Reports of lack of food, often linked to poverty surfaced in the current study and this challenge is addressed through a food scheme programme and TDG administered by SASSA.

5.2.5 The impact of Stigma

The issue of stigma in the family setting raised by some TB defaulters in this study appeared to be overlooked by some DOT supporters as the engagement between some DOT supporters and family members yielded evidence of a firm family support structure, this was also found in a study conducted in Pakistan where social stigma played a major role in poor treatment compliance amongst TB patients. (Liefooghe et al, 1995). In those instances where patients complained of poor family support, no evidence of intervention was reported on the part of the DOT supporters. Different cultural perspectives about TB are in existence in different communities and these may include exclusion of patient and family members from community contact. On the other hand, feelings of guilt and being ashamed of the disease affects patient adherence to treatment and disclosure of the disease to family members, employers and the community (Munro et al, 2007). Some TB patients are often treated differently by family or community members than other people with the same disease and Baral et al (2007) refers to this as direct discrimination. This was highlighted by some TB defaulters in the current study which also impacted negatively on their compliance to treatment. Contrary to that, some patients indicated unconditional support from friends and family members which was consistent with the findings of Baral et al (2007) where little evidence of discrimination within the family was found.

5.2.6 Role of family support

Family support is pivotal in TB treatment adherence and the lack of family support was evident in this study although not in all the cases. Some TB defaulters in this study were being shunned and verbally abused by family members and this could have influenced the decision of the TB defaulters on whether to inform the family members of having TB and also for not adhering to treatment (Munro et al, 2007). Self stigmatization as described by Baral et al (2007) was displayed by one defaulter who isolated herself from the family and the community. In this Nepal study, the patients reasoned that fear of discrimination drove them to isolate themselves from other (Baral et al., 2007). The lack of family support stems not only from families not being informed about TB but evidence also surfaced that some family members did not take an interest in the condition of the defaulters.

5.2.7 Impact of Alcohol abuse

Alcohol abuse is said to contribute to a wide range of social and health problems. The World Bank in its report on alcohol and poverty indicated expenditure on alcohol is significantly high in some societies (World Bank, 2007). In a systematic review by London (1999), as cited by Peltzer and Ramlagan (2009), 87% of farm workers in the Western Cape were potentially alcohol dependent, this can with caution be applicable to the Siyanda district due to the same type of farming and close proximity of the two districts. TB defaulters in this study although having no money to buy food, and were mostly depended on social security assistance mostly confirmed abusing alcohol during the period of treatment. According to the DOT supporters, they were often under the influence of alcohol therefore often failing to honour their appointment or delayed in seeking treatment. Ellis et al (1997) and Gelmanova et al (2007) established that substance abuse is a major cause of default amongst TB patients and similar findings were made in the current study. Given the history of the “dop system” in

the district, the cycle of poverty and dependency is inevitable. From the current study, it appears as if the lack of adherence counselling and rehabilitation services for the defaulters abusing alcohol exacerbates the situation as there is no way of stopping the cycle (Parker, 2004). With the high alcohol abuse marked in the area, there was no evidence of screening for alcohol prior to TB treatment start. This intervention would allow health professionals to develop comprehensive care strategy per patient. It is the researcher's opinion that with lack of psychological counselling and alcohol rehabilitation services in the area, TB patients abusing alcohol will find it difficult to abstain from alcohol.

In addition and evident in this study was poor family structure in many instances marked by alcohol abuse and poor communication system amongst family members which resulted in poor adherence to TB treatment. As is shown in a study done in Mamre by Coetzee, Yach & Joubert (1988), a strong correlation has been determined between TB and alcohol abuse in a household increasing the risk of poor adherence to TB treatment.

5.3 Health Services Related Factors

5.3.1 Quality of care

The quality of care in this study seems to have been influenced by different factors. Firstly, many of the PHC facilities in the district have no professional nurse dedicated to provide TB services. Key informants have reported that due to insufficient staff, they are unable to provide quality TB services and counsel TB patients on treatment adherence and this in their opinion might have led to increased poor adherence to treatment by the patient. The Siyanda district health department except at Gordonia Hospital has no dedicated social workers to address the social challenges experienced by patients at PHC level. However a referral system is in place to social workers at Department of Social Development. Due to this

limitation in resources, there were long waiting periods. Increased staff levels would afford the sister the opportunity to identify interrupters before defaulting and provide adherence counselling. With the advent of brain drain in South Africa, the utilization of CHCWs for adherence counselling has proven to be effective in a TB programme for the nomads in Ethiopia (Chiu, 2005). Other studies (Maher et al, 1999) and (Kironde and Kahirimnabyi, 2002) have also shown the effectiveness of CHCWs in contributing to the TB programme.

Each clinic catchment area has a limited number of DOT supporters, therefore limiting the choice of DOT supporters by TB defaulters. Similar to the study done by Thiam et al (2009), in most instances TB defaulters in the current study indicated that they were not given an opportunity to choose a DOT supporter. This implied that in many instances a rapport could not be built between the defaulter and the DOT supporter leading to missed appointment, treatment interruptions and defaulting. On occasions where a choice could be made, TB defaulters based their choice on a supporter staying in the immediate neighbourhood and this could yield positive results (Wandwalo et al, 2004).

TB patients on CBDOT in Tanzania favoured CBDOT as it was accessible and flexible (Wandwalo et al, 2004). Similar findings were made in the current study where implementation of two different methods of support namely support by the DOT supporter at home of the TB patients or the TB patient going to the home of the DOT supporter for DOT in the district made it feasible for the defaulter and the DOT supporter to agree on the terms of support. The defaulters in this study were supported at their own convenience which is the method that was favoured by the TB defaulters because it ensured that they continue with their normal daily activities. It however surfaced that some appointments were not honoured by both TB defaulters and DOT supporters resulting in TB treatment interruption. Because

the DOT supporters kept the medication of the some of the 'irresponsible' patients, this opened up an opportunity for the DOT supporters to administer TB treatment to the defaulters wherever they met. However, Contrary to the HBC guideline, (2005) the dignity and privacy of the TB defaulters was not respected because defaulters were on many occasions followed-up and approached at 'shebeens' and treated unprofessionally and with little sensitivity. Some TB patients in this study highlighted discrimination by community members and an act like that by the DOT supporters could have exacerbated TB patient discrimination and stigma which could lead to the dignity and privacy of the TB defaulters not being respected. On the other hand, the unprofessional behaviour by the DOT supporters highlights the frustrations of the DOTS supporters in their plight to ensure that TB patients complete their treatment. DOT supporters in a study conducted in Tanzania actually refused to support patients perceived to be rude and resolved that they should continue taking their treatment at the health facility (Wandwalo et al, 2004). It is hoped that this will not happen here.

The relationship between health officials and TB patients has been cited as a contributory factor to treatment defaulting in a study conducted by Wares et al (2003) and it appears that some similarities could be drawn from these findings. In the current study, some patients complained about unscheduled visits by DOT supporters. However, on overall, a good working relationship existed between health providers and the TB patients as was found in a study conducted by Naidoo, Dick and Cooper (2009) in the Western Cape. Good quality of care between health professionals and the TB patients recommended in the study conducted by Thiam et al (2009) was demonstrated in the current study when some TB defaulters working on the farms had to leave over the weekend on unplanned trips informed the DOT supporters of the unplanned trip and the DOT supporters would in turn put together adequate

supply of TB treatment for the TB patients to continue with treatment whilst on the farm. In addition, DOT supporters made an extra effort to look for the defaulters and to administer treatment when the defaulters did not honour their appointment, showing their commitment. On the other hand, a threatening demeanour, demonstrating paternalistic attitude by some DOT supporters when the patients did not arrive to take treatment in this study was also found in a study conducted by Wares et al (2003) and this contributed to defaulting treatment. The support of the clinic sisters of the DOT supporters in the current study is very encouraging because without that support they might not be able to function optimally. The commitment and dedication of the DOT supporters and clinic sisters is clearly an important factor in adherence to TB treatment.

Some reports show that TB patients were generally not satisfied with care provided by CHCW (Comolet et al, 1998). In a study done in Nepal, the negative attitude, inept behaviour and aggression of CHCWs was cited as the second most common reason for non-adherence (Wares et al, 2003). However, the outcomes of the current study proved that CHCW are innovative and responsive to the needs of TB patients. This is true to the statement uttered by Health Systems Trust when evaluating its activities in Thabo Mofutsanyana District in the Free State that: " NGO workers and volunteers are energetic and enthusiastic youth, who with a little support can provide a lot of support to PHC services at community level" (Elgoni, 2004).

5.4 Personal Factors

5.4.1 Lack of knowledge, attitude and behaviour

Low or poor literacy level has been cited by Gopi et al (2007) and Hoa et al (2004) as a common factor for non-adherence although Haynes et al (2002) and Comolet et al (1998)

found no clear or significant relationship between adherence, educational experience and intelligence. All defaulters interviewed in this study completed some level of their education although the highest level was grade nine (standard seven) and these findings were consistent with the Siyanda district integrated development plan (2007). Even though the defaulters were informed about the disease upon diagnosis and were asked to sign a contract in agreement to complete treatment, the defaulters with low education levels in this study still seemed to have little knowledge on TB. This brings to question the quality of education and counselling that the patients received from the health care workers. This became evident in this study when TB patients actually stopped taking their treatment at about two or three months as the TB symptoms had subsided or they felt better because they said that they were not well informed. These findings are similar to findings in other studies where patients were not satisfied with the explanation given to them by the health workers on TB and treatment, the patients felt that patients in facility based DOT received better information than they received (Munro et al, 2007; Estifanos and Lindtjørn, 2005: Comolet et al (1998). This is further supported by the findings in the study done by Ratzan and Parker (2000) where the defaulters even though they were given information they do not seem to understand it sufficiently to follow given instructions.

TB patients are known to adhere better to treatment during the initial phase of treatment and stop TB treatment when they feel better (Comolet et al, 1998; Naidoo et al, 2009). This was also found in this study where some of the defaulters stopped taking treatment around two or three months. Although TB defaulters were informed about TB and treatment duration, some defaulters interpreted their wellness and disease differently from the health providers and some defaulters in this study thought that they had been cured when they felt better.

5.4.2 Effect of lack of counselling services

All defaulters interviewed interrupted treatment on several occasions before defaulting and had defaulted on more than one occasion. The outcome of this study clearly indicate lack of proactive intervention to treatment interruption by the TB nurse or the DOT supporter through provision of adherence counselling as cited in the Western Cape study (Thiam et al, 2009). Failure to intervene could have been attributed to lack of training of some DOT supporters and one clinic sister on adherence counselling. The clinic sister and DOT supporter were however expected to provide ongoing support and counselling for clients and families (DOH, 2007). Munro et al. (2007) recommend patient centred intervention to ensure TB treatment adherence. The adherence counselling strategy implemented by Médecins Sans Frontières in Ethiopia appears to have had positive outcomes. More than a 100 consultations were conducted by the counsellor per month out of 200 patients (Chiu, 2005).

In addition, due to insufficient professional staff, continuous adherence counselling which is time consuming was not prioritized by the clinic sister in this study. South Africa like other developing countries is faced with a persistent exodus of skilled health workers to the developed world and movement of health care workers is also noted from rural to urban and public to private migration making provision of basic health services at rural level a challenge (Chin, 2009). Innovative approaches are required to retain skilled professionals and strengthen the health system (Kautzky and Tollman, 2008).

Lack of counselling services for TB defaulters also resulted in defaulters not being informed about drug side effects. This lack of information can have repercussions as described earlier on. However, like in the study conducted by Comolet et al (1998) where side effects were reasonably proportional in defaulters and adherent patients, this did not appear to be the case

in this study because TB defaulters reported to have continued with the treatment even though they experienced the side effects.

CONCLUSION

This chapter formed a discussion on the different factors that contributed to TB defaulting amongst patients on the CBDOT programme in the Siyanda District. Research literature was drawn on to compare with the findings in this study. An interrelationship common between economic, health services- related, social and personal factors was evident and highlighted. The following chapter draws conclusions from the discussion and gives recommendations on what could be done to improve the system.

CHAPTER 6

CONCLUSION AND RECOMMENDATIONS

This chapter draws conclusions about the findings and makes recommendations based on these findings. The study explored and highlighted factors that contributed to TB defaulting amongst patients on the CBDOT programme in the Siyanda District, Northern Cape Province, South Africa. The increase in the number of TB patients defaulting whilst on CBDOT is as a result of numerous factors which require a comprehensive intervention approach.

Amongst the patient-related areas identified in the study that need to be strengthened, is the lack of knowledge about TB and its treatment amongst the TB defaulters on the CBDOT programme, and this could be applicable to other TB patients. The low level of education amongst TB defaulters in this study seems to have resulted in the patients being unable to comprehend TB messages they received. An integrated, capacitating community, patient and family education programme should be developed. This programme should be informed by a knowledge, attitude and behaviour survey. Appropriate information, education and communication messages should complement the education programme. The treatment literacy projects implemented by TAC (Healthlink Worldwide, 2006) and implemented by BroadReach Health Care in Windhoek (2009) have proven to be effective and to drastically improve the adherence of HIV positive patients to ARVs. This model could be duplicated in the TB Control Programme. Knowledgeable TB defaulters are better prepared to adhere to the long duration of TB treatment, as they would have an understanding of the importance of adherence and the impact this will have on their lives.

The socio-economic circumstances of the TB defaulters impact on their ability to adhere to TB treatment. TB patients in the Siyanda District are referred from the health facility-based DOT to the CBDOT programme at two or three months, once they have a negative smear and are in the continuous phase of their treatment. This group of patients faces different challenges that impact on their adherence to TB treatment, in comparison to when they were on facility-based DOT. Unlike TB patients on the facility-based DOT in the Siyanda District, TB patients on the CBDOT programme with no stable jobs, will return to work or seek work with the aim of earning a living and providing for their families, once they are less infectious. Because of the working hours and lack of jobs in the vicinity, TB patients on the CBDOT programme end up moving unintentionally and unannounced to areas where there are jobs. The support programme for these patients will differ from the support programme for other patients with stable jobs. Their programme should be patient-centred with an efficient referral system that can be implemented over the weekend, and not at the convenience of health care workers. To ensure continuity, TB patients on the CBDOT programme, similar to other patients, should be able to access their treatment at any given time, including weekends, the time when most of them leave for the farms.

It is evident that there is some abuse of the TDG and this should be further explored. To further achieve maximum outcomes and to ensure streamlining and monitoring of social services to TB patients on the CBDOT programme, collaboration between SASSA and the DOH in the Siyanda District would be of importance.

To address the poor adherence by TB patients on the CBDOT programme, the provision of counselling services should be strengthened. This can be done through the appointment and

training of former TB patients that were on the CBDOT programme, and have experienced the same treatment period. Their duties should include: provide counselling services to TB patients on the CBDOT programme; conducting treatment education programmes where patients will be taught about the TB disease, treatment period and side effects with the purpose of improving self efficacy. Counselling should be ongoing but the major sessions should be done upon diagnosis and upon referral to the CBDOT programme, which is their continuation phase. It was evident from this study that patients defaulted more during the continuation phase. However, counselling should not eliminate the need for treatment support.

An urgent, comprehensive intervention strategy that could benefit both the facility-based and the CBDOT programme patient should be developed and it should include the establishment of patient support groups which could serve as a platform for patients to share TB treatment adherence-related experiences. From this information and experience-sharing sessions, TB defaulters will in addition realise that what they experience is common amongst other TB patients; learn how to support each as they have a common disease; and learn coping skills from each other that will keep them motivated to adhere to TB treatment. Coupled with support groups amongst existing TB patients, could be the individual support by one former TB patient to another TB patient in addition to providing counselling services. Former TB patients in Tanzania showed a willingness to support TB patients (Wandwalo et al, 2006). The challenges specifically faced by TB patients on the CBDOT programme in the Siyanda District are common and pertinent to them and could have been experienced by former patients. They would have the opportunity to share how they coped with treatment with TB

defaulters in the event of challenges, including those of job seeking and migration from one farm to another.

To address challenges faced by TB patients, including those on the CBDOT programme, will require collaboration between community structures that are currently in place. The NCDOH has completed an HIV and AIDS and TB service directory, which details type and location of community services currently in place (NCDOH and COMPASS, 2009). Some DOT supporters in this study provided adherence counselling in addition to DOT support services. This is an indication that the DOT supporters have the ability to provide the counselling services but will require adequate support and guidance from the clinic nurses. Counselling services can further be extended to the support structures and faith-based NGOs detailed in the service directory.

In addition to patient-related interventions, are health system-related interventions. The limited availability of professional nurses makes counselling TB patients prior to the patients` referral to the CBDOT programme unattainable. The overhauling of PHC services is an important intervention, which should include increases in the nursing staff component at PHC level. Training of nurses on TB counselling and integration of TB services in all areas of PHC will ensure that intensive adherence counselling occurs at diagnosis and referral to the CBDOT programme yielding better treatment outcomes. Furthermore, staff attitudes and behaviour can reinforce stigma. Intervention strategies should also target staff behaviour change and training to improve the quality of care and relations between TB patients on the CBDOT programme and health care workers. Patients will, in turn, feel free

to approach health care workers without fear of retribution should they encounter problems with treatment or should the need arise for them to relocate.

Pertinent not only to TB defaulters on the CBDOT programme, but throughout the grape farming community, is the abuse of alcohol. It therefore becomes imperative to screen for alcohol abuse and other drugs and ensure that TB patients addicted to alcohol and other drugs are treated from the onset to improve adherence to treatment and better treatment outcomes. The establishment of drug and alcohol rehabilitation services for TB defaulters, which can also be utilised by other community members with the same problems, requires a collaborative effort with all stakeholders. The employment of social workers in the Siyanda district would assist in addressing social challenges faced by TB patients.

In conclusion, it is worth noting that although TB patients on the CBDOT programme experienced challenges impacting on their ability to adhere to treatment, many of these challenges are common amongst TB patients on other models of treatment support, although more pronounced amongst TB patients on the CBDOT programme. The intervention strategies therefore highlighted recommendations, which could be common for both groups, but some recommendations are more specifically for TB patients on the CBDOT programme.

CONCLUSION

In conclusion, it is worth noting that although TB patients on CBDOT experienced challenges impacting on their ability to adhere to treatment, many of these challenges are

common amongst TB patients on other models of treatment support although more pronounced amongst TB patients on CBDOT. The recommendations highlighted are therefore common for both groups but also specifically for TB patients on CBDOT.

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ANNEXURE A

Participant Information Sheet

August 2008

Dear Participant

The purpose of this information sheet is to explain the research project and how it will affect you if you participate. The research is being conducted for a mini-thesis. This is a requirement for the Masters in Public Health which I am completing at the University of the Western Cape. Should you require any further explanation or additional information on the study, please ask me. My contact details and those of my supervisor are detailed at the end of this memorandum.

TITLE OF THE RESEARCH

An exploration of the reasons for defaulting amongst Tuberculosis patients on the Community-based Directly Observed Treatment Programme in Siyanda District, Northern Cape Province.

PURPOSE OF THE STUDY

The Department of Health has implemented the DOT programme which is aimed at supervising TB patients when they take their medication. It has been reported that despite this intervention,

many TB patients are still not adhering to their treatment. It is hoped that your participation will assist us in understanding the reasons why patients do not adhere to TB treatment. The outcomes of this research will assist in the development of recommendations that will potentially improve the system to ensure that more TB patients are adherent to their treatment thereby reducing the number of new TB cases.

DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT

The study will include individual interviews with TB patients who have defaulted from treatment and Focus Group Discussions will be conducted with DOT Supporters. Questions will guide discussions about your experiences and perceptions of the CBDOT programme and reasons for non-adherence to treatment. The sessions will take about 30-40 minutes.

CONFIDENTIALITY

Your name and medical information will be kept confidential at all times. I shall keep all records of your participation in a safe place including the consent form which I will need from you should you agree to participate in the research study. These records will be destroyed after the research is completed. Your name will never appear in any papers or presentations about this study.

VOLUNTARY PARTICIPATION AND WITHDRAWAL

Participation in this study is completely voluntary and therefore you are under no obligation to participate if you do not wish to do so. Your medical care will not be compromised in any way. Should you change your mind later and decide not to participate, you can contact me at the telephone number given at the end of the memorandum. In addition, if there are any questions you are not willing to answer or any issues you are not willing to discuss, you are free to let me know. Should you be willing to be interviewed as part of the research study, please read and sign the attached consent form.

BENEFITS AND COSTS

There are no specific benefits to taking part in the study, unless you wish to re-establish contact with your clinic and resume your TB treatment. If you participate in the study, the hope is that

the outcome will benefit other people who might contract TB in future. Participating in the research study will not be of any cost to you.

INFORMED CONSENT

Before you participate in the study, I will need you to sign the consent form which is attached to this information sheet.

QUESTIONS

Should you have further questions or would like to know more about the study, my contact details are:

Phyllis Baitsiwe
Student number: 2405779
Cell phone: 0824693494
E-mail address: pbaitsiwe@ncpg.gov.za
Telephone number: 053-8300660
Fax number: 053-8300655

I am accountable to Ms Suraya Mohamed, my supervisor at the School of Public Health, University of the Western Cape. Her contact details are:

c/o The School of Public Health
Telephone number: 021-959 2809
Fax number:021- 959 2872
E-mail:sumohamed@uwc.ac.za

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ANNEXURE B

CONSENT FORM

TITLE: **An exploration of the reasons for defaulting amongst Tuberculosis patients on the Community-based Directly Observed Treatment Programme in Siyanda District, Northern Cape Province.**

As was mentioned in the Participation Information Sheet, participation is voluntary. Should you decide not to participate and change your mind later, you are welcome to participate. You can stop the interview at any time without any problems. In addition, if there are any questions you are not willing to answer or any issues you are not willing to discuss, you are free to let me know. I shall keep all records of your participation including the consent in a safe place.

Should you be willing to participate in the research study, I will require you to sign this consent form before I proceed with the interview.

I hereby confirm that I have been informed about the study. I have read and understood the information as stated on the Participant Information Sheet. I have been given the opportunity to ask questions and have received satisfactory explanations.

I consent voluntarily to participate in the research study.

I agree to take part in the study.

Participant's name **(printed)**

Participant's signature

Date

Name of researcher conducting informed consent **(printed)**

Signature of researcher

Date

ANNEXURE C

INTERVIEW GUIDE FOR FOCUS GROUP DISCUSSION WITH DOT SUPPORTERS

The researcher will open the session by providing background information to the research study and the purpose of the study. In addition, the researcher will highlight the expected outcomes of the discussion group.

The following questions will guide the discussion:

1. Participants to share information about DOT support services and their roles and responsibilities.
    - Reflect on the current DOT support model implemented by government and how, if at all, it contributed towards patient adherence to TB treatment?
    - Talk about training, understanding of patient support, and broadly about the DOT support programme.
2. Explain the relationship they have with TB patients on the CBDOT programme.
3. Think about the health system-related factors that could be contributing to defaulting of TB patients on the CBDOT programme.
    - Reflect on the referral pathway and if, in any way, it affects the adherence to TB treatment by CBDOT patients.
    - Has the referral pathway been explained to patients?
    - Has the referral pathway contributed to TB patients defaulting, in what way, and how does it benefit TB patients?
    - Reflect on availability or non-availability of medication and their perception of that and how the challenges, if any, can be addressed.

4. Community and other social and cultural factors

    - DOT supporters will be asked how they view the support of the family, community and employers towards people with TB, and if this has impacted on the TB patients defaulting from treatment.

    - DOT supporters will be asked about social relief or disability grants and their perception about the grant and if it impacts on the socio-economic lives of the TB patients.

    - Explain the use of alcohol amongst TB patients and how it impacts on TB treatment adherence.

    - Reflect on their relationship with the community.

5. Explain the role played by traditional healers in patient adherence to TB treatment.

6. Reflect on the movement of TB patients within the farming and mining sectors and how it affects their adherence to TB treatment.

7. DOT supporters will be asked to recommend methods that can be implemented to make the CBDOT programme function optimally

ANNEXURE D

INTERVIEW GUIDE FOR IN-DEPTH INTERVIEW WITH TB DEFAULTERS

The researcher will open each interview session by providing background information to the research study and the purpose of the study. In addition, the researcher will highlight the expected outcomes of the individual interview.

The following questions will guide the discussion:

1. Level of literacy will be determined
   - What is the highest standard passed?
2. TB education by the clinic nurse or DOT supporter, including side effects of the drugs
   - Can you tell me what you know about TB and TB treatment?
3. Can you tell me about the CBDOT programme and what you understand the responsibilities of DOT Supporters to be?
   - Introduction to the DOT Support system
   - Choice of a mode of support (CBDOT, self-supervised, workplace DOT or clinic DOT)
   - Can you explain why you stopped taking TB treatment?
   - Can you explain the type of support you receive from the DOT supporter and, in your view, do you find it satisfactory? What would you want to see happening?
   - How do you feel about the treatment and care you receive from the department?
   - Availability of TB medication
4. Explain the visits conducted by the DOT supporter.
5. Do you think that your family knows enough about TB
6. Do you think that the community knows enough about TB

7. What is your understanding of DOT support services and the roles and responsibilities of DOT supporters.

8. How do you think the community treats TB patients

   Should there be challenges raised, the participants will be asked to share information about how they think the challenges can be addressed

9. Do you know of any support structures for TB or TB and HIV patients in the community?

10. During treatment, could you afford to have a balanced diet consisting of all nutrients? (examples will be given)

11. Tell me about your financial income during TB treatment.

    - What other social support did you have
    - Do you think that being on the grant has made it financially easier for you and your and family members
    - How long have you been on the disability grant

12. Did you continue taking treatment in one facility or did you have to move whilst on treatment? How did this affect you taking your treatment?

    - Communication between the TB defaulter and clinic sister
    - Accessibility of treatment at other health facilities

13. How does the utilization of alcohol and substances contribute to defaulting from treatment?

14. Did you inform your employer about your disease and what was his attitude?

15. Utilization of services of traditional healers after being diagnosed with TB

ANNEXURE E

INTERVIEW GUIDE FOR KEY INFORMANT INTERVIEW

The researcher will open each interview session by providing background information to the research study and the purpose of the study. In addition, the researcher will highlight the expected outcomes of the individual interview.

The following questions will guide the discussion:

1. Key informant will be asked to reflect on the following:
    - Demography of patients that default
    - Literacy levels
    - Socio-economic status
    - Level of alcohol and substance abuse in community and amongst TB defaulters
2. Key informants will be asked to describe the how the CBDOT programme functions in the facility
    - Frequency of visits
3. Key informant will be asked to give information about their perceptions of the CBDOT programme
    - Do the CBDOT supporters render quality care to TB patients?
    - If not, what could be the reason?
    - Do the DOT supporters participate in any other community projects where they receive stipends?
    - Could this influence the quality of support rendered and TB defaulting?
    - Perceived relationship of DOT Supporters with TB patients and their communities

- What type and level of support clinic sister gives to DOT Supporters

4. Key informant will be requested to discuss what the reasons for defaulting are, based on her experience and interaction with TB patients on CBDOT programme.

5. Key informant will be asked to reflect on other treatment that TB patients seek outside the public health sector that could be influencing patients adherence to treatment

6. Recommendations to improve the CBDOT Programme