

**BARRIERS IN ACCESSING DOTS AMONG ADULT
PATIENTS WITH PULMONARY TUBERCULOSIS IN NDOLA
URBAN DISTRICT**

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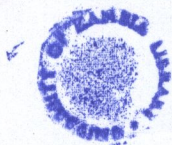
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of the requirements for the Degree of Masters in Public Health

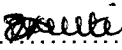
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DECLARATION

I declare that this dissertation represents my own work and that all the sources I have quoted have been indicated and acknowledged by means of complete references. I further declare that this dissertation has not previously been submitted for a degree, diploma or other qualifications at this or another University. It has been prepared in accordance with the guidelines for Masters in Public Health Dissertations of the University of Zambia.

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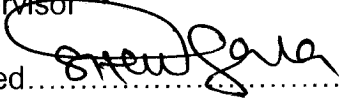
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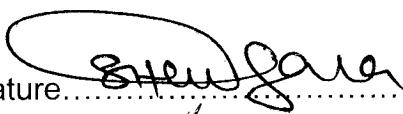
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ABSTRACT

The aim of the study was to explore barriers experienced by adult Pulmonary Tuberculosis patients in accessing Directly Observed Therapy Short course in Ndola Urban district. A randomized cross section study of 198 patients on the TB register was conducted in Ndola urban. Data was collected using a structured interview schedule and a focus discussion guide. A population study for focus group discussion was done where there were at least 6 health workers working at the TB corner and all those working at the TB corner were included. Sixteen health workers participated in three respective focus groups in this order FGD1 = 5, FGD 2= 6 and FGD 3= 5.

Epi-info version 6 and SPSS 12.0.1 windows was used to analyse the data. Chi-square was used to test association of variables. ie the dependent variable (access to DOTS) and the independent variable barriers (Side effects of drugs, distance, support, waiting time and stigma). Confidence interval was set at 95% and level of significance at 5%, statistical significance achieved if p value is <0.05 .

In this study, findings revealed that 58% had easy access as compared to only 42% who could not access TB drugs easily. The most significant factors associated with accessing DOTS were adverse side effects of TB drugs, stigma and support patients received from health workers. Waiting time and distance were not significantly associated with accessing DOTS.

A significant association was found between adverse side effects of TB drugs and accessing DOTS (96.4%). Respondents who experienced joint pains, stayed away from drug collection (P -value <0.001). Among the respondents who took 0-30 minutes to reach the health centre, 1.5% stayed away from drug collection appointments compared to those who took more than 30 minutes to reach the health centre of whom 6.6% stayed away from drug collection (P value 0.070). There was no association between distance and accessing DOTS. Among the respondents who waited for more than one hour 5% stayed away from drug collection appointments while those respondents who waited up to 60 minutes 4.2% stayed away from drug

collection appointments (P value 1.000). Waiting time was not a barrier in accessing DOTS. 16.6% of those who did not receive support from health workers stayed away from drug collection appointments but 83.3% tried to collect their drugs even if they did not receive support from health workers (P value 0.006). Lack of support from health workers was a barrier in accessing DOTS. 15.8 % who acknowledged that they were being called names (stigmatised) stayed away from drug collection appointments but 84.1% despite being called names tried to collect their drugs (p – value<0.001). Stigma was a barrier in accessing DOTS.

DEDICATION

To my beloved husband Mr. B Milimo Who encouraged me to come for studies and took up the responsibility of looking after the children, and supported me spiritually, physically, psychologically as well as financially throughout my training.

To my two sons Miyanda and Choolwe, my daughter Mutinta, the family members and friends for their encouragements, support, prayers and for giving me time to concentrate on my study.

To my late father Mr. Noah Munyati, who really wanted me to attain masters degree.

To my mother Mrs. Nolia Munyati who consistently reminded me that the sky is the limit in terms of education.

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- Dr Mutale and Prof Baboo who helped me develop my proposal
- Mr Mwanza lecturer School of humanities- UNZA

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LIST OF ABBREVIATIONS

AIDS	-	Acquired Immune Deficiency Syndrome
CBOH	-	Central Board of Health
CITC	-	Current Issues on Tuberculosis Control
DOT	-	Directly Observed Therapy
DOTS	-	Directly Observed Therapy short course
EPI-INFO	-	Epidemiological Information system
FDC	-	Fixed Dose Combination
FGD	-	Focus Group Discussion
HIV	-	Human Immune Deficiency Virus
IEC	-	Information Education and Communication
ITG	-	Integrated Technical Guidelines
IUATLD	-	International Union Against Tuberculosis and Lung Disease
MDR-TB	-	Multi Drug Resistant Tuberculosis
PTB	-	Pulmonary Tuberculosis
TB	-	Tuberculosis
NHMHC	-	New Hampshire Minority Health Coalition
NTLP	-	National Tuberculosis and Leprosy Programme
SAT	-	Self Administered Treatment
SPSS	-	Software Package for social sciences
UHCAN	-	Universal Health Care Action Network
WHO	-	World Health Organization
ZDHS	-	Zambia Demographic and Health Survey
ZNTLP	-	Zambia National Tuberculosis and Leprosy Programme

CHAPTER ONE- INTRODUCTION

1.1 Background Information

Tuberculosis (TB) has been the greatest killer ever known to mankind. Accounts of tuberculosis were found in the writings of ancient Egyptians and in those of Hippocrates. On account of its menacing effects, it was called "The Captain of All These Men of Death" by English writer John Bunyan. Tragically, though, the disease is still so prevalent that, in 1993, 111 years after the causative organism was identified and half a century after the introduction of effective therapy, the World Health Organization (WHO) deemed it necessary to take the unprecedented step of declaring it a Global Emergency (WHO, 1994). This was as a result of its re-emergence in the mid-1980s.

At the moment, tuberculosis remains the deadliest single infectious disease among adults in the world (Dye et al., 1999; WHO, 2001; WHO, 2005). Globally, 9.2 million new cases and 1.7 million deaths from tuberculosis occurred in 2006, of which 0.7 million cases and 0.2 million deaths were in HIV-positive people (WHO, 2007). In 2002, nearly twice as many men died from tuberculosis as women (1 055 000 deaths or 3.5% of all deaths in men and 550 000 deaths or 2.0% of all deaths in women) (WHO, 2003). The women and men suffering from tuberculosis are likely to be in their most productive years, that is, in the age range 15-44 years old (Stop TB, WHO 2006). In this age group, men are typically responsible for earning and supporting their families, whereas women as workers, mothers and caregivers usually have families and children who suffer additionally from their illness and death. Just close to home, the prevalence of tuberculosis in Sub-Saharan Africa in 2004 was estimated to be 487 per 100 000 population compared to 290 per 100 000 in 2000, with a tuberculosis -specific mortality rate in Africa of 81 per 100 000 population in 2004 (Corbert et al., 2003; Human Development Report, 2005).

TB is a major public health problem in Zambia, ranking among the top ten causes of morbidity and mortality. The notification rates of tuberculosis in Zambia reflect an increasing trend in recent years. The country is counted among those with high burden of TB in Africa. The notification rates have increased from 100 per 100 000 in 1984 to 500 per 100 000, in 2005. Approximately two thirds of the TB burden in Zambia is from three provinces namely, Lusaka, Copperbelt and Southern Provinces (ZNTLP Annual Report 2006). The notification rates do not only affect Zambia but trends seem to show a global pattern and a cause of desperation among researchers and policy makers.

The battle with tuberculosis has created a lot of desperation among experts of ever controlling the disease in poverty-stricken regions of the world. Much research has been conducted over the last 40 years to improve and shorten the duration of TB treatment (Fox 1981). Several decades ago, TB treatment regimens demanded that patients maintain drug intake over 18 months or more, increasing the risk of premature discontinuation and the development of drug resistance, and placing high cost burdens on health care systems for long-term hospitalization. Numerous regimens have been tested throughout the world, leading to the recommendation of highly effective short-course chemotherapy regimens of six to eight months, using a combination of four drugs including rifampicin, isoniazid and pyrazinamide during the initial phase of treatment. In spite of these regimens, researchers have raised so many concerns on efficacy and compliance as shown by the results. These disquieting results did not daunt the International Union Against Tuberculosis and Lung diseases (IUATLD) Under the inspired leadership of Dr Karel Styblo, the redoubtable Director of Scientific Activities. The IUATLD introduced a novel comprehensive tuberculosis control program in some of the poorest nations in the world, beginning in Tanzania, and later in Malawi, Mozambique, Kenya, Benin, Senegal and Nicaragua. Twenty years later, the success of these model programs was undeniable. Arising from this research (Enarson 1991; Styblo 1991), a model for global TB control was developed by the IUATLD and WHO, with the objective of reducing mortality, morbidity and disease transmission worldwide. The model was to cut the chain of transmission by diagnosing and treating smear-positive pulmonary TB cases so as to render them rapidly non-infectious (Kochi 1991; Bloom and

Murray, 1992). This is why IUATLD was called the hero of the peace by championing the fight against the resurgence of tuberculosis. In addition, the success of the IUATLD's model program furnished sound scientific support for WHO's Global Tuberculosis Programme (Kochi, 1991) and IUATLD's tested concepts form the basic core of what WHO has adopted, packaged, and widely publicized under the rubric, Directly Observed Therapy Short Course, better known as DOTS. There are multiple reports of TB control programmes using various types of intervention to promote adherence and enhance case-holding, but most of these interventions depend on external funding, which bring into question their long-term sustainability. In their paper, they addressed the problems related to operational variabilities in the implementation of the Directly Observed Therapy Short Course strategy in resource-poor countries and questioned the appropriateness of a universal paradigm for global TB control (Lienhardt et al., 2004).

The re-emergence of tuberculosis (TB) as a global public health problem in the mid-1980s brought back to the attention of the international health community the existence of an old disease that many considered historic, or at least under control. After the decline of TB in the first three quarters of the 20th century (McKeown 1979), the re-emergence of TB in industrialized countries was attributed to the combined effects of the HIV epidemic and the return of social factors such as rising poverty, homelessness, overcrowded conditions and immigration from countries with high prevalence of TB (Snider & Roper 1992; Cantwell *et al.* 1994). In developing countries, where TB was never fully controlled and where the number of reported TB cases continued to increase consistently, the dramatic increase in TB case rates observed in the last decade has been attributed to the HIV epidemic in the context of increased demographic pressure and poorly organized control programmes with low case finding and cure rates (WHO 1994; Raviglione *et al.* 1995). At present, >95% of the estimated 8 million new cases occurring each year are in the developing world, where >80% of cases occur among people between the ages of 15–59 years (Dye *et al.* 1999). It is estimated that there are about 2 million adult deaths annually from TB in developing countries, which accounts for a quarter of all avoidable adult deaths, and in sub-Saharan Africa, TB is a leading cause of mortality (Raviglione *et al.* 1997).

This was the context for the declaration of TB as a global emergency decades ago, leading to strong recommendations to improve TB control worldwide (WHO 1994). However, despite this increased effort invested in TB control, the epidemic rages on. Strikingly, with the return of TB, we face the paradox of a well-defined disease, caused by a well-identified germ, fully treatable with efficient and affordable drugs according to internationally recommended guidelines, which yet causes increasing human suffering and death. Today, as the world is in the grips of a devastating human immunodeficiency virus (HIV) epidemic, time has come to ask ourselves why we have so far failed to control TB and define limits of the global TB control paradigm (Raviglione & Pio 2002) and particularly the Directly Observed Therapy strategy.

The aims of Directly Observed Therapy Short Course are; to prevent relapses, to reduce chances of drug resistance developing, to prolong the lives of people with HIV/TB and to reduce the incidence of TB (Current Issues on TB control (CITC) 1999). For DOTS to work effectively its components should be combined well, these components are:

- There should be **a sustained political commitment**.
- There should be **access to quality assured TB sputum microscopy** for detection among persons presenting or found through screening to have symptoms of TB, sputum culture is also used for diagnosis in other countries but direct sputum smear microscopy should still be performed for suspected cases.
- There should be **standardized short course chemotherapy** for all cases of TB under proper case management conditions including direct observation of treatment regimens of 6-8 months for at least all confirmed smear positive cases.
- There should be **no interrupted supply of quality assured drugs** with reliable drug procurement and distribution systems.
- There should be **a recording and reporting system** that ought to enable outcome assessment of all patients and assessment of overall programme performance (WHO/CDS/TB 2003)

1.2 Statement of the Problem

Tuberculosis is a major public health problem in Zambia and is among the top ten causes of morbidity and mortality (ZNTLP Annual report 2006). In 1964 Zambia had a TB prevalence rate of approximately 100 cases per 100,000 persons. From 1984 to date, the prevalence of TB has risen dramatically. In 2004, the case rate of TB was 450 cases per 100,000 and approaching 500 cases per 100 000 cases (Chanda 2002). Zambia ranks 11th in the world in mortality rate due to TB (WHO 2005). In Ndola Urban District TB cases in the past six years are as shown below;

Table 1: TB Incidence 2002-2007

YEAR	TB INCIDENCE	CASES PER 1000
2002	3,562	11.1
2003	4,428	10.0
2004	3,656	8.7
2005	4,964	11.4
2006	2,339	5.2
2007	1,867	4.0

Source: HMIS Ndola DHMT

Though there is a general reduction in new cases recorded, figures are still on the high side compared to global standards.

So many people have died and suffered from this disease such that nowadays we have control programs to curtail transmission and mortality. The aim of TB control is to break the cycle of transmission by treating TB cases as early and efficiently as possible. Directly Observed Therapy Short Course, promotes compliance thus increasing the proportion of patients cured hence death rate decreases, the prevalence of drug resistance falls, relapse rates are reduced, and in the long term; transmission is interrupted and incidence falls (WHO/CDC/TB 2003). However, the diversity of patients' attitudes towards the disease and the extreme variability of access to Directly Observed Therapy Short Course, especially in resource-poor countries like Zambia, are amongst the many factors of social context that profoundly

affect the ability of control programmes to implement this policy effectively. In 2007 about 8% of TB patients in Ndola urban missed drug collection appointments (Ndola HIMS 2007). The problems which led to missing drug collection appointments are not known. Acceptable DOTS drop out is 5% (WHO 2003). TB patients, who miss their drug collection appointments In Ndola district, are followed up. Unfortunately not all followed up patients are traced. Others are traced and they continue taking drugs. This scenario may lead to drug resistance, on the other hand follow ups are time consuming because of staff shortages being experienced in the Ndola Urban district. Multi drug resistance TB is very expensive to treat. One case of MDR-TB costs \$200,000 of which is equivalent to treatment cost for 700 TB patients. MDR-TB treatment period is one year; during this period transmission period is prolonged.

Review of the records in Ndola has shown that, the district is unable to account for the problems which patients accessing Directly Observed Therapy Short Course experience. It is also not known at what stage following a diagnosis, what problems (barriers) tuberculosis patients experience in accessing Directly Observed Therapy Short Course. Noting that there is no empirical evidence of the problems, Ndola urban district is not in a position to plan how the problems of accessibility could be mitigated.

1.3 Factors contributing to difficulties in accessing DOTS

Literature on TB has shown that there are barriers that affect TB control and these range from: adverse drug effects, time, distance, cost, stigma, poverty, beliefs and health service. Each one of these is discussed below.

1.3.1 Duration, Supervision, Treatment and Adverse Effects

Literature documents specific groups of potential treatment defaulters. A study in Ethiopia concluded that men have twice the risk of treatment default than females. Also, the most excluded sectors of society are more likely to interrupt treatment such as migrants, undocumented workers, the unemployed, the homeless, the mentally ill, and drug addicts in the United States and Western Europe. In developing countries, rural, older and less educated people are more likely to default. One of main reasons for treatment default is lack of knowledge and side effects. In one study in South

America, by Gülbay, et al., (2006) ninety-five patients (8.3%), experienced side effects. While asymptomatic liver function disturbance was established in 56 of the patients (4.9%) with initiation of anti-TB therapy, the rate of hepatotoxicity was found to be 2.4%. No age or gender differences were observed among those who had hepatotoxicity and who had not. The major side effects were ototoxicity (1.7%), hepatotoxicity (0.8%), neuropsychiatric manifestations (0.7%), and hyperuricemia (0.6%).

Studies in India, Swaziland, Thailand and Zambia indicate that poor knowledge about the length of treatment predicts default behavior. Most defaulting patients interrupt treatment soon after they feel better and/or around two months after initiating chemotherapy. For example, findings from India suggest that patients' misconception of well-being with cure leads to default. Also, patients who did not know about potential side effects of medicines were more likely to default (Atre et al., 2004).

A study in India showed that key differences among compliers and non-compliers included motivation, perceived severity of disease, and self efficacy. That is, those who are more motivated have a higher perception of risk, and feel more confident about their ability to complete treatment are less likely to default. Similar findings were found in a study in Thailand where compliance was more likely among patients with good knowledge, who perceive their illness to be more serious, and believe that treatment will alleviate the condition.

The objective of DOTS requires that drug therapy be supervised to assure compliance. Unfortunately, this requirement and other significant barriers limit implementation; it is currently available to only 12% of patients with active disease worldwide. In addition, chemotherapy is expensive, has significant side effects and a cure requires 6-9 months of Directly Observed Therapy. As a consequence, patient compliance is difficult to maintain even in countries with strong tuberculosis control programs. Moreover, current DOTS drugs are largely ineffective against MDR-TB. This is a growing concern.

1.3.2 Distance

Distance to DOTS clinics has been noted to be a factor and this was seen in rural areas in The Gambia (Eastwood and Hill 2004), Tanzania (Wandwalo and Morkve, 2000), and Zambia (Needham et al. 1998). Transportation costs which are associated with distance between residence and DOTS clinics also account for variations in timing of accessibility to diagnostic and treatment centres in Zambia (Needham et al. 1998).

1.3.3 Beliefs

Erroneous beliefs about the cause of TB and how it could be treated have been described by a number of researchers (Liefoghe et al., 1997). There have been negative perceptions leading to abandoning treatment and delays in accessing treatment. Women in particular hold negative beliefs about TB. Negative associations (e.g., TB being a disease of the poor, dirty people, prostitutes, etc) may lead to unpleasant social consequences leading to considering alternative health care (Liefoghe et al., 1995; Liefoghe , 1998).

1.3.4 Stigma

TB stigma has been widely reported as a barrier in TB control. Stigma is perpetrated and reinforced by health staff, family, neighbors, and other groups. Patients postpone seeking care due to fears of finding out their HIV status, and suffering stigmatization and social rejection as a consequence of their HIV and TB status becoming known. Stigma is one social contextual factor that mediates behaviour via denial and concealment of disease; both phenomena have been found more common among women than men. These have been associated in turn with delay (Dale et al., 2001) and refusal to attend health care. Johansson et al. (2000) and Rubel and Carro (1992) have also shown how social stigma affects patients' familial relations and response to illness. Research has shown that stigma associated with TB often discourages patients from seeking treatment (Liefoghe et al. 1997; Auer et al. 2000). In one study done in Ethiopia by Cambanis et al. (2005) most of the people (61%) believed tuberculosis patients were not accepted in the community on account of the label assigned to them for having tuberculosis. It has been noted for instance

that due to increasing prevalence of HIV/AIDS throughout sub-Saharan Africa (Corbett et al. 2003), the stigma of tuberculosis has been heightened by its perceived - the two being synonymous for many people (Banerjee et al. 2000; Lawn 2000). In a survey in Addis Ababa, Gelaw et al. (2001) found that most people who feared tuberculosis did so because of its association with HIV, while the rest thought it was incurable. This notion was associated with the Amharic term for tuberculosis, *sanba nekersa*, which is also used for lung cancer or tumour. Knowledge and beliefs of the population about tuberculosis and the stigma associated with it are crucial determinants for the use of health services and should be kept under consideration when developing appropriate case-finding activities (Rubel and Garro 1992).

Other than these problems, labeling patient behavior as 'ignorant/vicious', 'recalcitrant' and 'non-compliant' has been known to hinder the process of negotiation and accommodation within the doctor/patient relationship (Lerner, 1997). In other settings, health workers' poor communication skills are known to lead to poor compliance of TB patients. For instance, health-seeking patterns among TB patients in India were attributable to the efficiency of health care providers (Balasubramanian, et al, 2004). It has been proposed by Cambanis et al. (2005:333) that education campaigns should be tailored to suit local perceptions and beliefs in order to have maximum effect, and studies are recommended at the local level to gather relevant information on stigma and not forgetting the gender component.

1.3.5 Socio-economic Factors

There are a number of social economic factors that seem to be linked to barriers in accessing a tuberculosis service and below we provide a profile.

In Malawi, significant sociodemographic factors were noted to be associated with delay and being female and having an education of less than 9 years were very prominent. Among health services factors, delay was associated with outpatient diagnosis of tuberculosis, having visited a private doctor or traditional healer, and more than six tuberculosis-related health seeking encounters (a health-seeking encounter being a visit to a pharmacy, traditional healer or any formal health service provider). The difference in mean delay between each group was approximately 2

weeks for most of the significant factors, except for those patients with more than six health-seeking encounters and those who sought care from a traditional healer, for whom the difference in mean delay was approximately 3 and 6 weeks, respectively (Dale et al., 2001). Although tuberculosis is a great economic burden on patients as stated by Gibson et al.(1998) and Needham et al. (1998), it was surprising that in low income countries like Zambia, economic factors unlike the Malawi studies (Nhlema, 2002) were not significant using the indirect measures considered in this analysis. There was a trend, however, toward shorter delay among patients who could obtain external financial assistance.

As stated earlier, studies in Malawi have shown that income has a bearing on health behaviour. It has been shown that poor people depend on low income earning livelihood strategies to buy and access health care. For example within urban settings, most poor people do *ganyu* work (daily employment), petty trading and in extreme cases begging to earn a living (Nhlema, 2002). This has two consequences: (a) it leaves the poor with limited disposable income to use for care seeking; (b) it means that the poor have to choose to lose a day's earnings if they need to take a day off to seek health care. The situation is similar in rural areas; most of the poor depend on *ganyu* or field work to earn a living (National Economic Council, 2000). Care for tuberculosis patients has both direct and indirect costs. Direct costs may consist of transport costs for the patient and guardian(s), food costs and any payments for diagnosis and treatment (Kemp et al., 2007). Indirect costs include number of working days lost due to illness, reduced income due to illness as well as loss of productivity in the medium term. The costs incurred seem to be generally higher before diagnosis. One of the factors contributing to this is the fact that patients have to make several visits to health providers before diagnosis. Most expenditure incurred is for transportation for both patients and their guardians. Poverty therefore affects one's ability to access services due to the necessary expenditure on transport and food costs for patient and guardians alike, even though tuberculosis services and drugs are free. Evidence available in Malawi indicates that the total delay for tuberculosis patients before diagnosis is up to 2 months (Salaniponi et al., 2000). In Malawi, studies have revealed that in urban areas, patients with symptoms suggestive of tuberculosis exhibit a variety of initial care-seeking patterns but care

seeking from public health facilities tend to occur more as symptoms progress (Kapulula et al., 2000).

In Africa, economic factors play a very critical role in seeking treatment. Treatment costs are not only an obstacle for adequate health-seeking of the poor; they also signify a higher burden for the poorer households compared to the more affluent. Even if the poor spend less or equal amounts on coping with illness, the percentage of the monthly or annual income is higher among the poor. The impact of health-seeking processes on the household economies of the poor is clearly shown with tuberculosis and AIDS. Similar negative impacts are observed also for illnesses which in principle are less costly, but where households can be faced with several episodes at a certain time of the year, particularly before the harvests when work load on the fields is intensive, when little money is available, and when coping strategies are most difficult to activate (Hausmann-Muela, 2000).

The resource-seeking processes for health have not necessarily been the same impact in all households with a similar poverty profile. To a great extent, health-seeking of households depends on their capacity and possibility at a specific moment to mobilise resources, both in material and social or symbolic terms (Corbett, 1989; Chasmbers, 1995). Lack of resources hampers adequate treatment, and favour development of parasite resistance, illness recrudescence and prolongation, which ultimately increases direct, indirect and opportunity costs. Long duration or concentration of illness episodes in a household can lead to selling of all available assets and other coping strategies (e.g. borrowing money), pushing the household into the vulnerability spiral. Illness can end up being extremely costly for the poor (Corbett, 1989). In general, the economic burden of illness can have a double impact on poor households. Firstly, it can have an impact on health if individuals see themselves forced to interrupt treatment because of lack of cash, leading to increased vulnerability in terms of health. And secondly, when coping strategies lead to a process of impoverishment, a household is placed in a position of vulnerability in terms of material survival. In the worst case, both processes mutually reinforce each other, generating a spiral of double vulnerability.

Within the Sahel, Malawi and Ethiopia have provided reliable information that poverty plays a very important role in health seeking behaviour. In Ethiopia, Cambanis et al., (2005) patient delay and factors associated with this delay were analysed. Patients took a mean of 10 weeks from onset of symptoms to diagnosis, with a median of just over 4 weeks, which is consistent with previous studies in the Sahel (Lawn et al. 1998; Pronyk et al. 2001; Demissie et al. 2002). Most of the factors associated with patient delay were economic: cost of transport, prolonged transport time, rural residence, overnight travel, and the need to sell personal belongings to be able to afford coming to the health centre. These factors are indicators of financial stress and underline economic barriers to health care. The importance of accessibility to transport cannot be overstated, as more than half of the 65 million inhabitants of Ethiopia live more than 10 km from the nearest health facility (WHO 2003). In order to meet the costs of transport and medical care, more than half of the patients had to borrow money; a quarter sold personal belongings, including important possessions such as cattle.

Poor patients in particular are likely to go first to the informal private sector where they face fewer costs and opportunity costs, and they tend to stay at this level longer than non-poor patients. Noting that tuberculosis is a chronic illness, once within the formal health system, patients need to make several visits due to the requirements for sputum submission for diagnosis. However, in all these studies, delay and economic costs were tagged with gender but the studies seem to affirm what was established in the past that lower class persons tended to under utilise health services because of financial cost or culture of poverty. In Zambia, the barriers of transportation and time costs were observed by Dale et al., (2001).

From this presentation, people living with tuberculosis may be gravely affected by the culture of poverty. The culture of poverty, as summarised by Goode and Eames (1996) is a phenomenon where poverty over time influences the development of certain social psychological traits among those trapped within it. These traits include dependency, fatalism, inability to delay gratification, and a lower value placed on health (being sick is not unusual). This eventually tends to reinforce a poor person's disadvantaged position.

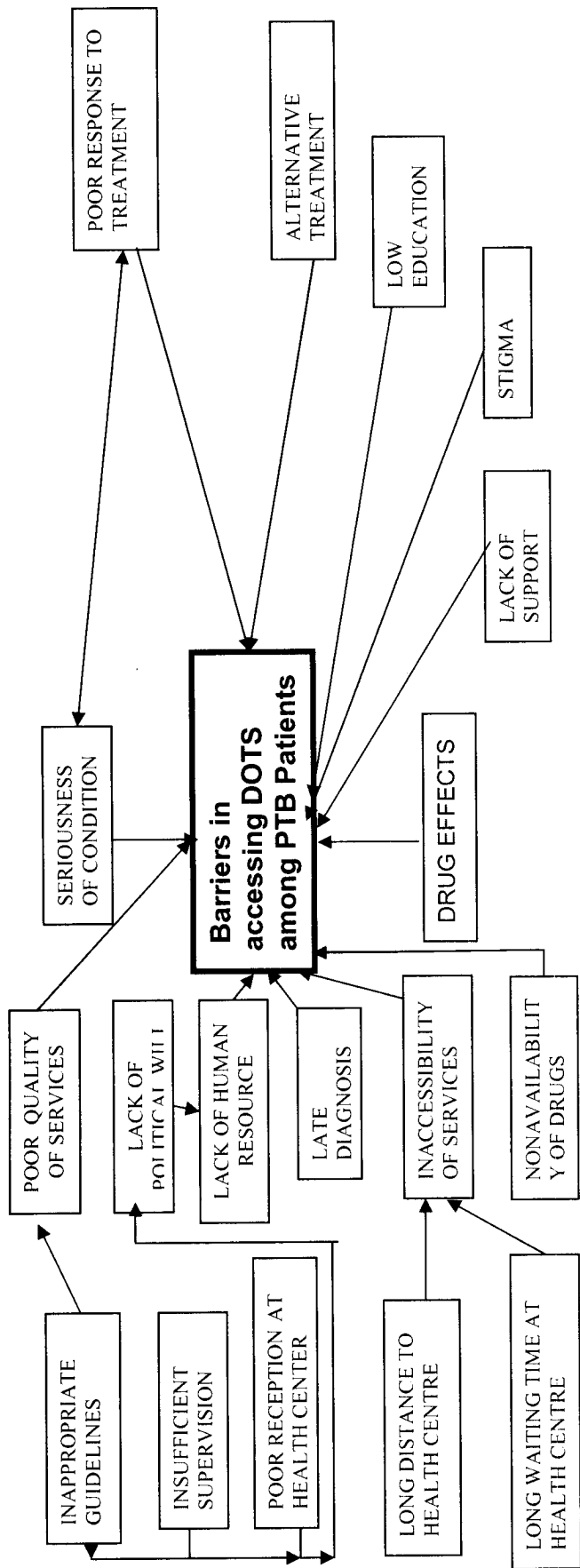
1.3.6 Service Related Factors

Other than income, patients' higher sensitivity to negative attitudes and behaviour of staff and other deficiencies in the health facilities have also been reported. Vlassoff (1993) once described how women often are treated in an inferior way by the health system and therefore hesitate to seek care. Interaction between staff and patients appears to be of great importance for the trust and confidence in health institutions and treatment. Consequences of poor attitudes and behaviour of staff has also been described by Smith (1993) from his experience in Nepal, where health workers frequently responded aggressively to people who finally presented for treatment in terminal stages of TB. Smith concluded that such attitudes may make the patients feel threatened, uncomfortable, unwelcome and unwilling to return. It is important to take consequences of poor care into consideration. Donabedian (1989) for example stated that poor care that could harm patients as well as being wasteful and that waste in any form depleted resources that could be used to treat more patients better.

Geographic mal-distribution of services, like geographic mal-distribution of personnel and facilities, and difficulties in access associated with age, language, sexual orientation and social conditions such as homelessness have been noted to be barriers to access health care.

1.4 Problem Analysis Diagram

SERVICE FACTORS DISEASE RELATED SOCIAL CULTURAL FACTORS



1.5 Research Question

Given the statement of the problem this study seeks to answer one main question which is: **what major obstacles do pulmonary tuberculosis patients experience in accessing Directly Observed Therapy Short Course?**

The main question will guide us to answer the following specific questions:

1. What are the common problems TB patients experience in accessing DOTS?
2. At what stage do these problems occur?
3. How can the problems be mitigated?

1.6 Significance of This Study

This study is significant in the sense that it is a pioneering one in looking at barriers patients face in accessing DOTS. The results are of great potential in improving service delivery. The methodology could be used for subsequent studies and TB interventions within Ndola Urban.

The other reason is related to little literature available regarding barriers in accessing Directly Observed Therapy Short Course. At the moment, there is indeed little known literature on the barriers of implementing Directly Observed Therapy Short Course. Therefore the study will generate first hand data based on health worker experiences and problems experienced by tuberculosis patients. Findings of this research could influence policy change or revisiting the DOTS program. It may influence decision making in policy formulation through the provision of empirical driven feedback to donors, service users, administrators and staff. This study will also provide guidance so that measures can be put in place to overcome the problems encountered in DOTS implementation hence reduce morbidity and mortality due to TB. The study will provide baseline information for a much wider country specific study and it will provide a framework for improving access to Directly Observed Therapy Short course.

It is expected that from this project, we shall be able to transfer our experiences into district plans and strategies for effective action at the community level later on.

1.7 LITERATURE REVIEW

1.7.1 Introduction

WHO introduced DOTS in the 1990s in an effort to control the spread of tuberculosis. DOTS is the management package that ensures that tuberculosis services are delivered effectively to patients. It is the best way of curing people with tuberculosis. DOTS consists of five elements: (i) case finding using sputum smear examination by microscopy; (ii) Directly observed, standardized short-course chemotherapy; (iii) regular supply of anti-TB drugs; (iv) establishment and maintenance of reliable recording and reporting for regular evaluation; and (v) political commitment to a nationwide and permanent TB programme (WHO/CDC/TB 2003). In 1997, the Director General of the World Health Organization termed Directly Observed Therapy Short Course the health breakthrough of the 1990s; and in 1993, the World Bank published their influential report, 'Investing in Health', and identified tuberculosis control as one of the most cost effective interventions in primary health care (Smith, 1999)

In order to ensure that TB is brought under control, WHO has recommended that a target of detection of infectious cases be set at 70% and a treatment success rate of 85% and that this should be achieved by 2005 (WHO 2003). One of the biggest barriers for the successful treatment of TB is poor adherence on the part of the patient. Therefore, in 1995 WHO urged the use of DOTS as a priority for effective TB control and as a means of reducing the development of drug resistance.

During the first 5 years of its promotion by WHO, DOTS did not enjoy the success initially anticipated. While more governments adopted the policy, recent epidemiological analysis indicated that effective control was still far from their grasp (Dye *et al.* 2002). The degree to which treatment is actually Directly supervised varies greatly between and within countries using the strategy (De Cock & Chaisson 1999). The WHO Directly Observed Treatment Short Course (DOTS) strategy has demonstrated an improved cure rate for those infected with tuberculosis and inhibited by severe economic and environmental conditions (CBOH, 2002).

This statement about improved cure for those using DOTS was confirmed by the WHO rapid assessment which showed that TB morbidity and mortality can be reduced with DOTS implementation (WHO/CDC/TB 2003). The beneficial effects of DOTS extend far beyond simply increasing the proportion of patients cured. Because more patients are cured, four further benefits accrue. The death rate decreases, the prevalence of drug resistance falls, relapse rates are reduced, and in the long term, transmission is interrupted and incidence falls.

There have been several reports of successful implementation of DOTS strategy in TB control programmes (China Tuberculosis Control Collaboration 1996; Chowdhury *et al.* 1997; Netto *et al.* 1999). However, some countries continue to experience problems in the implementation of DOTS, as indicated by persistently high infection rates. One reason may be that DOTS does not offer guidelines on its implementation, especially for the key component of the package, Directly Observed Therapy.

Literature search has shown that there are few studies which have been done on barriers in accessing DOTS. However, there are other studies which have been done on barriers in accessing TB drugs and other TB services. As a result literature review in this study will be based on this information.

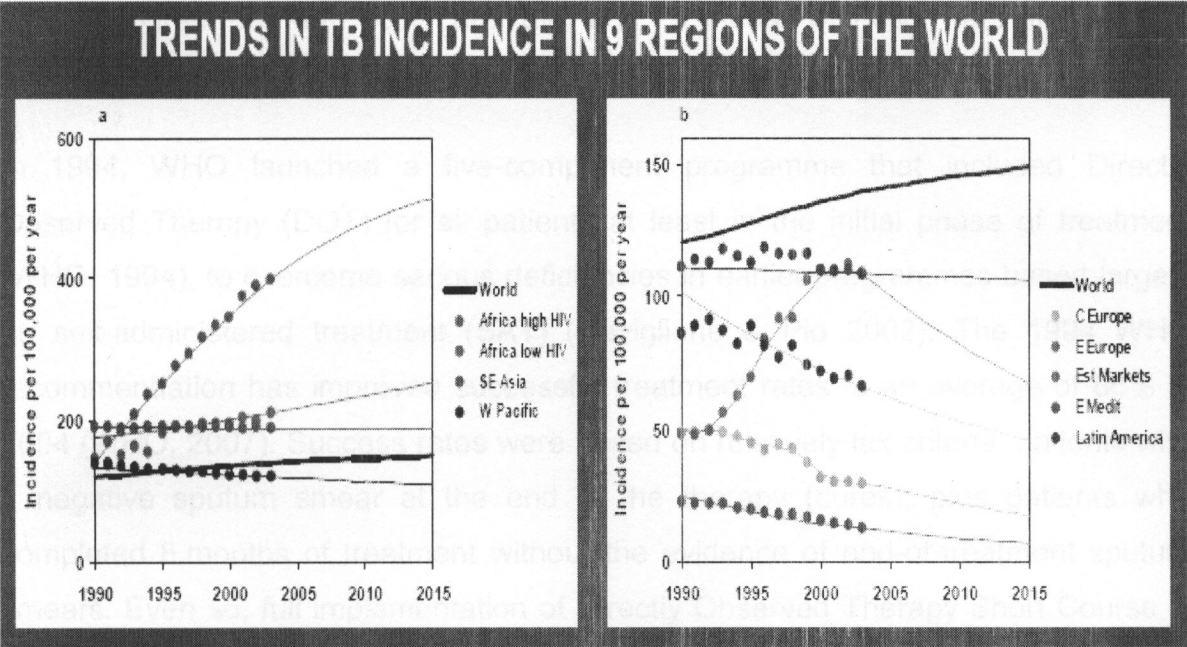
1.7.2 Global Perspective

The number of notified cases and mortality has been rising. For instance, in 1995, 3.3 million cases were reported to the Global Tuberculosis Programme of WHO, whereas a more likely number could have been 8.8 million. Of the reported cases, 62% were said to have occurred in the Southeast Asian and Western Pacific regions, 16% in sub-Saharan Africa, and 7% to 8% in each of the regions of the America, Eastern Mediterranean, and Europe. It has been noted that many countries, especially those with few resources, are unable to make all tuberculosis notifications because of difficulties in identifying suspected cases, establishing a diagnosis, and recording and reporting cases (Corbett *et al.*, 2003; WHO, 2003,2006).

The impact of tuberculosis is greatest on the poor; 99% of the deaths and 95% of all cases occur in the developing world (WHO 2005). The majority of people affected by tuberculosis are in the economically active age groups. Families and communities are deprived of their parents and their work force. Tuberculosis and poverty go hand in hand - people who are poor get tuberculosis, and people who get tuberculosis become poor. Tuberculosis also shares a deadly synergism with HIV. People who have been infected with tubercle bacilli have a 10% lifetime risk of developing active tuberculosis disease. If they are also infected with HIV, the risk increases to nearly 10% per year. As a result, countries with a high prevalence of HIV are witnessing high rates of TB (Corbert et al., 2003; Williams and Dye, 2003).

Now it is estimated that the incidence of tuberculosis is growing and it stands at 1.8 % per year (Corbett et al., 2003). This translates to about 2 billion or a third of the world's people getting infected with tuberculosis. 5 000 people at the moment are dying every day and 98% of these occur in developing countries affecting mostly young adults in their productive years (WHO, STOP TB, 2005). Overall, there were an estimated 9.2 million new cases of TB in 2006 (139 per 100 000 population), including 4.1 million new smear-positive cases (44% of the total) and 0.7 million HIV-positive cases (8% of the total). This is an increase from 9.1 million cases in 2005 due to population growth (WHO, 2008:3) and tends to have a spatial and temporal variation (figures 1). There were an estimated 14.4 million prevalent cases of TB and estimated 0.5 million cases of multidrug-resistant TB (MDR-TB) in 2006. In 2006 there were also an estimated 1.5 million deaths from TB in HIV-negative people and 0.2 million among people infected with HIV. In 2007, a total of 202 (out of 212) countries and territories reported TB notification data for 2006 to WHO. A total of 5.1 million new cases (out of the estimated 9.2 million new cases) were notified for 2006 among these 202 countries and territories, of which 2.5 million (50%) were new smear-positive cases. The African, South-East Asia and Western Pacific regions accounted for 83% of total case notifications (WHO, 2008:3)

Figure 1: Spatial and Temporal Variation of Tuberculosis



Source: (WHO, 2005)

Spatially, there are 22 countries in the world, which constitute 80% of global tuberculosis cases. Looking at the global distribution of tuberculosis mortality and morbidity data, Corbett et al., (2003:1013) observed that there was a spatial and temporal variation in incidence. This variation in tuberculosis incidence is strongly associated with the prevalence of HIV infection. In 2000, for instance, 11% of all new tuberculosis cases in adults (612 000) occurred in persons infected with HIV, and 9% of all new TB cases were directly attributable to HIV. The prevalence rate of HIV infection in new tuberculosis cases varied markedly between regions and countries: from 1% in the WHO Western Pacific Region, to 14% in industrialized countries and 38% in the WHO African Region; from under 1% in Afghanistan, Bangladesh, China, and Indonesia, to 60% or more in South Africa and Zimbabwe. The proportion of cases directly attributable to HIV was necessarily smaller (e.g. 31% in the WHO African Region).

World Health Organisation and International Union Against Tuberculosis and Lung Disease (IUATLD) have advocated Directly Observed Treatment Short Course since 1993 (Bloom and Murray, 1992). WHO estimate that with expansion of good-quality DOTS programmes with 85% cure rate, and 70% case detection rate achieved by 2010, 23% of cases would be prevented by 2020 (Range et al., 2000).

In 1994, WHO launched a five-component programme that included Directly Observed Therapy (DOT) for all patients at least in the initial phase of treatment (WHO, 1994), to overcome serious deficiencies in earlier programmes based largely on self-administered treatment (SAT) (Raviglione & Pio 2002). The 1994 WHO recommendation has improved successful treatment rates to an average of 86% in 2004 (WHO, 2007). Success rates were based on relatively lax criteria: patients with a negative sputum smear at the end of the therapy (cures), plus patients who completed 8 months of treatment without the evidence of end-of-treatment sputum smears. Even so, full implementation of Directly Observed Therapy Short Course is very difficult, and programmes without sufficient resources often fail to reach this modest goal. For instance, a carefully evaluated Directly Observed Therapy Short Course programme in Tamil Nadu in India only achieved 75% success at the end of the treatment with 12% relapses within 18 months (Thomas *et al.* 2005).

A Cochrane database review (Volmink & Garner 2006) found Directly Observed Therapy to be no better than SAT in 10 trials. Neither this review, nor other randomized controlled trials studied the development of drug resistance in Directly Observed Therapy vs. SAT regimens (Rusen *et al.* 2007). Because multiple visits per week to a health facility require significant patient motivation, one might speculate that many if not most of the successful Directly Observed Therapy patients could have been successfully treated with SAT. Khan *et al.* (2002) showed Directly Observed Therapy to be less cost-effective than SAT. In two resource-limited programmes, 60–65% of the patients were successfully treated with SAT (Zwarenstein *et al.* 1998; Walley *et al.* 2001).

During the piloting of DOTS in India, for example, it was found that lack of clear guidance on how to implement DOT was resulting in frontline health providers *deselecting* those patients deemed least likely to comply with therapy (Jaiswal *et al.*

2003) an unforeseen development with potentially devastating effects for individual TB sufferers and for overall programme effectiveness and efficiency.

The operational research studies in two pilot sites in New Delhi from 1996 to 1998, a variety of operational research methods were used, including semi-structured interviews, focus group discussions, non-participant observations and collection of data from the TB registers. The cure rates for the clinics were 71 and 75% with a default rate of 6% and 11%, respectively. Other patients, largely those who were in absolute poverty, socially marginalized, itinerant labourers, poorly integrated in the city, were put on standard TB treatment as for the previous National TB Programme. (Central TB Division Delhi 2001).

A trial in Thailand showed a clear benefit from DOT ensured daily by a family member and reinforced by a weekly motivating visit by the health workers over self-administered treatment (Kamolratanakul *et al.* 1999). In the last trial, conducted in Pakistan, there was no difference between self-supervised treatment (fortnight collection of drugs by the patients) and DOT by a health worker or a family member, although higher cure rates were obtained when treatment was given under direct observation of a family member contrary to a health worker (Walley *et al.* 2001). Results from the first and third trial suggest that, in these populations, there was little to be gained by DOT compared with self-administered treatment but, in both settings, about 30% of patients interrupted treatment before completion in each arm, which raises doubts about the basic effectiveness of the TB control programme in these sites.

In a retrospective study, comparing 407 cases of unsupervised treatment given from 1980 to 1986 with 581 treatment courses of DOT from 1986 to 1992, in Texas, USA, the proportion of patients with primary drug resistance fell from 13% to 6.7%; acquired drug resistance dropped from 14% to 2.1% and the frequency of relapse declined from 20.9% to 5.5%. Similarly, the failure rate in previously treated patients fell from 17.6% to 6.2%, following the introduction of Directly Observed Therapy in China.

Globally countries applying DOTS on a wide scale have witnessed remarkable results. In Peru for example incidence of TB has dropped by approximately 6 percent per year over the past decade, mortality has fallen in China.

Wang W, et al (2006) conducted a study on Barriers in accessing tuberculosis care among non-residents in Shanghai: a descriptive study of delays in diagnosis; The results of this study indicate that patient and health system related factors contribute significantly to delays in the diagnosis of non-resident TB patients in Chinese cities. Non-resident's poor economic status, the onset of symptoms and the complexities in referral and diagnostic procedure at different districts accounted for delayed TB care-seeking and diagnosis.

Some authors believe that differences in case detection rates are spurious and that far greater numbers of women are truly affected, their diagnosis being prevented by social factors and cultural barriers in access to health care (Uplekar et al., 1999). The strongest evidence for a social basis in the gender discrepancy is the comparison of active and passive case finding methods, where significantly more female cases are identified with active case finding (Uplekar 2001).

In a nationwide study of migrant farm workers, 57% listed clinic hours as the main barrier to receiving dental care. Greatest barriers to accessing care, clinic hours and transportation ranked second and third, respectively, behind cost. In a similar study conducted by the North Carolina Center for Public Policy Research, 55.2% named transportation as one of the top three barriers to health care. It could take as many as three bus rides and two hours to get to a health care provider and patients are likely to miss appointments. (NHMHC 2004)

Health literacy is another potential barrier to access health care. Healthy People 2010 defines health literacy as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (Collins et al. 2002). Problems with health literacy can make it difficult to complete intake forms, enroll in insurance programs, read appointment slips, and understand how to navigate the health care system. Patients with a poor understanding of good health may not know when it is necessary to seek

care for certain symptoms. A recent survey revealed that between 20 and 25 percent of minorities believe that staying healthy is a matter of luck (versus 12 percent for whites), indicating that these groups may not be educated about the benefits of preventive care (UHCAN 2004)

EQUI-TB's research 2006 in china "Barriers to access, case detection and adherence to treatment" showed that economic barriers, geographical barriers, social and cultural barriers, and health system barriers affect the way in which poor and vulnerable people seek and access diagnosis and treatment for TB. High levels of economic burden among poor and vulnerable people and long distances from health services can result in people not seeking health care at all for TB. Gender, age and socio-economic status all influence how, when and if health care is sought. These factors combine with lack of awareness of TB and social stigma to increase barriers for effective TB control. Ineffective health systems also play a major role in reinforcing barriers to poor and vulnerable people. Lack of cooperation and coordination between national, regional and country health facilities and TB services can prevent patients from gaining accurate diagnosis and treatment. Lack of awareness of TB symptoms by healthcare providers, low referral rates to TB centres, and extra "hidden" costs for patients contribute to a less effective response to TB in China.

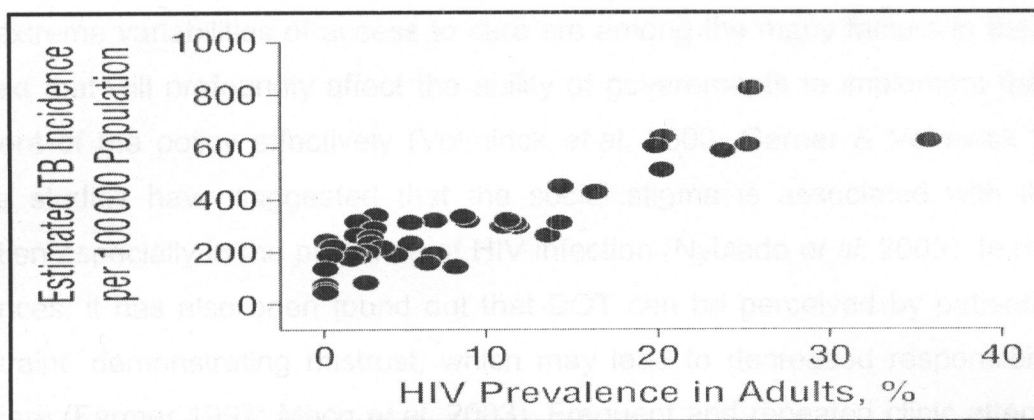
1.7.3 Regional Perspective

The morbidity and mortality caused by TB currently place it among the highest priorities for disease control. Three quarters of the world's HIV-infected individuals live in Sub-Saharan Africa, where annual tuberculosis case notification rates have risen up to fourfold since the mid1980s, reaching peaks of more than 400 cases per 100 000 in some countries with the highest rate of 1000/100 000 around Cape Town, South Africa. Over two-thirds of patients with active tuberculosis are co-infected with HIV in some areas of Sub-Saharan Africa with an average in Africa of 31% of tuberculosis cases being attributable to HIV in 2000 (Corbert et al., 2003). The superimposition of HIV infection in people with pre-existing tuberculosis infection increases the risk of developing tuberculosis from 5% to 10% over a lifetime to

around 15% per year (Corbert et al., 2003; Brock et al., 2004) and each year 200 000 tuberculosis deaths are attributable to HIV co-infection in Sub-Saharan Africa (Williams and Dye, 2003).

It has been noted that tuberculosis morbidity and mortality has been increasing over the years, one variable which has been shown to have an influence is HIV/AIDS. In this HIV/AIDS era, tuberculosis has again become a feared disease. Prevalence, morbidity and mortality rates among HIV-infected people are extremely high in Africa. The worldwide incidence of HIV-attributable TB cases were estimated to increase from 315,000 (4% of the total TB cases) in 1990 to 1.4 million (14% of the total TB cases) by the year 2000. In 2000, approximately 40% of these HIV-attributable cases were estimated to occur in sub-Saharan Africa and 40% in Southeast Asia. Ten percent of the total number of TB cases that occurred during 1990 to 1999 was estimated to be attributable to HIV infection although demographic factors, such as population growth and changes in population structure, they largely account for the expected increase in tuberculosis.

It is noteworthy that among HIV-negative tuberculosis patients, the tuberculosis Case Fatality Rates (CFR) is higher in high HIV prevalence populations and this has been evident in Malawi and Zambia than in low HIV prevalence populations in the Comoros and Mali (Moorman, 1999). Several studies have shown a higher (CFR) in HIV-positive than in HIV-negative individuals among patients with pulmonary tuberculosis who tested positive by sputum smear or culture and the following stand out: Malawi showed the rates of 18% and 10% in the City of Zomba (Harries et al, 1998), 14% and 0.5% in Johannesburg, South Africa (Muray, 1999), and 13% and 0% in Zaire (Perriens et al., 1995). The lowest tuberculosis CFR in HIV-positive patients was reported in Cote d'Ivoire.



and extreme variabilities of access to care are among the many factors in the social context that will profoundly affect the ability of governments to implement the DOT element of the policy effectively (Volminck *et al.* 2000; Garner & Volminck 2003). Some studies have suggested that the social stigma is associated with the TB infection especially in the presence of HIV infection (Nyblade *et al.* 2003). In multiple instances, it has also been found out that DOT can be perceived by patients as a constraint, demonstrating mistrust, which may lead to decreased responsibility for self-care (Farmer 1997; Macq *et al.* 2003). Frequent and repeated clinic attendance is also likely to have an impact on costs incurred by the patients and may force them to drop out of treatment (Needham *et al.* 1998).

The implementation of a universal strategy is thus challenged on operational, epidemiological, economic and sociological grounds. In their systematic review of published reports on direct observation for TB control, Volminck and colleagues (2000) concluded that health care delivery oriented towards the needs and preferences of patients seemed to lead to more satisfied patients. The direction was thus given to a shift in perspective, considering the well-being of TB patients, taking into account their social and economic environment as well as the presence of the disease. This can be achieved through the confluence and complementarities of an interdisciplinary approach (Ogden 2000)

There has been extensive debate around the relative importance of provider vs. patient factors in non-adherence, the appropriateness of a universal policy of Directly Observed Therapy, the feasibility and acceptability of DOTS in different settings, and the importance of the relative costs of different DOTS options for providers and patients (Jochem disease is an obstacle to its treatment and that Directly Observed Therapy may aggravate this stigma (Ogden & Porter 1999), & Walley 1999).

A randomized controlled trial (RCT) in South Africa tested a set of interventions, aiming at improving communication and the patient “provider’s interaction. Results were inconclusive (Dick *et al.* 2004; Lewin *et al.* 2005), probably because they depended on contextual factors, including cultural competence ((New Jersey Medical School National Tuberculosis Center 2004)

(Eastwood S.V.; Hill P.C.2004); A gender-focused qualitative study of barriers to accessing tuberculosis treatment in The Gambia, West Africa reviewed that Tuberculosis is a stigmatized disease in The Gambia, particularly in women, and its management is associated with access problems. Health education is required to provide basic knowledge about the disease and to reduce stigma, and further decentralization of tuberculosis services is needed to improve access.

1.7.4 National perspective

The impact of TB in Zambia can be demonstrated by first reviewing the prevalence and incidence of this disease. Other important factors to consider are the co morbidity with HIV/AIDS and current intervention plans to treat TB in Zambia. Each of these topics will be briefly discussed. In 1964, Zambia had a TB prevalence rate of approximately 100 cases per 100,000 persons. That figure remained constant for the next 20 years. The first case of Human Immunodeficiency Virus/Auto Immune Deficiency Syndrome (HIV/AIDS) in Zambia was diagnosed in 1984. Between 1984 and the present, the prevalence of TB has risen dramatically. In 2004, the case rate of TB was 450 cases per 100,000 and in 2005 is approaching 500 cases per 100,000 (See figure 3). The mortality rate is 88.7 per 100,000 persons. According to 2002 World Health Organization data, Zambia ranks 11th in the world in mortality rate due to TB (Chanda, 2002; WHO, 2005).

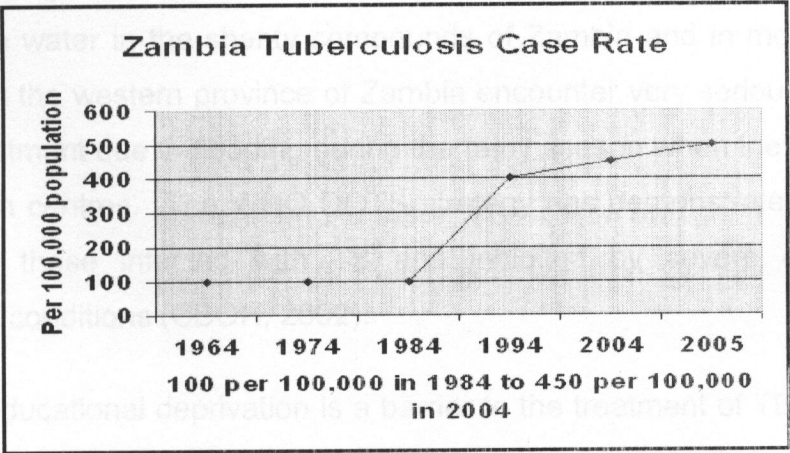


Figure 3: Zambia Tuberculosis case rate

Prevalence data in Zambia is not different from what is seen globally. Notable differences between men and women in reported rates of tuberculosis and other

aspects of tuberculosis control have made pulmonary tuberculosis an important focus of gender and health studies. Notification rates are nearly always higher for men than for women, suggesting either greater vulnerability of men to the disease or greater probability of women with tuberculosis to remain undetected. Reports from the nine provinces and for all age groups, except young adolescents, count fewer women. These data suggest important questions for both men's and women's health. Prevalence studies in Zambia have shown similar findings as those seen elsewhere. For instance, delay has been noted to be a factor for prognosis. The median (mean) diagnostic delay was 8.6 (9) weeks, and was significantly associated with the following factors: sex, lower education, more than six instances of health-seeking encounters, outpatient diagnosis of tuberculosis, and visiting a private doctor or traditional healer.

Tuberculosis has placed an ever increasing economic burden on the country of Zambia. Due to the high morbidity and mortality rates, there is an acute loss of workforce manpower, both in days of work, time lost and in the decreased numbers of available employees. In addition, treatment costs, though seemingly minimal, are often far beyond the means of many families in a country where half the population is unemployed. Economic burdens resulting from low income and related treatment costs, such as x-rays, nutritional needs, and travel to the health centre, pose further barriers to treatment (Chanda, 2002). Living conditions are often less than adequate with densely congested space, communal sharing of lavatory facilities and lack of access to safe water in the shanty compounds of Zambia and in most rural areas. Some areas in the western province of Zambia encounter very serious geographical barriers to treatment due to flooding during the rainy season when they are unable to travel to health centres. The WHO DOTS strategy has demonstrated an improved cure rate for those infected with TB and inhibited by severe economic and environmental conditions (CBOH, 2002).

Cultural and educational deprivation is a barrier to the treatment of TB. Patients with little or no education often believe that they have been bewitched. Anecdotal reports exist of patients who opt for traditional home remedies, instead of modern treatment for TB, especially when relatives are of the same mindset. The effect of education, or lack thereof, is a barrier to treatment, according to Munthali (2004) who notes that

high education may make it easier for TB patients' relatives to understand information about TB, its treatment, and prevention of drug resistance. Relatives with low educational attainment are not likely to encourage their family members to comply with the medication regimen.

People relate TB with HIV/AIDS and an associated social stigma results which may act as a barrier to access health care. In the Munthali (2004) study, HIV/AIDS was found to be closely linked with TB. Munthali reported that some members of the community considered every TB patient to also have HIV/AIDS. Family members caring for a TB patient may hold a silent belief that the patient also has HIV/AIDS. The strength of this belief may even lead caregivers (often relatives) to condemn the patient for having TB. Thus, the TB patient may develop low self esteem, a negative attitude towards him or herself and the disease, and may comply with treatment.

Family roles are often disturbed due to the chronicity of tuberculosis. Prolonged care and treatment is frequently needed, which causes extended periods of incapacitation, loss of productivity, and poor participation in community and family duties. Social support is very important if the TB patient is to respond favourably to the treatment. The family may offer this social support system. It may also be offered by the church, home-based care givers, and other Non Governmental Organizations (NGOs). Although able family members are encouraged to look after sick relatives, the chronic nature of the disease and prolonged treatment protocol can be barriers to effective treatment, even with family support (Munthali, 2004).

Kaona et al 2004 conducted an assessment on factors contributing to treatment adherence and knowledge on TB transmission among patients on TB treatment in Ndola. Factors associated with defaulting in the study, included patients beginning to feel better, lack of knowledge on the benefits of completing a course, running out of drugs at home and TB drugs being too strong. However, the major and striking determinant of non-compliance was the patient beginning to feel better.

In the study at Lusaka University Teaching Hospital (Luo et al 1994), it was found that over 45% of the TB patients could not comply with drug treatment instructions

for various reasons, including poor transportation to the hospital and lack of family support.

In a study conducted by Mooneye Catholic diocese of Ndola (2000) on Home based care programme on implementation of DOTS at community level. The findings were that community DOTS has proven to be highly effective. Its implementation is economically cheap both for the home care providers and for the patients and families.

Another study conducted in Monze in 2000 by Monze District Health Board on implementation revealed that the implementation of DOTS through families and community involvement is the only way of controlling TB in Zambia. The other results of the study were; improved cure rate from 70% to 82% with DOTS, improved success rate from 65% to 95%, defaulter rate from 10% to 1.5%.

In Lusaka also a study was conducted in 2000 by a community based Tuberculosis organization – Kamanga project on DOTS implementation as reported at the National TB conference. The findings were that the cure rate improve from 40% to 76.6%, defaulter rate from 20% in 1998 to 3% in 2000 and there was increased number of people attending the clinic in an early stage of the disease. The conclusion was that community treatment supporters can actively improve detection and early presentation of affected individuals. They can provide support and encouragement and trace those who fail to attend clinic.

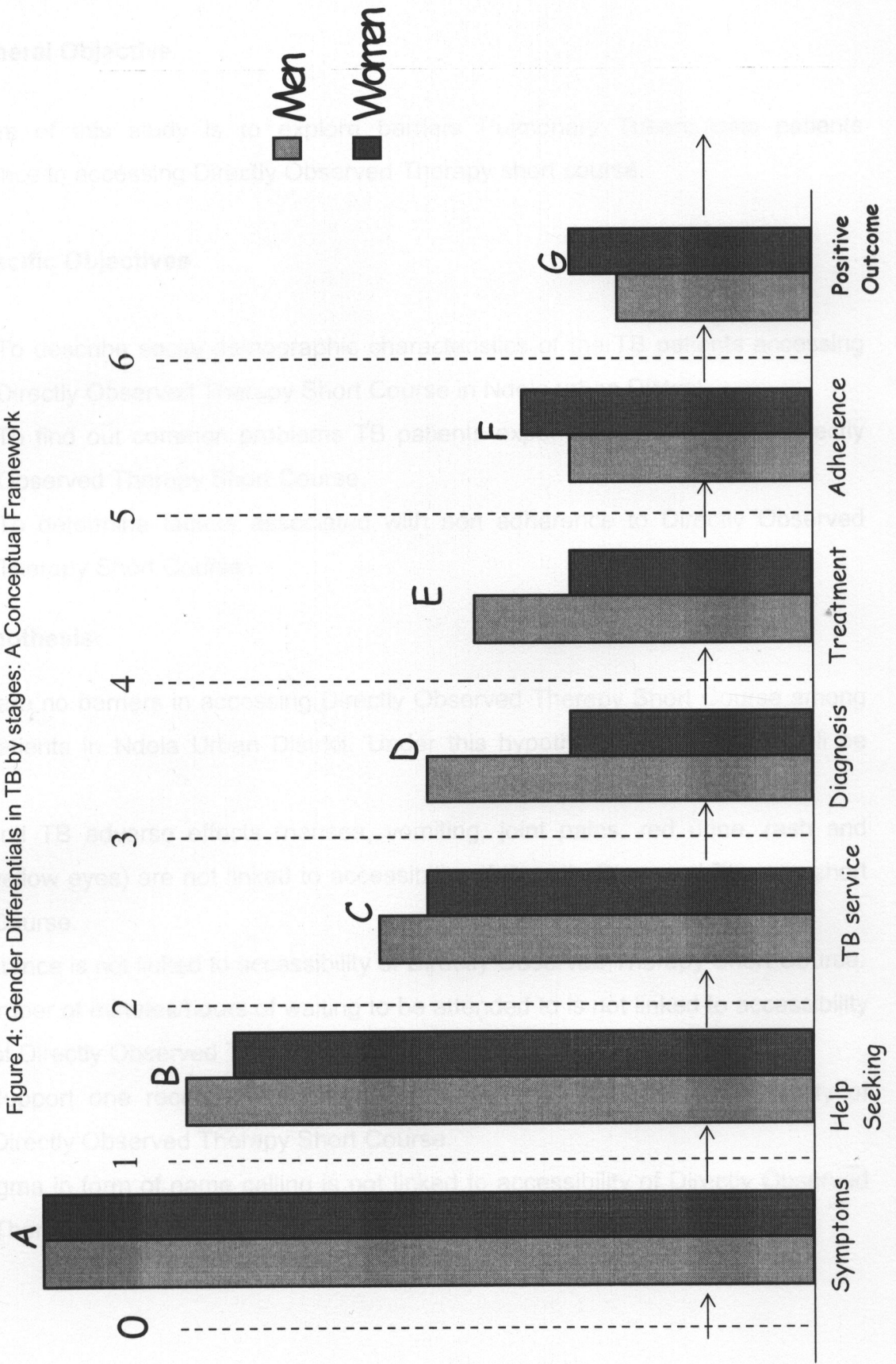
1.8 Existing Model Used in the Study of Tuberculosis

In this study, i have adopted the Uplekar model to ground the trajectory (route/path) of barriers in a TB service. The model starts from experiencing symptoms to seeking help and taking treatment either for relief or cure. The model further illustrates the process of attrition that occurs as people move through the various steps of TB disease and treatment, accounting for sex differences at each stage. The space between successive columns (A to G) represents determinants of patient's progress from a previous step to the next. The vertical dashed lines (0 to 6) represent barriers to progress and may be said to be responsible for the “depletion” along the course of the disease.

To illustrate, column C represents TB suspects referred to a TB service. These will be men and women suspects; a question arises about the sex-ratio among TB suspects presenting to a TB service. It is partly determined by the sex-ratio among symptoms presenting to a general health service (column B), which in turn depends on the sex-ratio among chest symptoms prevalent in a community (column A), and partly by differential barriers men and women face in presenting to a health service (barrier 1), and in getting referred to a TB service as suspects (barrier 2). Like wise, the sex-ratio among those diagnosed as TB (column D) will reflect and depend on sex-ratio among TB suspects (column C) and partly for reasons hidden in barrier 3; for instance, women may be embarrassed to provide sputum, or providers may send more men than women for sputum examination. The columns A to G thus represent mainly clinical, statistical and epidemiological questions while the dashed lines broadly indicate nodes for social science enquiry. The horizontal arrows indicate the process of movement which begins even before symptoms are expressed and presented and continues often beyond the disease outcome, as a result of persistent morbidity and stigma.

1.8 Justification of this model

This is the only model in TB prevention and control though it was developed when focusing on gender. It is important in this study in that the directly observed therapy traverses this trajectory and adherence is affected by the barriers along the model. The model provides a framework of interventions at any of the six specific points.



CHAPTER TWO- OBJECTIVES

2.1 General Objective

The aim of this study is to explore barriers Pulmonary Tuberculosis patients experience in accessing Directly Observed Therapy short course.

2.2 Specific Objectives

1. To describe social demographic characteristics of the TB patients accessing Directly Observed Therapy Short Course in Ndola urban District.
2. To find out common problems TB patients experience in accessing Directly Observed Therapy Short Course.
3. To determine factors associated with non adherence to Directly Observed Therapy Short Course.

2.3 Hypothesis:

There are no barriers in accessing Directly Observed Therapy Short Course among PTB patients in Ndola Urban District. Under this hypothesis, the following will be tested:

H_{01} : Anti TB adverse effects (nausea, vomiting, joint pains, red urine, rash and yellow eyes) are not linked to accessibility of Directly Observed Therapy short Course.

H_{02} Distance is not linked to accessibility of Directly Observed Therapy Short Course.

H_{03} Number of minutes/hours of waiting to be attended to is not linked to accessibility of Directly Observed Therapy Short Course.

H_{04} : Support one receives from health workers is not linked to accessibility of Directly Observed Therapy Short Course.

H_{05} Stigma in form of name calling is not linked to accessibility of Directly Observed Therapy Short Course.

2.4 Variables of interest

In this study there are two key variables of interest and these are barriers and accessibility to DOTS.

2.4.1 Operationalisation of the dependant variable

The dependent variable in this study is “accessibility to Directly Observed Therapy Short Course”. Accessibility will be operationalised in two ways as a step a TB patient takes when there is an obstacle to getting therapy. Accessibility will be measured on a nominal scale as:

- (i) I try to collect drugs, and
- (ii) I stay away. “I try to collect drugs” will be assigned a value label 1 and “I stay away” will be assigned a label 2.

2.4.2 Independent variables

The independent variables in this study are “barriers to accessing Directly Observed Therapy Short Course”. Barriers will be operationalised as difficulties or obstacles a patient faces who take a step to get to the clinic for drug refill. Barriers will be measured on a nominal scale as (i) drug adverse effects (nausea, vomiting, joint pains, red urine, rash and yellow eyes) (ii) comfortable with the distance taken to get to the health centre (iii) reception by the health centre staff (iv) comfort with the number of minutes/hours waiting to be attended to (v) support received from health workers and (vi) extent people call one names? Barriers will be measured on a nominal scale using Labels 1 for Yes and 2 for No.

2.4.3 Conceptual Definition of variables

2.4.3.1 Access is the right to use the services

2.4.3.2 Barrier is an obstacle or difficulty experienced in using the services.

2.5 VARIABLES, CUT OFF POINTS AND INDICATORS

VARIABLES	CUT OFF POINTS	INDICATOR
INDEPENDENT VARIABLES		
BARRIERS		
Side effects of TB drugs	Yes	Stay away
	No	Try to collect drugs
Distance	medium	0-30 minutes walk
	Long	30-60 minutes walk
	Too long	Above 1hour walk
Stigma	Yes	Stay away
	No	Try to collect drugs
Waiting Time	medium	0-30 minutes
	Long	30-60 minutes
	Too long	Above 1 hour
Support	Yes	Try to collect drugs
	No	Stay away
DEPENDENT VARIABLE		
Access to Directly Observed Therapy short course	Easily accessible	Try to collect drugs
	Not easily accessible	Stay away

CHAPTER THREE- METHODOLOGY

3.1 Research design

This was an exploratory and descriptive study in the sense that the researcher ventured into the unknown (barriers that influence access to Directly Observed Therapy Short Course) by trying to investigate an issue since there are few studies to refer to. This research design was suited to meet the objectives and research questions I developed which seek to present quantitative and qualitative data.

3.2 Study Setting

The study was conducted in Ndola Urban District which is divided into three zones namely; southern, northern and central and has a total population of 462,459 (Ndola DHMT HMIS 2007). There are eight government health centers in southern zone, seven in northern zone and five in the central zone. All the health centers in Ndola urban district implement Directly Observed Therapy Short Course. Health centers were sampled from zones for focus group discussion and all zones were represented.

3.3 Study Population

The study population was the health workers at the TB corner and the adult PTB patients in Ndola Urban District. Study population was the PTB patients on DOTS at the health centre because most patients in Ndola urban prefer clinic DOTS than any other arrangement. On the other hand these patients encounter a lot of problems in accessing anti TB drugs which was what the researcher was exploring. Accessible population is a portion of the target population that the researcher can have contact and sample from. The accessible population in this case was the adult PTB patients.

3.3.1 Inclusion Criteria

Tuberculosis patients aged 18 and above were eligible to be included in the sample. According to Zambian law a person becomes an adult when he/she is 18 years. In

this regard age 18 years was the criterion which was used to pick adult patients. Patients belonged to the designated catchment areas in the three zones (Northern, Southern and central). PTB patients were those in intensive and continuation phase.

- PTB patients who were in the TB register at the health center.
- PTB patients aged 18 years and above.
- Patients who had a TB card showing that they are on treatment
- Patients who consented to participate in the study
- Patient staying in Ndola and registered in Ndola urban health facility
- Patients who were mentally sound.
- Only those health workers working at the TB corner were eligible for the study (usually six members of staff work at TB corner) because they are the implementers of DOTS and knew some of the problems patients experience in accessing DOTS.

3.3.2 Exclusion Criteria

- PTB patients who were not on the TB register at the health center.
- PTB patients below the age of 18.
- Health workers not working at the TB corner
- Those who were not willing to participate

3.4 Sample Selection

Patients were randomly selected using an existing sampling frame (TB register). Study units were drawn using simple random probability sampling, all the TB patients were listed in the district register and numbers were assigned to each name. Using stata computer soft ware, a table of random numbers was created for the study population and 232 numbers were picked at random using a computer. These numbers picked were then compared to the list and individual patients bearing that number were included in the sample. A population study of health workers was convenient in this study for a focus group discussion because there were at least six staff at the TB corner.

Sample size

Sample size was calculated using Epi info version 6 stat calc

- Defaulter rate 8%
- Confidence level 95%
- Target population 651

Sample size required was 212. Data for this cross section study was about three focus group discussions with members of staff working at the TB corners and 198 tuberculosis patients. All respondents were volunteers who signed a written informed consent statement prior to taking part in the study. For the current analyses, the initial sample consisted of 232 tuberculosis patients and 16 health workers at the tuberculosis corners. The sample size that was determined priori was 212. However i over sampled by 20 to control for questionnaires (unreturned), unfound subjects and uncooperative subjects using Fink's (1995: 107) formula and supported by Cochran (1977:36) who states that over sampling increases the power of estimate. Of the 232 potential respondents, 34 respondents did not participate in the study. 3 were mentally confused, 5 did not come for their drug refills, 7 on the register were immediate transfers from other districts and 19 declined to be part in the study for various reasons. The response rate was 85.34% which was well over by 10% of the expected response rate.

Concerning focus groups, 16 health worker staff participated in the three focus groups in this order FGD1 = 5, FGD 2= 6 and FGD 3= 5.

3.6 Data Collection.

Data was collected over a period of one month beginning second week of December 2008 to second week of January 2009. Two types of data collection tools were used in this study and these are structured interview schedule and focus group discussion guide.

3.6.1 Structured interview schedule

The structured interview schedule was used. The tool was modified from previous study questionnaires. The questionnaire items were identified and adopted from review of literature, statements and findings from previous studies such as Eastwood S.V. Hill P.C. (2004; NHMHC 2004). The semi structured interview schedule had the study variables on which data was collected. A structured interview schedule was used which included closed ended questions. The use of an interview schedule permitted clarification of questions and it ensured high response rate. The use of an interview helps to produce additional information through observation. It also allowed probing to elicit information than what was volunteered in the initial reply. This type of information was useful in interpreting responses. The interview was conducted on all patients who came to collect drugs at the clinic and at a time when it was convenient to them- at the health centre or in their home. At least 10-12 participants were interviewed every day with each interview lasting 15 minutes. The interview was done in a secluded room.

The limitation of this method is that the presence of an interviewer can influence responses. This limitation was taken care of through documentary review.

3.6.2 Focus Group discussion

Focus group discussion was conducted at a health center with the health workers at the TB corner because they knew some of the problems patients face. A focus group guide was also used with open ended questions. Areas which were discussed included what problems patients face in accessing DOTS. Focus group discussions took 45 minutes to 1 hour. The limitation of this method is that some people are uncomfortable expressing their views or describing their experiences in front of a group. To avoid this problem the facilitator encouraged participation by trying to avoid a question and answer session, clarification was encouraged instead. When dealing with a dormant participant the principal investigator avoided eye contact which can discourage a person from speaking. The researcher led the discussion

according to the set of questions whereas the research assistants helped with note taking during FGD, time keeping while the researcher was asking questions.

The combination of data collection techniques is known as triangulation; it maximizes the quality of data collection and reduces the chance of bias. In this study semi-structured questionnaire and focus group guide were used. By using two different methods of data collection, it is hoped that true information was obtained as triangulation helps to converge on the truth.

3.6.3 Validity and Reliability

This study employed closed ended survey questionnaire. In this study a Cronbach alpha coefficient of 0.70 was selected as a measure of reliability). If the item scores agree very closely with the universal score, then they should also be very closely related to one another as well. This way of assessing reliability is referred to as internal consistency, and is the approach presented in this study. Some questions which scored below 0.75 were dropped while others were revised depending on what came up in the focus groups. In this way, reliability was achieved.

3.7 Pre-Test

Pre-testing of data collection tools was done using Tuberculosis patients at Twapia clinic in Ndola urban which was not included in the main study. Twapia clinic is a government clinic located in Ndola urban catchment area. This clinic was chosen because health center staff attend to Tuberculosis patients using DOTS. This means that participants for the pre-test were under similar circumstances as those for the main study.

Participants for the pre-test were selected using convenient sample and 10% of the sample for the main study was selected for pre-test. The purpose of the pre-test was to test the data collection tools, detect flaws such as ambiguous and illogically sequenced questions and make revision to strengthen the methodology. The pre-test also helped to assess whether the variables are observable and measurable.

The original questionnaire was administered to a few respondents before the main survey. When both the focus group discussions were done and the questionnaire was pilot tested, the questionnaire was reviewed to see if it was consistent with the research questions and the literature inductively.

The researcher had an opportunity to perfect the questionnaire from the observed reactions of the respondents during the pilot testing at Twapia clinic which was not included in the main study. This pilot testing also helped to determine how much time was needed to administer the questionnaire and to analyse it. The lessons learnt from the pilot tests coupled with the outcomes of the focus group discussions, enabled the researcher to develop a reliable and locally focussed modified questionnaire.

3.8 Ethical Consideration

Ethical clearance was obtained from the University of Zambia Research Ethics Committee. Since the study involved human subjects, verbal and written consent was obtained from participants and from the District Health Management Team (DHMT), in charge from sampled health centers and Copperbelt Provincial Health Office. The purpose and nature of the study was explained to the study participants. Those who declined to participate were reassured that no privileges will be taken away from them. Those who agreed to take part in the study were requested to sign a consent form. Those who participated were not remunerated in any way. Participants were at liberty to withdraw from the study at any time.

Study participants were assured of anonymity and confidentiality by interviewing them individually and in privacy. Participants' names were not written on the interview schedules and no other person apart from the researcher and supervisor would be allowed access to research data. Participants were in a natural setting and research did not involve any invasive procedure hence were not exposed to emotional or physical harm.

3.9 Data Processing and Analysis

Quantitative data

After collecting data, the semi-structured interview schedules were sorted out and edited for internal consistency, completeness, legibility and accuracy. This was done to ensure quality control. The investigator ensured that all the interview schedules were complete prior to data analysis. For incomplete questionnaires the investigator returned them to the respondents for clarification. All closed ended questions were categorized and assigned numeric codes. The responses were entered into the computer using SPSS software computer package and analyzed using both Epi-info and SPSS. The data was analysed by univariate analysis to make frequencies then bivariate analysis.

Chi-square was used to test association of variables. Confidence interval was set at 95% and level of significance at 5%, statistical significance achieved if P value is <0.05 . The data has been presented using frequency tables, pie charts, bar charts and cross tabulations.

Qualitative data Management and Analysis

This research was based in part on data derived from field notes and recordings.. All the data was reduced to text. Textual Data that was derived from focus group discussion was analysed using qualitative content analysis. A basic issue when performing qualitative content analysis of textual data is to decide whether the analysis should focus on manifest or latent content only or both (Downe, 1992; Kondracki et al., 2002). This study covered both forms of content analysis. An analysis of what the text says deals with the content aspect and describes the visible, obvious components, which are referred to as the *manifest content*. Both manifest and latent content deal with interpretation of what has been constructed by the producers of the data but the interpretations are done by both the producers and the researcher invariably in terms of depth, level of abstraction and purpose.

The data reduction process involved the combinations of steps drawn from Hycner (1985:279-303), Rhothstein (1990; 322-327) and Boyatzis (1998:4-6).

The process of analysing textual data started with efforts to understand what was written during the interviews by developing a consistent approach to apprehend the essential features of the texts and to account for the data. This called for being submerged into the data by reading the texts several times and part-by-part interpretation of key thoughts throughout each text to try to elucidate the general meaning of units or substantive content statements that really said something. Once the researcher was satisfied with the content of the textual data, all interviews were later aggregated into files of textual units.

Each focus group had a textual unit composed of the leading focus questions and the group's answers that were presented. From the textual units, the researcher was able by virtue of searching in the contents causal conditions, context, action/interactional strategies, and consequences. By doing this, it was easy to create a story line or phenomena of interest. From this process, it was possible to uncover the invariant features of experienced phenomena in order to provide a rigorous description of them by looking for common themes and categories as well as individual variations and to write a composite summary of what the medical life world of serving at a Direct Observed Therapy Short Course centre was like.

CHAPTER FOUR

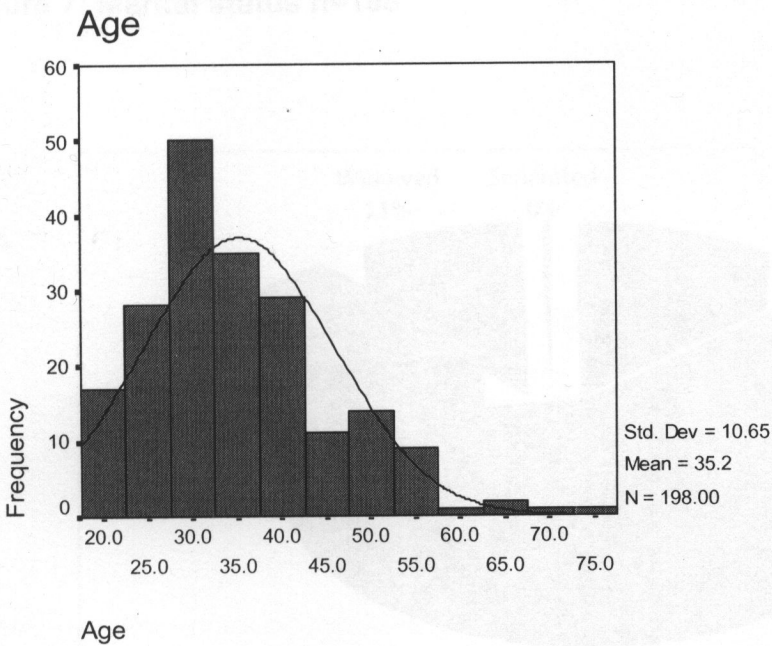
4.0 PRESENTATION OF FINDINGS

4.1 Introduction

A total of 198 respondents were interviewed and three focus group discussions were conducted with health workers. The results are divided into three sections as follows: (i) Social demographic characteristics (ii) Factors contributing to difficulties in accessing DOTS and (iii) Linking Barriers to accessibility.

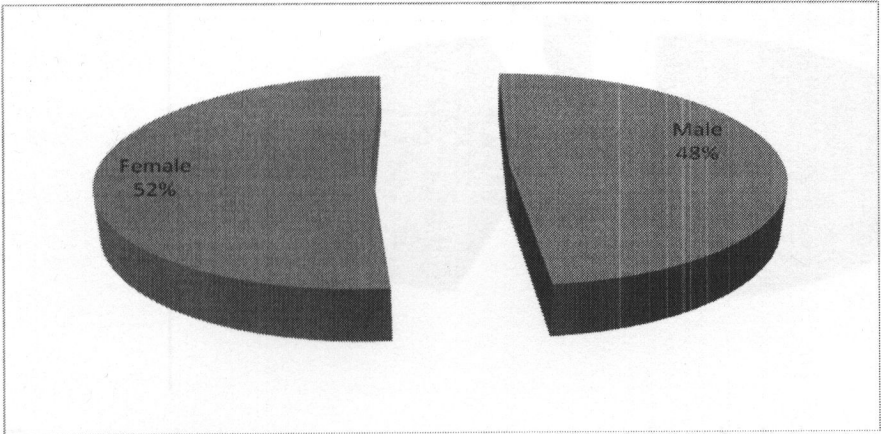
4.2 Social Demographic Characteristics

Figure 5: Age: N=198



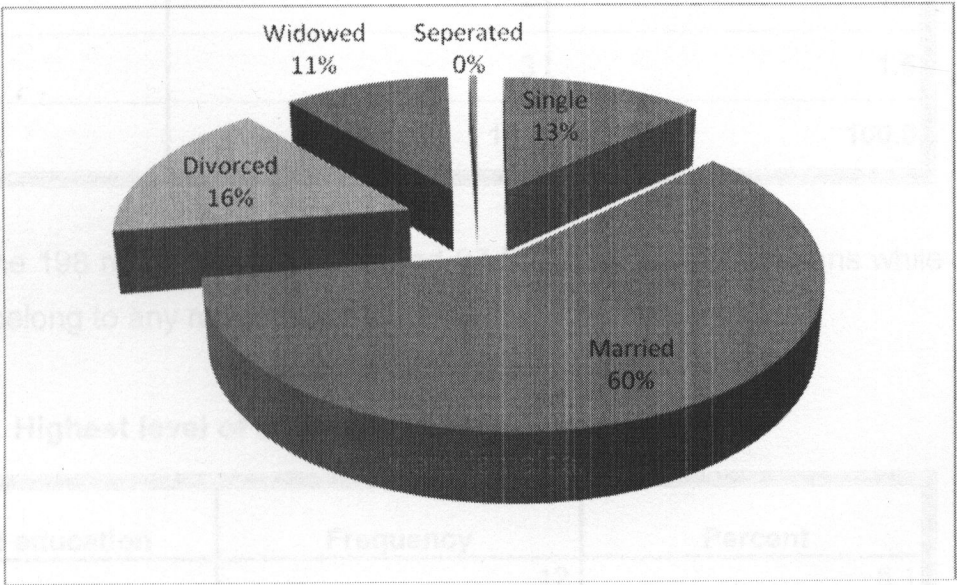
This patient sample was predominantly youthful. The youngest was 18 and the oldest was 77 years. The mean age of respondents was 35 (SD $\pm$ 10.6) years. The age distribution showed a right skew of .984.

Figure 6: Sex n =198



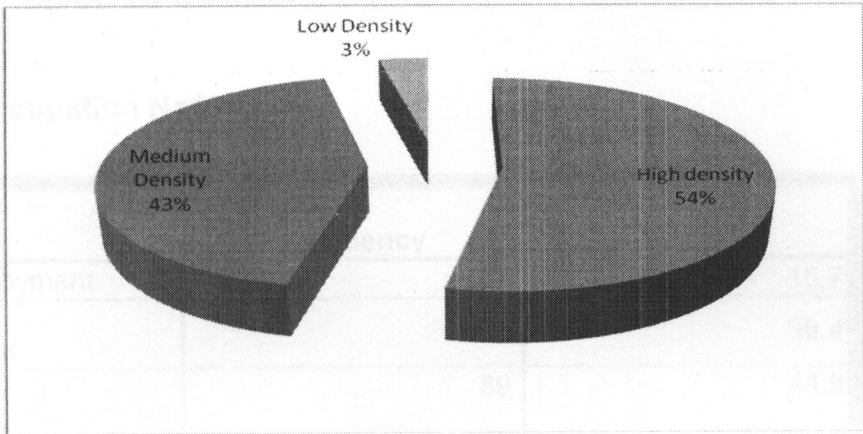
Out of 198 respondents, 52% (102) were females.

Figure 7: Marital status n=198



The majority of the respondents 60% (118) were married more than any other status (figure 7).

Figure 8: Residence N=198



The respondents were predominantly coming from high density locations 54% (106) (figure 8).

Table 2: Religion N=198

Religion	Frequency	Percent
Christian	193	97.5
Muslim	2	1.0
none	3	1.5
Total	198	100.0

Out of the 198 respondents interviewed 97.5% (193) were Christians while 1.5% (3) did not belong to any religion (Table 2).

Table 3: Highest level of education N=198

Level of education	Frequency	Percent
None	12	6.1
Primary	101	51.0
Secondary	75	37.9
College	10	5.1
Total	198	100.0

A greater number of the respondents had only been to primary school 51% (101) and only 5.1% (10) had attained college education (Table 3).

Table 4: Occupation N=198

Occupation	Frequency	Percent
Formal employment	31	15.7
self employed	78	39.4
Unemployed	89	44.9
Total	198	100.0

Most of the respondents 44.9% (89) interviewed were unemployed and 15.7% (31) were in formal employment (Table 4).

Table 5: Income N=198

Income	Frequency	Percent
None	37	18.7
Less than 500 000	114	57.6
500 000 to 1 000 000	38	19.2
Over 1 000 000	9	4.5
Total	198	100.0

Majority 57.6% (114) of the respondents had house hold income below K500,000 per month while 18.7% (37) did not have any income in a month and only 4.5% (9) had house hold income above K1,000,000 (Table 5).

Figure 9: Access to DOTS

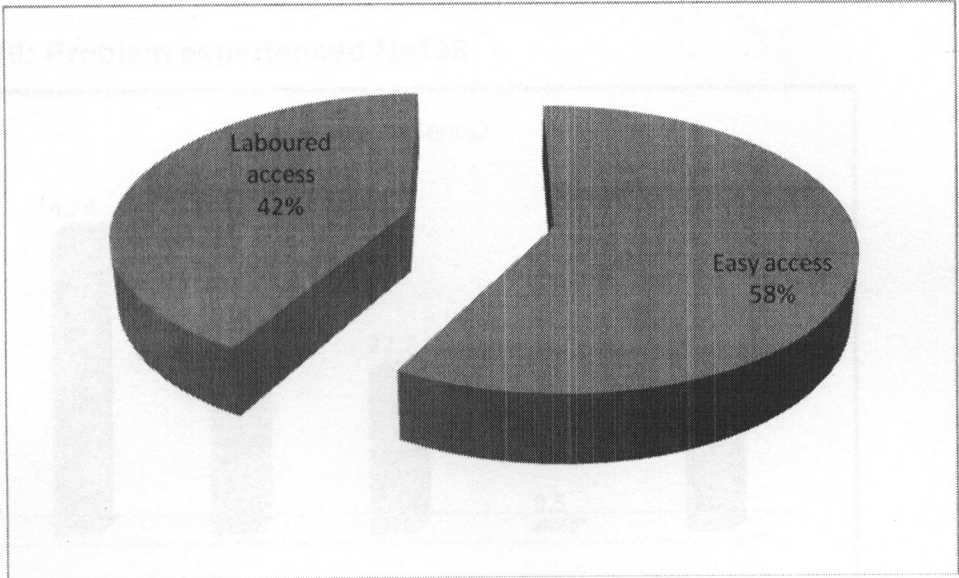


Figure 9 shows that 42% (83) of the respondents could not easily access drugs.

Table 6: Treatment phase n=198

treatment phase	Frequency	Percent
Intensive phase	78	39.4
Continuation phase	120	60.6
Total	198	100.0

Most of the respondents 60.6% (120) were in the continuation phase (Table 6).

Table 7: Discomfort as a result of TB drugs N=198

Discomfort	Frequency	Percent
Yes	167	84.3
No	31	15.7
Total	198	100.0

A greater number of respondents 84.3% (167) experienced discomfort due to TB drugs they were taking (Table 7).

Figure 10: Problem experienced N=198

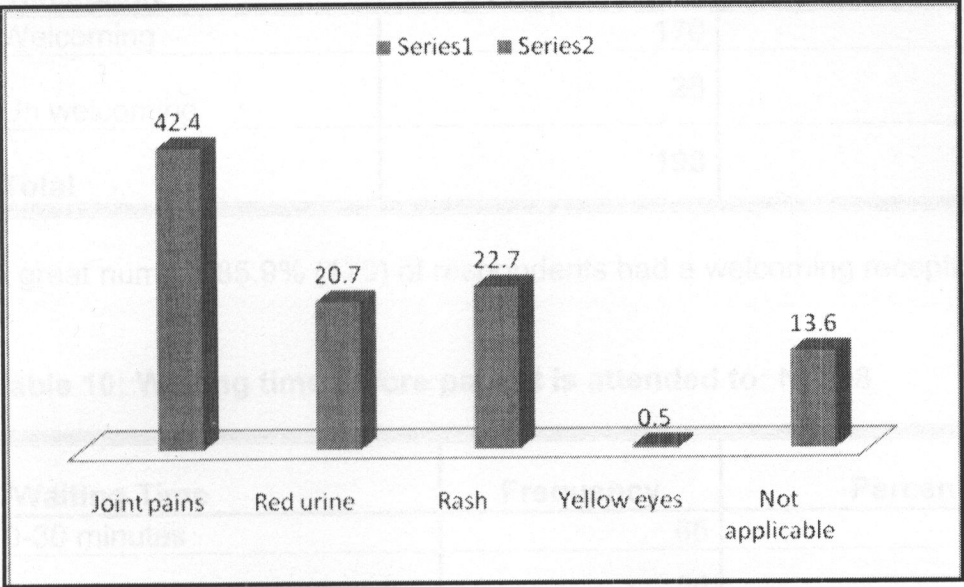


Figure 10 shows that the commonest problem 42.4% (84) respondents experienced was joint pains and a few 13.6% (27) did not experience any problem.

Table 8: Action upon experiencing joint pains

Action	Frequency	Percentage
I try to go and collect the drugs	114	57.6
I stay away	84	42.4
Total	198	100.0

Table 8 shows that 42.4% (84) of the respondents who experienced problems, stayed away from collecting TB drugs.

4.3 Factors contributing to difficulties in accessing DOTS

Table 9: Reception by the health workers: N=198

Reception	Frequency	Percent
Welcoming	170	85.9
Un welcoming	28	14.1
Total	198	100.0

A great number 85.9% (170) of respondents had a welcoming reception (Table 9).

Table 10: Waiting time before patient is attended to: N=198

Waiting Time	Frequency	Percent
0-30 minutes	65	32.8
31-60 minutes	54	27.3
Above 60 minutes	79	39.9
Total	198	100.0

Out Of 198 respondents, 39.9% (79) waited for more than 60 minutes before being attended to (Table10).

Table 11: Availability of drugs at Health centre: N=198

Availability of drugs	Frequency	Percent
Always	139	70.2
Sometimes	58	29.3
Never available	1	.5
Total	198	100.0

Table 11 shows that 29.3 % (58) of the respondents did not find the TB drugs sometimes at the health centre when they went to collect, while the majority 70.2% (139) always found the TB drugs at the health centre.

Table 12: Receiving Support from health workers N=198

Receive Support	Frequency	Percent
Yes	180	90.9
No	18	9.1
Total	198	100.0

Majority of the respondents 90.9% (180) received support from the health workers (Table 12).

Table 13: Stigma N=198

Stigma	Frequency	Percent
No	116	58.6
Yes	82	41.4
Total	198	100.0

Table 13 shows that 82% (41.4%) of the respondents acknowledged that TB patients were being stigmatized.

Table 14: Accessing TB drugs Easily and treatment Phase: N=198

Access TB drugs easily	treatment phase		Total	P Value
	Intensive phase	Continuation phase		
Yes	44(56.4%)	71(59.1%)	115(58%)	0.701
No	34(43.5%)	49(40.8%)	83(41.9%)	
Total	78(100%)	120(100%)	198(100%)	

Out of 78 patients who were in intensive phase 43.5% (34) did not access TB drugs easily compared to those in continuation phase where 40.8% (49) did not access TB drugs easily. There was no difference, patients in both phases did not access TB drugs easily. (Chi-Square=0.148, df=1, p value 0.701) (Table 14).

Table 15: Sex and marital status

SEX	Marital Status					
	Married	Single				P Value
		Never married	widowed	Divorced/ Separated	Total	
Male	49(51%)	15(15.6%)	15(15.6%)	18(18.7%)	96(100%)	0.113
Female	69(67.6%)	11(10.8%)	7(6.9%)	15(14.6%)	102(100%)	
Total	118(59.5%)	26(13.1%)	21(10.6%)	33(16.6%)	198(100%)	

Table 15 shows that there were more 67.6% (69) married females than married males 51% (49). There was no difference in marriage between males and females. (Chi-square 5.965, df 3, P Value 0.113).

Table 16: Level of Education and Occupation Distribution N=198

level of education	Occupation			Total	P value
	Formal employment	self employed	Unemployed		
None/Primary	4 (4.2%)	42(44.6%)	48(51%)	94(100%)	<0.001
Secondary/ College	27(25.9%)	48(46.1%)	29(27.8%)	104(100%)	
Total	31(15.6%)	90 (45.4%)	77(38.8%)	198(100%)	

Table 16 shows that 51% (48) of the respondents who were unemployed had attained none/primary education as compared to 27.8% (29) respondents who had secondary/college education. Being employed was associated with education. (Chi-Square=21.703, df=2, P Value<0.001).

Table 17: Sex and Income N=198

		income			P Value
Sex		None	Less than 500 000	500 000 to 1 000 000/over 1 000 000	
	Male	27(28.1%)	56(58.3%)	13(13.5%)	<0.001
	Female	10(9.8%)	58(56.8%)	34(33.3%)	
Total		37(18.6%)	114(57.5%)	47(23.7%)	198(100%)

Table 17 shows that 18.6% (37) of the respondents did not have any income per month while more females 33.3% (34) earned more than 500,000 as compared to only 13.5% (13) males in the same income range. There was an association between sex and income. (Chi- Square=17.063, df=2, P value< 0.001).

Table 18: Barriers and accessibility N=198

		ACTION		Total	P value
		I try to go and collect my drugs	I stay away because they do not please me		
RECEPTION	Welcoming	169 (99.4%)	1 (.5%)	170(100%)	<0.001
	Un welcoming	12 (42.8%)	16 (57.1%)	*28(100%)	
	Total	181(91.4%)	17(8.5%)	197(100%)	
AVAILABILITY OF DRUGS	Always	121 (87%)	18 (12.9%)	139(100%)	0.001
	Sometimes/ Never available	40 (67.7%)	19(32.2%)	59 (100%)	
	Total	161 (81%)	37(18.6%)	198(100%)	

*Note: interpretation should be done with caution because denominator is less than



Table 18 shows that 57.1% (16) of the respondents who acknowledged that the health workers were not welcoming stayed away from drug collection appointments compared to .5% (1) of the respondents who received a welcoming reception and stayed away from drug collection appointments. There was an association between reception and drug collection (Chi- Square=97.967, df=1, P value< 0.001).

A significant association was found between TB drug shortages and accessing DOTS where 32.2% (19) of the respondents who said TB drugs were not available sometimes/Never available, stayed away from drug collection appointments, while 12.9% (18) who acknowledged that TB drugs were always available stayed away from drug collection appointments. (Chi- Square=10.105, df=1, P value= 0.001) (Table 18).

Table 19: Distance and comfort N=198

		Comfortable with the distance to get to the health centre			
Minutes to get to the health centre		Yes	No	Total	P Value
	0-30 minutes walk/ a short drive	123(89.1%)	15(10.8%)	138(100%)	<0.001
	31minutes to 1 hour walk/more than 1 hour	14(23.3%)	46(76.6%)	60(100%)	
	Total	137(69.1%)	61(30.8%)	198(100%)	

Table 19 shows that the longer (more than 31 minutes) the patient took to reach the health centre, the more 76.6% (46) uncomfortable patients became with the distance, while only 10.8% (15) who took 0-30 minutes to reach the health centre were uncomfortable with the distance.(Chi-square=84.930, df=1, P value< 0.001). There was an association between time taken to reach the health centre and comfortability.

Table 20: Treatment phase and problems experienced N=198

Problems Experienced	Treatment Phase		Total	P value
	Intensive phase	Continuation phase		
Joint pains	34(43.5%)	50(41.6%)	84(42.4%)	0.507
Red urine	20(25.6 %)	21(17.5%)	41(20.7%)	
Rash	15(19.2%)	30(25 %)	45(22.7%)	
Yellow eyes	0(0%)	1(0.8%)	*1(0.5%)	
Not applicable	9(11.5%)	18(15%)	*27(13.6%)	
Total	78(100%)	120(100%)	198(100%)	

*Note: interpretation should be done with caution because denominator is less than 30

Table 20 shows 41.6% (50) of the respondents who experienced joint pains were in continuation phase compared to 43.5% (34) in intensive phase. (Chi-square 3.312, df =4, P- value 0.507) Irrespective of the treatment phase (intensive or continuation) patients experienced similar problems.

4.4: Linking Barriers to Accessibility

Table 21: Stigma and accessibility N=198

STIGMA	ACTION			P value
	I try to go and collect the drugs	I stay away	Total	
No	115(99.1%)	1(0.8%)	116(100%)	<0.001
Yes	69(84.1%)	13(15.8%)	82(100%)	
Total	184(92.9%)	14(7%)	198(100%)	

Some respondents15.8% (13) who acknowledged that they were being called names (stigmatised) stayed away from drug collection appointments compared to 0.8% (1) who said they were not stigmatised stayed away from drug collection appointments. (Chi-square=16.432, df=1, P-value<0.001) stigma was significantly associated with accessing DOTS (Table 21).

Table 22: Support and accessibility: N=198

Support	Action			
	I try to go and collect the drugs	I stay away	Total	P Value
Yes	178(98.8%)	2 (1.1%)	180 (100%)	0.006
No	15 (83.3%)	3(16.6%)	*18 (100%)	
Total	193(97.4%)	5(2.5%)	198(100%)	

*Note: interpretation should be done with caution because denominator is less than 30

Table 22 shows that 16.6% (3) of those who did not receive support from health workers stayed away from drug collection appointments compared to 1.1% (2) of those who received support but stayed away from drug collection appointments (Fishers exact test P value 0.006). Lack of support from health workers was a barrier in accessing DOTS.

Table 23: Waiting Time and accessibility: N=198

WAITING TIME	ACTION			
	I try to go and collect the drugs	I stay away	Total	P Value
0-60 minutes	114 (95.7%)	5(4.2%)	119 (100%)	1.000
Above 60 minutes	75 (94.9%)	4(5%)	79 (100%)	
Total	189(95.4%)	9(4.5%)	198(100%)	

Among the respondents who waited for more than one hour 5% (4) stayed away from drug collection appointments while those respondents who waited up to 60 minutes 4.2% (5) stayed away from drug collection appointments. (Fishers exact test P value 1.000) waiting time was not a barrier in accessing DOTS (Table 23).

Table 24: Distance and accessibility N=198

DISTANCE	Action			
	I try to collect my drugs	I stay home at times because I have no means	Total	P Value
0-30 minutes walk/a short drive	136(98.5%)	2(1.5%)	138(100%)	0.070
30 minutes-1 hour/more than 1 hour Walk	56(93.3%)	4(6.6%)	60(100%)	
Total	192(96.9%)	6(3%)	198(100%)	

Among the respondents who took 0-30 minutes to reach the health centre, 1.5% (2) stayed away from drug collection appointments compared to those who took above 30 minutes to reach the health centre and 6.6% (4) stayed away from drug collection appointments (Fishers exact test P value 0.070). There was no association between distance and accessing DOTS (Table 24).

Table 25: Problem experienced and accessibility N=198

PROBLEMS	ACTION			
	I try to go and collect the drugs	I stay away	TOTAL	P Value
Joint pains	3(3.5%)	81(96.4%)	84(100%)	<0.001
Red urine	39(95.1%)	2(4.8%)	41(100%)	
Rash	44(97.7%)	1(2.2%)	45(100%)	
Yellow eyes	1(100%)	0(0%)	*1(100%)	
Not applicable	27(100%)	0(0%)	*27(100%)	
Total	114(57.5%)	84(42.4%)	198(100%)	

*Note: interpretation should be done with caution because denominator is less than 30

A significant association was found between problems experienced as a result of TB drugs and accessing DOTS with more respondents 96.4% (81) who experienced joint pains staying away from drug collection appointments (Chi-Square=174.365, df=1, P-value<0.001) (Table 25).

4.5: FOCUS GROUP DISCUSSION

4.5.1 Demographic Characteristics of the Respondents

The respondents were from medium and low density areas in Ndola urban. They were divided into three groups which comprised of one (1) male.

The first group comprised of five (5) nurses working at the TB, all of them had attained college education. Only one (1) participant was not married the other four were married and had children. All the five participants were Christians. The second group had 6 nurses also working at the TB corner and third group had five (5) nurses also working at the TB corner. All the participants had attained college education, were Christians and married.

The social, economic and physical side effects of TB and its treatment, lack of drugs and inadequate staff emerged from the qualitative review as powerful barriers to completing treatment that needed care. However, health workers had differing views on mitigation and how they described the social position of TB patients. The excerpts below show the varying positions and experiences of health workers on Directly Observed Therapy Short Course.

Shortage of drugs

Health workers noted that Directly Observed Therapy Short Course was not doing well because of lack of drugs. TB corner nurses in all sites affirmed to this as demonstrated below:

“Anyway we were not told which other problems they are facing (patients), as I said this is a very big problem how can we treat TB without drugs?”

“As a TB corner nurse I also feel bad over this problem of lack of drugs. Patients don’t have money to buy TB drugs as a result they don’t access the drugs. Just imagine 1 tablet FDC (Fixed Drug Combination) costs K2 500, Ethina 1 500 per two tablets so as I said earlier on its very difficult for

patients to access Directly Observed Therapy Short Course even to adhere to treatment”.

“The other problem here in (mentioned township) is poverty, most of these TB patients are poor they do not have food to eat so if they do not have food to eat they do not take drugs. I personally talked to people who give soya in my capacity as sister in charge to increase the soya portions given to patients as they are only given 2 and half kg per month which is not enough as a result they shun collecting drugs or they collect and don’t take the drugs because of lack of food.”

Weak state of patients

“The other problem is that the patients are too weak to walk to clinic to collect drugs.”

“Anyway patients who are weak TB supports follow them up but at times patients give wrong addresses so such patients do not access Directly Observed Therapy Short Course and don’t adhere to treatment.”

Long waiting times, Staff shortage for Community Supervisory Visits

Health workers acknowledged patient delay in accessing treatment because of staff inadequacies, workloads and numerous tasks they were expected to perform.

“Also as nurses who work at the TB corner first we have to start screening then that’s when we go to attend to TB patients this is because there is shortage and (mentions a township centre) is a mini hospital so patients wait for a long time before they are attended to”

“Me what I have also observed as a problem, its shortage of nurses. The TB patients are made to wait for a long time before they are attended to because we are not many. But we try to give first priority to TB patients but at times its inevitable they wait for a long time before they are attended to”.

Mitigation

Health workers raised several issues that needed mitigation and the notable and most frequent ones included the following:

“I think in our discussion we mentioned some, the soya portions should be increased to enable patients take their drugs.”

“Anyway I don’t know but the district or whether the nation to improve on drug supply its really bad.”

“There is need for more sensitization because stigma is actually there even the patients stigmatise themselves.”

“Thus, it is a popular view of health care professionals that treatment should be mandatory for ‘undisciplined’ patients who ‘do not want to get treatment.’”

“We should just be very aggressive with those who default. But we should consider better those who are weak to walk. Patients are most of the times weak or have joint pains and are unable to walk to the clinic to collect drugs. But that problem I think the TB supporters can take drugs to those patients.”

“TB supporters are doing fine here. Many do not even complain because they know its voluntary work they reach out to even those patients who stay very far from the clinic. TB supporters really help us; the government needs to do something I mean giving them money at the end of the month.”

“We must emphasize Counseling and IEC to the patients and family members regarding TB to reduce stigma.’

Transport (bicycles) should be provided to reach out those patients who cannot walk to the clinic to collect drugs.

“Health workers to be trained in Directly Observed Therapy Short Course because others do not know and are not willing to work at the TB corner.”

CHAPTER FIVE

5.0 DISCUSSION AND CONCLUSION

5.1 Introduction

This was a cross section study where about 198 respondents were interviewed. It was dominated by youths and females of whom the majority were of low social economic status. The main objective of this study was to explore barriers Pulmonary Tuberculosis patients experienced in accessing Directly Observed Therapy Short Course in Ndola Urban. The data was from the 198 patients using an interview schedule and three focus group discussions from 16 nurse health workers and established the following.

5.2 Social Demographic Characteristics

The social demographic characteristics of the study population are shown in tables 2-5, Figures 5-8. Majority (42.9%) of the respondents interviewed were in the age group 28-37 and 1% was in age group 68-77 which shows that this was a youthful population.

This is in agreement with the ZDHS which shows that Zambia has a much higher population of the younger (46%) than the older. The youngest was 18 and the oldest was 77 years. The mean age of respondents was 35 (SD $\pm$ 10.6) years. The age distribution showed a right skew of .984.

More females (52%) were interviewed than males (48%) just like the findings in the ZDHS which showed that the females are more (50.7%) than males (49.3%).

The majority of respondents (60%) were married than living solitary lives (single 13%, widowed 11%, divorced 16% or separated. looking at sex population marriage rates, there were more female (67.6%) married persons than males (51%). However there were twice (15.6%) the number of widowed males than females (6.9%) and a seemingly equal rate of divorces. The explanation of these findings is that early

marriages are likely to have occurred and since study population had more youths where a lot of marriages occurred.

A greater number of these respondents had only been to primary school 51.5% than secondary (37.9%), none (6.1%) or college (5.1%). When level of education was related to the type of occupation one was engaged in, it was noted that 51% of the respondents who were unemployed had attained none/primary education as compared to 27.8% respondents who had secondary/college education. Being employed was associated with education. People with low education were neither in formal employment nor self employment.

Most of the respondents (54%) were staying in high density areas and (43%) came from medium density and only (3%) were from low residential areas. This could be due to the fact that TB is often thought to be a disease of the poor. Majority of the poor live in shanty compounds where the living conditions are poor coupled with over crowding which favours transmission. When people are unemployed and of low social economic status usually suffer from TB because they may be malnourished hence low immunity. These findings are in line with WHO 2005 which says that The impact of tuberculosis is greatest on the poor; 99% of the deaths and 95% of all cases occur in the developing world (WHO 2005). Banda 2000 had similar findings which showed that 46% of the TB patients were from high residential areas. As earlier mention in high density areas TB can easily be transmitted because of poor ventilation coupled with over crowding.

More females were engaged in income generating activities than men. However the majority of the respondents earned less than K 500 000 (57.6%) and the income was skewed to the left where an extremely low number (4.5%) got more than K 1 000 000 per month. The mean income was K 372 439 falling within the lowest income band of less than K 500 000. This shows that the majority of the respondents lived in poverty. The above finding is in line with the International Monetary Funds (IMF) programs and health expenditures background paper which states that Zambia remains a country with wide spread poverty and weak health outcomes (Goldsbrough and Cheelo, 2007).

5.3 Common problems TB patients experience in accessing Directly Observed Therapy Short Course

The Directly Observed Therapy Short Course strategy does not exist in isolation. For it to achieve its goals and be sustainable, many aspects of the public health system, including the identification and addressing of barriers, the need for institutional regulatory and financial elements that ought to work effectively is ideal. This study has shown that there were barriers in accessing Directly Observed Therapy Short Course. Forty percent of the respondents did not access DOTS easily. One can say that these barriers create a complex problem on the poor people as evidenced by their low social economic status. This study has affirmed Gülbay, et al., (2006) assertions that barriers which may manifest in defaulting are linked to knowledge and side effects. In one study in South America, by Gülbay, et al., (2006) 8.3% experienced side effects. However, there was some dissimilarity in this study findings from the classical southern African study by Gülbay, et al., (2006). This study concentrated on occurrence of joint pains, red urine, rash and hepatotoxicity unlike Gülbay, et al., (2006) who focused on drug reactions and their trends across age and sex. However, similar to this study were low rates of hepatotoxicity in form of jaundice. They found the rate to be 2.4% and in this study 5%.

Majority of those who experienced joint pains and a few who did not but had other problems 57.6% asserted that they tried to make an effort to get the drugs as compared to 42.4% that opted to stay away. All patients resided within 4 kilometer radius which is by far very near when the standard 12km radius is used to determine nearness. However in trying to see whether these patients who were residing near the health centre took long to reach the health centre, it was not surprising to note that the longer the distance, the more time it took. Looking at their conditions that they were sick and experiencing joint pains nearly all respondents were uncomfortable to walk even the shortest distance of even 30 minutes walk to get to the health centre.

I can further affirm the findings to be related to those of distance. Previous studies in Africa and Asia have also demonstrated a robust association between external

constraints and patient difficulty and inability to access Directly Observed Therapy Short Course. Distance in excess of 12 km has been noted to be a factor in rural areas in The Gambia (Eastwood and Hill 2004), Tanzania (Wandwalo and Morkve, 2000), and Zambia (Needham et al. 1998). However distance in urban areas has been linked to increased transportation costs which are associated with distance between residence and Directly Observed Therapy Short Course in most treatment centres in Zambia (Needham et al. 1998). Though most of the patients lived within 4 km radius where distances were shorter than those referred to in rural areas, they experienced hardships taking at least 0-30 minutes of walking. It may appear that the travelling cost to access Directly Observed Therapy Short Course is negligible in Ndola because the distances are short but there is a cost for a mini bus or taxi for those who could not walk. In one study in Pakistan, the additional cost for the patient of attending the nearest health facility for 2 months was equivalent to 6 days' wages (Walley et al. 2000) and this may be more in Zambia. This seems to suggest that Directly Observed Therapy Short Course may have to be delivered to the patients by staff from the health facility or community health workers. This in essence is a proposal bordering on an interdisciplinary approach to rendering care more in the home than at the facility. This proposal has been made because frequent and repeated clinic attendance is also likely to have a negative impact on costs incurred by the patients and may force them to drop out of treatment an observation which Needham et al. (1998) and Walley et al. (2000) once made.

The objective of an interdisciplinary approach is to incorporate a range of disciplines to explore the physical, social and economic determinants of diseases in individuals and communities, and, on the basis of this, to help develop appropriate and effective interventions to support case holding. By taking into consideration the social dimensions of disease and well-being, the interdisciplinary approach considers the individual in the context of the community and addresses questions that are fundamental to control, such as access to health care, delivery of care and completion of treatment (Ogden and Porter 1999). The principle underlying the approach is that, because lay people manage and make sense of illness in the context of everyday life, infectious disease interventions must also 'make sense' to people in those terms. While for some aspects of infectious disease control, a

biomedical focus and orientation may be appropriate, programmes to control diseases that have far-reaching social implications and which require long term treatment and care need to take fuller account of social context in their inception and delivery. If programmes rely on patients to break the cycle of transmission and to protect the drugs that have been developed, it is up to the programmes to enable the patients to carry out this mandate. This is even more important in the case of dual HIV/TB infection.

Findings of this study have also shown that TB stigma which has been widely reported as a barrier in TB control is a factor in Zambia (Dale et al., 2001). 41.4% of the respondents in this study were stigmatized which led to some 15.8% of the patients not going for drug collection for fear of being seen at the TB clinic. Rubel and Carro (1992) have also shown how social stigma affects patients' familial relations and response to illness. Knowledge and beliefs of the population about tuberculosis and stigma associated with it are crucial determinants for the use of health services and for this reason, Rubel and Garro (1992) advised that stigma should be kept under consideration when developing appropriate case-finding activities. It has also been noticed that public attitudes and stigma appear to be important deterrents from seeking timely care, the consequences of which are not only damaging to the personal well-being of TB patients, but also likely to undermine effective TB control and promote disease transmission. Changing public attitudes towards people with TB could be addressed in the long term through information campaigns about TB and its treatment, using existing communication channels to convey messages; and creating user-friendly entry points for diagnosis and treatment.

In this study it was found that waiting time irrespective of duration before patients were attended to did not discourage patients from going to the clinic to access DOTS. Instead they were willing to wait as long as over one hour. Some of the patients (39.9%) waited for more than 1 hour before being attended to. However, (5%) of these patients stayed away because they were not pleased to wait for a long time before collecting their drugs. These findings are different from the findings by the North Carolina Centre for Public Policy Research. In their nationwide study of

migrant farm workers, the study revealed that waiting time was a barrier where 57 % listed clinic hours as the main barrier to receiving health care (NHMHC 2004).

This study has also shown that tuberculosis patients have a higher sensitivity to negative attitudes like stigma and behaviour of staff and other deficiencies in the health facilities. Like Johanson et al 2000 who once described how patients often are treated in an inferior way by the health system and therefore hesitate to seek care, patients in this study demonstrated dissatisfaction with service. Interaction between staff and patients appears to be of great importance for the trust and confidence in health institutions and treatment. Consequences of poor attitudes and behaviour of staff has also been described by Dolin et al (1994) from his experience in Nepal, where health workers frequently responded aggressively to people who finally presented for treatment in terminal stages of TB. Dolin concluded that such attitudes may make the patients feel threatened, uncomfortable, unwelcome and unwilling to return. In this study 57.1% of the patients who acknowledged that health workers were not welcoming stayed away from drug collection appointments. It is important to take consequences of poor care into consideration.

5.4 Factors Associated with non Adherence to DOTS

In this study non adherence to DOTS was staying away from drug collection appointments. The study findings revealed that the common problems patients were facing in accessing DOTS were the same factors associated with non adherence to DOTS. In this study stigma was found to be associated with non adherence to DOTS where 15.8% of those who were stigmatized stayed away from drug collection appointments. Other factors are: anti TB drugs adverse effects (nausea, vomiting, joint pains, red urine, rash and yellow eyes), (ii) distance, (iii) number of minutes/hours waiting to be attended to, (iv) Support one receives from health workers. All these factors have already been discussed above.

5.5 The Meaning of This Study Based On the Outcomes

There is no doubt that any clinician or patient will be surprised by the accounts given, but the case study methods achieve authenticity in the sense that they are fair (all views are included) and catalytic (the findings lead to actual or potential stimulation of action according to Jackson et al., (2001)). Although this small-scale local survey may seem to lack the robustness of larger studies, these findings may be applied in other medical settings within Ndola. In addition, the findings have important policy implications for the TB control system that is applied in Ndola, other districts and the country as a whole, where similar public health systems exist and where patients have to get to the health facility for drug refill. Introducing the Directly Observed Therapy Short Course strategy and improving the efficiency with which existing resources are used will require reform of health system norms and regulations related to Directly Observed Therapy Short Course service delivery and social welfare care. Given the rigidity of Zambia's public health structures, these changes may take time. National and international agencies would do well to support the Directly Observed Therapy Short Course as part of our health system to reform over the medium to long term.

The Directly Observed Therapy Short Course strategy is a disease-specific strategy that aims to support tuberculosis control, but does not address inefficiencies of the health care system. Yet for the public health benefits of the Directly Observed Therapy Short Course strategy to accrue and efficiencies to be realized and sustained, what is needed is more than simply the adoption of the principles of Directly Observed Therapy Short Course (which have been realized through national regulations in 2003) and a vertical implementation of control strategies. Structural reforms to prevailing health systems and social care financing mechanisms are also needed.

5.6 Limitations and Strengths of the Study

Most patients may have given their opinions on what they were experiencing then and may have forgotten about the past hence the need to be cautious in interpreting the results.

Although the study was able to elicit the views of a large number of patients and health workers in this survey, the findings need to be read with an awareness of high levels of dissatisfaction found with the illness experience and poor service delivery of our health care and large patient loads. Surveys are not necessarily the best way to elicit opinions on complex issues like quality of care, but in this case the survey included opportunities for brief descriptions of experiences to be incorporated in the responses, and was also set in the context of a multimethod rapid appraisal.

However in spite of this limitation, the findings are valid because current rather than retrospective capture of views about the quality of services does not run the risk of recall bias. An on spot time inquiries in eliciting experience are useful because an experience immediately after or before an episode of service utilization tends to reflect the quality of service (Manthorpe et al., 2007).

Despite the sampling strategy and particularly for the survey, the 40 and-over age group was under-represented among respondents. This may reflect the current population distribution with fewer numbers of people living above 35. Nevertheless, this study could highlight some interesting features of the Directly Observed Therapy Short Course delivery system. While this suggests that this case study has value as an evaluation of service performance, the trustworthiness of the data and our analysis of it depend on (i) its credibility to others with experience of the topic, (ii) transferability to other settings especially to those on the line of rail, (iii) dependability (depth of description of methods, peer analysis of data, third-party evaluation of data gathering) and conformability (iv) by independent review of the roll data (Guba and Lincoln, 1981). In my view, the dependability of this case study and particularly the qualitative accounts rests on the methods used and described here and the conformability through Ndola Urban District review and utilization of the findings. The credibility and transferability or generalisability to health settings in Ndola are left for the reader to judge.

5.7 Conclusion

Patients experienced five sets of barriers as they tried to successfully access Directly Observed Therapy Short Course in Ndola: (i) anti TB drugs adverse effects (nausea, vomiting, joint pains, red urine, rash and yellow eyes), (ii) distance, (iii) number of minutes/hours waiting to be attended to, (iv) Support one received from health workers and (v) stigma. Despite the barriers that patients face, many providers still believe that accessing treatment depends on the patients' good will and fundamentally remains the responsibility of patients, a familiar refrain (Farmer 2001). However, many health care professionals were aware that this proposition is ethically problematic because it potentially reinforces stigma, marginalizes further already vulnerable individuals, and may hinder the effective and timely provision of care.

As stated, recognizing and defining the scope and nature of the existing barriers to access care is important if access to care is to improve. Professionals' attitudes need to be understood and to inform them of the change process. Models of good practice exist and most professionals are clearly committed to both their work and the patients whose care they are responsible for. Frequently forces beyond their control mean that their efforts result in limited public health improvements. This is true in Zambia where resources are limiting. If the energy, skills and knowledge of health care professionals are to be drawn upon effectively in efforts to control TB, then reform processes – including shifts to ambulatory care, restructuring of TB detection, treatment and care facilities and provision of social support – need to be informed by professionals' knowledge, experience and insights.

Accessibility to Directly Observed Therapy Short Course can be enhanced if providers and programmers ask 'how can we best enable patients to get well?' rather than simply 'how can we best control the drug intake by patients?' Results of trials conducted so far question whether, in areas where cure rates are still low, a change to self-administered treatment instead of Directly Observed Therapy would have a significant impact on cure rates. As long as TB considered control as a bio-medical intervention only, focusing on achieving cure through the observation of patient's drug intake, we will be bound to fail. Control of TB is not only about how to give

treatment but also how to support the process of care from detection and diagnosis of disease through to completion of appropriate treatment.

The challenge is important. Zambia, confronted with a high prevalence of HIV infection and an increasing burden of dual HIV/TB epidemic, has a pressing need to identify ways to jointly deliver anti-retroviral therapy and anti-TB treatment. Control programmes are now facing the difficulty of ensuring lifetime adherence to relatively toxic and complex treatment regimens. Directly Observed Therapy Short Course alone will not be sufficient to control TB in settings with high HIV infection rates. The clear challenge is to move beyond the identification of barriers towards operationalising innovative strategies to resolve them. This will only be possible through the participation of all the key stakeholders involved in caring for TB patients. Of great importance are the TB patients themselves, who need to be recognised, empowered and encouraged to participate in initiatives tackling the barriers they face in accessing quality care.

5.7.1 Conclusion according to Uplekar model - Existing Model Used in the Study of Tuberculosis

In this study, I adopted the Uplekar model (Figure 4) to ground the trajectory (route/path) of barriers in a TB service. The model starts from experiencing symptoms to seeking help and taking treatment either for relief or cure. The model further illustrates the process of attrition that occurs as people move through the various steps of TB disease and treatment, accounting for sex differences at each stage. Generally patients irrespective of the treatment phase (intensive or continuation) problems were not a factor implying that Uplekar's model in Ndola cannot explain any differences in accessibility to DOTS. However It was evident that patients experienced more problems during the intensive phase than the continuation phase. However, when a significant test was done, it was not statistically significant ($p < 507$).

CHAPTER SIX

6.0 Recommendations

The District Health Management Team should endeavour to reduce these barriers in order to increase accessibility to Directly Observed Therapy Short Course. This may be done in the following ways: (i) patients may need to be given longer time drug refills or drugs and reviews may have to be packaged so that care is delivered in the home through appropriately trained community staff like TB supporters with the help of staff from the health centre and (ii) developing an intervention package targeting together health staff, patients and communities .The package may include the following components:

1. Strengthening the competences of the health personnel involved in TB care and improving communication between patients and carers through appropriate training.
2. Decentralizing treatment to remote health posts with involvement of community health workers.
3. Improving supervision of activities by district health team.
4. Strengthening Directly Observed Therapy Short Course by giving the patients opportunity to choose their treatment supporter.
5. Increasing the soya portions to enable patients take their drugs.
6. Improving sustainability of drug supply because patients cannot afford To buy TB drugs.
7. Sensitizing patients and health workers on effects of TB stigma because stigma is actually there even the patients stigmatize themselves.
8. Emphasizing on Counseling and IEC to the patients and family members regarding TB to reduce stigma.
9. Being strict with those who default from DOTS
10. Providing transport (bicycles) to reach out those patients who cannot walk to the clinic to collect drugs.
11. Training health workers in Directly Observed Therapy Short Course because others do not know and not willing to work at the TB corner.

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.Appendix I –FOCUS GROUP GUIDE WITH HEALTH WORKERS

TOPIC: BARRIERS IN ACCESSING DOTS AMONG ADULT PATIENTS WITH PULMONARY TUBERCULOSIS IN NDOLA URBAN DISTRICT

Before we started, I reminded them that there was no right or wrong answer in the discussion. We were interested in knowing what barriers patients experience in accessing Directly Observed Therapy Short Course. So participants were encouraged to feel free to be frank and to share their point of view, regardless of whether one agrees or disagrees with what they heard. It was very important that we heard all their opinions.

We started by going around the circle and having each person introducing herself/himself. (Members of the research team also introduced themselves and described each of their roles.)

In our discussion we looked at the following;

1. The problems that patients faced regarding Directly Observed Therapy Short Course.
2. The phase in which patients faced more barriers and the barriers they faced
3. The problems they experienced in ensuring that TB patients adhere to treatment.
4. How they could mitigate the problems patients experienced in accessing Directly Observed Therapy Short Course.

After the discussion we summarized some of the key points from our discussion. Those who had questions were given chance to ask.

Appendix II STRUCTURED INTERVIEW SHEDULE WITH PATIENTS

**THE UNIVERSITY OF ZAMBIA
SCHOOL OF MEDICINE
DEPARTMENT OF COMMUNITY MEDICINE**

STRUCTURED QUESTIONNAIRE FOR INTERVIEW SCHEDULE

**TOPIC: BARRIERS IN ACCESSING DOTS AMONG ADULT PATIENTS WITH
PULMONARY TUBERCULOSIS IN NDOLA URBAN DISTRICT.**

DATE..... SERIAL NO.....

INSTRUCTIONS FOR THE INTERVIEWER

- 1. Do not write name of respondent on the interview schedule.
- 2. Circle the most appropriate response to the question in the spaces provided.
- 3. Request the respondent to sign consent before you start the interview.
- 4. All the information provided by the respondent should be kept in strict confidence.
- 5. Respondents should not be forced to be interviewed.

SECTION A: DEMOGRAPHIC DATA

FOR OFFICIAL USE ONLY

1. Age of respondent..... []
2. Sex []
- a) Female
- b) Male
3. What is your marital status? []
- a) Single
- b) Married
- c) Divorced
- d) Widowed
- e) Separated
4. Residential area []
- a) High density
- b) Medium density
- c) Low density
5. What is your religion? []
- a) Hindu
- b) Christian
- c) Muslim
6. What is your highest level of education? []
- a) None
- b) Primary
- c) Secondary
- d) College
- e) University
7. What is your occupation []
- a) Formal employment
- b) Self employed
- c) Unemployed
8. What do you actually get per month? []
- a) None
- b) Less than 500,000
- c) 500,000 to 1,000,000

d) Above 1,000,000

9. Are you able to get your TB drugs easily?

a) Yes

b) No

SECTION B: BARRIERS IN ACCESSING DOTS

9. Does the TB treatment duration prevent you from accessing DOTS? []

a) Yes

b) No

11. Which treatment phase are you? []

a) Intensive phase

b) Continuation phase

12. Do you experience any discomfort as a result of TB drugs? []

a) Yes

b) No

13. If yes to question 12 which problems do you experience? []

a) Nausea and vomiting

b) Joint pains

c) Red urine

d) Rash

e) Yellow eyes

14. What did you do when you experienced such problems? []

a) I try to come and collect drugs

b) I stay away

SECTION C: ACCESSING DIRECTLY OBSERVED THERAPY SHORT COURSE

15. How far is your home from the health centre?

a) Within 1 km

b) 2 km

c) 3 km

d) Above 4 km

16. How long does it take to reach the health centre? []

a) 0-30 minutes walk

b) 31minutes to 1 hour walk

c) More than 1 hour walk

d) A short drive

16. Looking at your condition are you comfortable with the distance you cover to reach the health centre? []

a) Yes

b) NO

17. Depending on your answer to question 16 what do you do? []

a) I try to come and collect my drugs

b) I stay home because I have no means

18. When you go to the health centre, how is the reception by the health workers? []

a) Welcoming

b) Not welcoming

19. Depending on your answer to question 18 what do you do?

a) I try to come and collect my drugs

b) I stay away because they do not please me

20. How long do you wait at the clinic before you are attended to? []

a) 0-30 minutes

b) 31-60 minutes

c) Above 60 minutes

21. Are you comfortable with the number of minutes/hours waiting to be attended to at the health centre? []

a) Yes

b) NO

22. Depending on your answer to question 21 what do you do? []

a) I try to wait and collect my drugs

b) I leave and next time I stay away

23. Are the drugs available at the health centre? []

a) Always

b) Sometimes

c) Never available

25. How would you rate the amount of drugs given to you until your next refill?

a) Enough

b) Little

c) more than enough

26. Depending on your answer to question 25 what do you do? []

a) I try to come and collect drugs

b) I stay away

27. Are you happy with support you receive from health workers? []

a) Yes

b) No

28. Depending on your answer to question 27 what do you do? []

a) I try to come and collect my drugs

b) I stay home because I am disappointed with them

29. To what extent do people call you names? []

a) Not at all

b) Much

30. Depending on your answer to question 29 what do you do? []

a) I try to come and collect my drugs

b) I stay home because I am discouraged

31. Have you ever missed taking drugs taking drugs? []

a) Yes

b) No

32. If yes to question 31 what was the reason for missing? []

a) Was too weak to go to collect drugs

b) Did not have food

c) Did not have enough supply

THANK YOU VERY MUCH

GOD BLESS YOU

APPENDIX III

INFORMED CONSENT

TOPIC: BARRIERS IN ACCESSING DOTS AMONG ADULT PATIENTS WITH PULMONARY TUBERCULOSIS IN NDOLA URBAN DISTRICT.

INTRODUCTION

I, Ellen Munyati Milimo; a student of Masters in Public Health from University of Zambia is kindly requesting for your participation in the research study mentioned above.

PURPOSE OF THE STUDY

The study will assist to obtain more information on problems patients experience in accessing Directly Observed Therapy Short course. This is important, as the data from the study will assist to provide feedback to a variety of audiences including sponsors, donors, service-users, administrators and staff which will influence decision making or policy formulation which in turn will reduce the morbidity and mortality due to TB and consequently improving the care.

VOLUNTARY PARTICIPATION

Your participation in this study is entirely voluntary. You are not being forced to participate in this study. You are free to decline to participate. Your refusal will not affect the standard of care that which you receive since your participation is voluntary. You are free to withdraw from the study at any time.

RISKS AND DISCOMFORTS

No risks and discomforts involved apart from the use of your time in answering questions. Answering questions will take approximately 30 minutes.

BENEFITS

By taking part in this study, you will be able to provide us with information that will help relevant authorities and policy makers to come up with strategies and policies that will help improve Directly Observed Therapy short course strategy. This will in

turn reduce morbidity and mortality due to tuberculosis. No monetary favours will be given in exchange for information obtained.

CONFIDENTIALITY

Your research records and any information you will give will be confidential to the extent permitted by the law. You will be identified by a number, and personal information will not be released without your written permission except when required by law. The ministry of Health, the University of Zambia Research ethics committee or the school of Medicine may review your records again which will be done with confidentiality.

INFORMATION AND CLARIFICATION

Please be notified that at any time you want clarifications or want to ask any questions about Directly Observed Therapy short course or researcher we will be pleased to offer you information or clarification and answers to your questions.

If you wish to seek any further clarification, please contact:

Ellen Munyati Milimo

University of Zambia

School of Medicine

Department of Community Medicine

P.O. Box 50110

Lusaka.

Cell: 0977772785.

Email emunyati@yahoo.co.uk.

The chairperson

Research Ethics Committee

University of Zambia

P.O Box 50110

Lusaka. Zambia

E-mail: unzarec@zamtel.zm

Fax: +260-1-250753

Tel. no. 01 2560 67

CONSENT FORM

The purpose of this study has been explained to me and I understand the purpose, the benefits, risks and discomforts and confidentiality of this study. I further understand that:

If I agree to take part in this study, I can withdraw at any time without having to give an explanation and that taking part in this study is purely voluntary.

I.....(Names)

Agree to take part in this study.

Signed/Thumb print _____ Date: _____ (Participant)

Signed: _____ Date: _____ (Witness)

Signed: _____ Date: _____ (Researcher)

APPENDIX IV: BUDGET

BUDGET CATEGORY	QUANTITY	UNIT COST (ZMK)	TOTAL
1. STATIONARY			
(a) Flash Disc	X1	300,000.00	300,000.00
(b) Staples	1 Box	15,000.00	15,000.00
(c) Bond paper	X5	35,000.00	175,000.00
(d) Pens	X15	1,500.00	22,500.00
(e) pencils	X10	1,000.00	10,000.00
(f) Rubbers	X5	1,000.00	5,000.00
(g) Note books	X4	10,000.00	40,000.00
(h) Tippex	X2	15,000.00	30,000.00
(i) Bags for interview schedules	X3	70,000.00	210,000.00
(j) Stapler	X1	40,000.00	40,000.00
(k) CDs	X2	10,000.00	20,000.00
(l) Tape recorder	X1	120,000.00	120,000.00
(m) Tapes	X5	5,000.00	25,000.00
(n) Flip chart	X2	40,000.00	40,000.00
(o) Markers	X6	6,000.00	18,000.00
(p) Scientific calculator	X1	80,000.00	80,000.00
SUBTOTAL			1,150,500.00
2. SERVICES			
(a) Ethics committee	X1	250,000.00	250,000.00
(b) Data entry	X1	750,000.00	750,000.00
(c) Data analysis	X1	1,000,000.00	1,000,000.00
(d) printing questionnaire	7pages X1 copy	2,000.00	14,000.00
(d) Photocopying questionnaire	7 pagesx200 copies	300.00	420,000.00
(e) Printing thesis	100 pages X 1 copy	2,000.00	200,000.00
(f) Photocopying thesis	100pagesx6 copies	300.00	180,000.00
(g) Binding thesis			
(h) Spiral (examiners)			
(i) Final	X 5copies	15 000.00	75, 000.00
	X 6 copies	250 000.00	1,500,000.00
SUBTOTAL			4,389,000

3. FIELD WORK			
(a) Principal Researcher			
(i) Transport costs Lusaka to Ndola	8 trips	150,000.00	1,200,000.00
(ii) Local	X1x 60 days	30,000.00	1,800,000.00
(iii) Lunch allowance	X1x60 days	50,000.00	3,000,000.00
(b) Research Assistants			
(i) transport costs Local	X3x 60days	30,000.00	5,400,000.00
(ii) Lunch Allowance	X3x60 days	30,000.00	5,400,000.00
(c) Snacks for participants			
(i) pie	200	6,000.00	1,200,000.00
(ii) cabana drink	200	4,000.00	800,000.00
SUBTOTAL			18,800,000.00
TOTAL			24,339,500.00
Contingency 10%			2,433,950.00
GRAND TOTAL			26,773,450.00

JUSTIFICATION FOR THE BUDGET

STATIONARY

The 5 reams of bond paper were used to print the thesis that is the draft and final copies.

The flash disc was for copying, storage and safe keeping of research data. CD was used as a back up to store information.

The bags for interview schedules were for the research assistants to ensure that the interview schedules were kept safe.

Other accessories such as pens, pencils, rubbers, stapler, staples and note books were required for routine collection of data.

FIELD WORK

Data collection was conducted through out the day and data collectors needed lunch allowance to buy their lunch, the researcher needed 3 research assistants to assist in conducting interviews and these people needed research bags, transport money to move to and from their respective homes. They were also trained before they started doing the actual work.

TYPING SERVICES

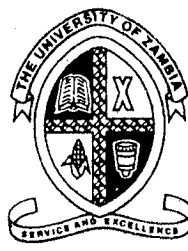
The typing services were needed to enable the researcher type and photocopy questionnaire and the thesis.

CONTINGENCY FUND

Contingency fund which is 10% of the budget was required for any extra costs due to inflation and for any eventualities.

SNACKS FOR PARTICIPANTS

Participants were given snacks to show appreciation for delaying them during interviews and focus group discussion



THE UNIVERSITY OF ZAMBIA

BIOMEDICAL RESEARCH ETHICS COMMITTEE

Telephone: 260-1-256067
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Ridgeway Campus
P.O. Box 50110
Lusaka, Zambia

Assurance No. FWA00000338
IRB00001131 of IORG0000774

23 February, 2009
Ref.: 007-10-08

Ms Ellen Munyati Milimo
Department of Community Medicine
School of Medicine
University of Zambia
P.O. Box 50110
LUSAKA

Dear Ms Milimo,

RE: SUBMITTED RESEARCH PROPOSAL: **"BARRIERS IN ACCESSING DIRECTLY OBSERVED THERAPY SHORT COURSE AMONG ADULT PATIENTS WITH PULMONARY TUBERCULOSIS IN NDOLA URBAN DISTRICT"**

The above-mentioned research proposal was presented to the Biomedical Research Ethics Committee meeting held on 1st October, 2008 where changes were recommended. We would like to acknowledge receipt of the corrected version with clarifications. The proposal is now approved.

CONDITIONS:

- This approval is based strictly on your submitted proposal. Should there be need for you to modify or change the study design or methodology, you will need to seek clearance from the Research Ethics Committee.
- If you have need for further clarification please consult this office. Please note that it is mandatory that you submit a detailed progress report of your study to this Committee every six months and a final copy of your report at the end of the study.
- Any serious adverse events must be reported at once to this Committee.
- Please note that when your approval expires you may need to request for renewal. The request should be accompanied by a Progress Report (Progress Report Forms can be obtained from the Secretariat).

Yours sincerely,

Dr E. Munalula-Nkandu, BSc (Hons), MSc, PgD R/Ethics, PhD
CHAIRPERSON

Date of approval: 23 February, 2009

Date of expiry: 22 February, 2010



THE UNIVERSITY OF ZAMBIA
SCHOOL OF MEDICINE
DEPARTMENT OF COMMUNITY MEDICINE

Telephone: 252641,
Fax: + 263-1-250753,

P.O. BOX 50110,
Lusaka, Zambia.

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27th May 2008.

The Permanent Secretary,
Ministry of Health,
LUSAKA.

Dear Sir,

**RE: REQUEST FOR PERMISSION FOR MPH STUDENT TO COLLECT
INFORMATION FOR RESEARCH**

We are writing to kindly request for permission for Ms Ellen Munyati Milimo who is currently studying for her Masters in Public Health (MPH) Part II to collect information in your health facilities in Ndola urban district. The collected information would serve the purpose of writing her Research on:

"Study **BARRIERS IN ACCESSING DOTS AMONG ADULT PATIENTS
PULMONARY TUBERCULOSIS IN NDOLA URBAN DISTRICT**"

We appreciate your support to our MPH programme and the student.

Yours Faithfully,

Dr. W Mutale,
MPH –Coordinator.

cc: The Provincial Health Director- Copperbelt Province
The District Health Direct – Ndola DHMT ✓

*All Correspondence should be addressed to the
Permanent Secretary
Telephone: +260 1 253040/5
Fax: +260 1 253344*



REPUBLIC OF ZAMBIA
MINISTRY OF HEALTH

In reply to

No.

NDEKE
P. O. BOX
LUSAKA

30th May, 2008

The District Director of Health,
Ndola District Health Office,
NDOLA.

Dear Dr. Kakungu,

**RE: AUTHORITY FOR MS. ELLEN MUNYATI MILIMO, A MASTER OF
PUBLIC HEALTH (MPH) STUDENT TO COLLECT DATA FOR HER
STUDY IN NDOLA DISTRICT**

Ms. Ellen Munyati Milimo, a student pursuing a Master of Public Health (MPH) at the University of Zambia (UNZA). In partial fulfillment of the degree, she is required to conduct a research study and her topic is "Study on **BARRIERS IN ACCESSING DOTs AMONG ADULT PTB PATIENTS IN NDOLA**". Therefore, she requires to collect data for her study from Ndola DHMT and Ndola Central Hospital.

The purpose of this letter is to request your office to accord Ms. Ms. Milimo the necessary support to enable her collect the data for her study.


Dr. S.K Miti
PERMANENT SECRETARY



Republic of Zambia
Ndola District Health Board

Naidu Close Kanini
P.O.Box 70672
Ndola - Zambia

All communication to be addressed to
District Director of Health

Telephone : 610306
Telefax : 612819
Cell: 097-7-835660

Internal Memo

From Manager Planning and Development

To The Health Centre
 In-charges

Ref DHMT

Date 16th December 2008

Re **MS. ELLEN MUNYATI MILIMO**

The above mentioned student has been granted permission to study on Barriers in Accessing DOTS among Adult PTB patients in Ndola.

Please render her the necessary support she may need.

Signed:
 Dr L. S. Nyendwa