# A THEMATIC ANALYSIS OF THE CHALLENGES EXPRIENCED BY THOSE LIVING WITH TUBERCULOSIS

A mini-thesis submitted in fulfilment of the
requirements for the degree of
MASTER OF SOCIAL SCIENCE IN SOCIOLOGY

of

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by

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# Abstract

Friedrich Engels (1820-1895) in his study, *The condition of the working class in England*, argued that the cause of illness and death amongst the working class was due to their living conditions such as poor housing, over-crowding, poor sanitation, food shortage, low paying jobs and a lack of material resources. The objective of the study was to understand the experiences of six South African individuals who have shared their experiences and challenges of living with TB on the TB&ME blog, and to show how TB is linked to the living conditions of these individuals. The study found that the challenges experienced by TB patient bloggers are of a social nature and confirms Engel's study findings on the conditions of the working class in England. For example, a disease such as TB has a direct association with the living conditions of people, especially the poor. Thus, socio economic status of TB patient bloggers plays a role in the escalation of their ill health. Further, the study found that gender is central in understanding non-compliance to treatment. This is significant as it highlights the need to not only focus on issues of socioeconomics, but gender issues in fighting TB. Despite the negative consequences associated with living with TB, the bloggers have noted that the support from loved ones and other stakeholders in the fight against TB alleviates the challenges inherent in living with TB.

# Declaration

I declare that this thesis is my own unaided work. It is submitted for the degree of Master of Social Science in Sociology, Faculty of Humanities, Rhodes University, South Africa. It has not been submitted before for any other degree or to any other university.

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# List of Abbreviation

| | |
|---|---|
| AIDS | Acquired Immune Deficiency Syndrome |
| ANC | African National Congress |
| ARVs | Anti-Retrovirals |
| ART | Anti-Retroviral Treatment |
| CDC | Centre for Disease Control |
| DOH | Department of Health |
| DOTS | Directly Observed Treatment Short |
| HIV | Human Immunology Virus |
| M | Mycobacterium |
| MD-R | Multi-Drug Resistant |
| MSF | Médecins Sans Frontières/Doctors Without Borders |
| NDoH | National Department of Health |
| TB | Tuberculosis |
| XDR | Extensively Drug Resistant |

# Chapter 1
# Introduction and Outline

## Introduction

Tuberculosis is a contagious and airborne disease, it ranks as the second leading cause of death from a single infectious agent after the human immunodeficiency virus (WHO, 2014; Kaye and Frieden, 1996). The disease affects the lungs, it is transmitted from person to person through airborne particles during normal social interactions and can cause death if not treated (Gandy and Zumla, 2000; Parkard, 1990). TB is a public-health problem and it is one of the most important yet neglected international health priorities (Murray, 1991). In 1993, TB was the world's leading cause of death from a single infectious agent. The UN warned that 35 million people could die of TB in the next following few decades (Daily Dispatch, 2004:7). The World Health Organization (WHO) declared the disease "a global health emergency" (Williams and Jones 1995:5; Kochi, 1991). In 1998, a meeting was held, and 22 countries believed to have around 80% of the total number of TB cases in the world attended. Under WHO as the global health parent, the STOP TB initiative was established, and TB became recognized as a serious health problem to the world.

Programs were initiated, and issues of poverty interrogated as an impediment. The STOP TB initiative brought countries across the world to work together in the fight against TB. In the twenty first century, half a decade and two years later TB was on the rise. Thus, in the year 2007, about 9.27 million new cases of TB developed, and 1.78 million people died (Corbett et al, 2003). In 2013, over 9 million people fell ill and about 1.5 million people died of tuberculosis (WHO, 2014). In addition, more than 2 billion people, equal to one-third of the world's population are infected with TB, and one in ten will go on to develop TB (Stop TB Partnership, 2015). Over two million new TB cases and over 500 000 TB related deaths were estimated to occur in the region of Africa annually (WHO, 2009). In the year 2011, there was an estimated 390,000 incident cases of TB in South Africa and 65% were co-infected with HIV. TB incidences in South Africa were on the rise as the number of new cases increased from 981 to 1000 cases per 100,000 people in the year 2010-2013 (WHO, 2013).

The global and local stats on TB brought about questions about the disease, questions which interrogated factors beyond medical explanations, but focused on social problems that have been neglected as they have given rise to the increase in TB infection. These factors have influenced the resurgence of the disease -i.e. poverty, deprivation, homelessness, overcrowding in close confines and deteriorating healthcare infrastructures and the Acquired Immune Deficiency Syndrome (AIDS) pandemic (Corbett et al, 2003). Further, historical neglect, poor management and problems within the health sector are also amongst the factors contributing to TB (Cullinan, 2008). As Kelly (1999:234) argues that "education, income, family, community, and culture all impact on how patients understand and experience an illness or disease". And that attitudes that different races have of TB also impact how it is exprienced. This highlights the fact that the experience of illness is challenging if you have a poor background, as compared to someone from a privileged background. For instance, the association between poverty and TB is well recognized. Often TB incidences are highest amongst the poorest of people in society (Davies, 2009). TB is can be argued to be a social problem with social ills, because it occurs predominantly around poor people, who stay in overcrowded environments and have low socio-economic status (Cantwell, Mckenna, McCray and Onorato, 1998). Thus, poverty becomes prevalent and this results in the TB transmission becoming prevalent especially amongst the poor segment of the population (Spence, Hotchkiss, Williams and Davies, 1993).

For example, 160 000 South Africans, predominantly poor black individuals become ill with TB every year and about 10 000 die (Edginton, 2000). This is a concern as nearly two thirds of the population in South Africa is infected with TB. Not everyone is at a greater risk of exposure, but the poor are at the centre of infection (Erstad, 2006). The experiences of illness often entail a process of suffering and eventual mortality on a large scale. Further, this suffering and eventual mortality of individuals with TB have brought to the light that the disease is a social disease not solely medical. In other words, this disease does not occur because of unhealthy living, but because of political and economic deprivation and income inequalities in South Africa (Davies, 2009; Kelly, 1999). Thus, experiences of ill individuals with TB become essential in understanding the challenges faced by those living with TB, in respect to the broader macro political and economic deprivation experienced by predominantly poor people in society. Therefore, the political economy of health perspective will be utilized in this study because of its emphasize on the analysis that goes beyond individual explanations of heath, towards a social analysis of health, illness and socio-economic statuses of people (Minkler et al, 1995).

The study investigated the challenges faced by those living with TB, especially their experiences of TB as a social disease and whether living with TB has any direct association with the living conditions of the six TB patient bloggers. Wilkinson (2005:60) states that “tuberculosis is a social disease, with risk factors such as a lack of a sense of control, depression, hopelessness, hostility, lack of confidence, lack of social support, bad social relationships, stressful life events, family conflict, stress at work, bereavement, singleness or divorced rather than married, and job and housing insecurity”. Those living with TB and their socioeconomic circumstances lose themselves because of the suffering, ordeal and challenges brought about by the macro consequences of the political and economic deprivations experienced in the process of being ill. Thus, people’s TB experiences are essential in understanding that health or ill health has its roots in social and political-economic realities. Therefore, it is necessary to comprehend TB as a social disease and not a medical condition. This involves moving away from common sense understanding of living with TB as the responsibility of the patient/individual, but looking at the macro structural limitations that have become part of the challenges faced by those living with TB. In Sociology, we call this “debunking” and my study will engage in that as it looks beyond medical surface appearances of those living with TB and the challenges experienced.

## Main aims

This study sought to understand and interpret the experiences of six South African individuals who have shared their stories of living with TB on the TB&ME blog and whether living with TB has any direct association with their living conditions. These individuals consider themselves as TB patient bloggers and are in collaboration with Médecins Sans Frontières/ Doctors without Borders (MSF). MSF is an ‘international, independent, medical humanitarian organization that delivers emergency aid to people affected by armed conflict, epidemics, natural disasters and exclusion from healthcare’. Related to this, the secondary aim was to investigate the role that socioeconomic statuses, gender and age play a role in the escalation of ill health or improved health on the part of TB patient bloggers. The focus is on the blogged narrated experiences on the TB&ME blog of individuals with TB, because of the blog’s belief is that TB patients should have the opportunity to speak out and share their experiences. As Dr James Orblinski, past MSF international President, when receiving the Nobel Peace Prize in 1999 noted that "we are not sure that words can always save lives, but we know that silence can certainly kill". The following is an extract from the TB and ME blog site, which highlights the relevance of the patient blog:

> *TB&ME is a collaborative blogging project by patients being treated for multidrug-resistant tuberculosis (MDR-TB) in locations all around the world. They are writing about their experiences of living with MDR-TB and the treatment that they receive. This treatment can often involve taking upwards of 20 pills a day for 24 months and suffering many painful side effects from the toxic drugs. TB&ME gives MDR-TB patients an opportunity to tell the world about the issues, which affect their lives, about how treatment and services could be improved and how it feels to have this disease. It also provides an opportunity for patients to tell the world that MDR-TB exists in their own words, that it is a global problem and to share their experiences with others who might be in the same position.*

This calls for studies focused on understanding the challenges faced by those living with TB, especially their experience/s of TB as a social disease. This thesis attempts to understand and interpret the experiences of six individuals who have shared their stories of living with TB on the TB&ME blog.

## Research Approach

Thematic analysis, a method for identifying, analyzing, and reporting patterns (themes) within data (Braun & Clarke, 2006) is the research method. This method of analysis offers an accessible and theoretically flexible approach to analyzing qualitative data (Braun & Clarke, 2006; Boyatzis, 1998; Roulston, 2001). Further, as Boyatzis (1998) notes, thematic analysis interprets various aspects of the research topic. This study examined and interpreted the experiences of six TB individuals who have shared their stories of living with TB on the TB&ME blog. The six TB patient blogs were selected because the feelings expressed provided a rich detailed account of living with TB and the challenges experienced. These individuals consider themselves as patient bloggers and have a common goal of sharing their experiences to help other TB patients. The patient bloggers were six in numbers, middle aged and one is a young adult. Further, there are three male and three female bloggers. These patient bloggers could be said to be deprived, disadvantaged and staying in poor neighborhoods such as Khayaletsha.

The above is based on the blogs as most TB patient bloggers wrote and touched on their struggles in the form of challenges experienced. These challenges experienced highlights the living conditions of the TB patient bloggers and the predicament they find themselves faced with, especially living with TB which often escalates matters not only of health, but of other important areas of their lives. The rationale for drawing participants from the TB&ME blog is due to the ethical consideration in health research, because it can be very difficult and time consuming to get permission to partake in health-related research, especially when it comes to sensitive diseases such as TB, HIV/AIDS and Cancer. The usage of blogs is attributed to the fact that…blogs allows access to information about the experiences and challenges faced by those living with TB, without any problems with the healthcare authorities. Thus, information can be easily identified, evaluated and analyzed to generate more constructive knowledge about TB's social causes and ills. Therefore, blogs are constructive in generating knowledge through making inferences that can be insightful and profound in understanding phenomenon or phenomena in society.

The written words of the TB patient bloggers highlight the negative side effects of structural inequality in quality living or rather income levels and ultimately in health care. To elaborate, TB patient bloggers are predominately black, stay in poor neighborhoods and their living environments are not conducive to creating social and ill health society. The demographics of the TB patient bloggers portray clearly, Engels assertion that the cause of illness, challenges and death amongst the working class was due to the living conditions of the workers. Conditions such as poor housing, crowding, poor sanitation, food shortage, low paying jobs and a lack of material resources. This assertion comes from Engel's study of 'The condition of the working class in England'. The study was phenomenal and it generated knowledge that was constructive and led to a realization that health or ill health is not just a physical element (individual problem), but that it entails factors pertaining to social factors such as the socio-economic status of individuals of group of people. Interestingly, social factors are said to be external to the sick individual as the cause of being sick is attributed to such things as lack of taking good care of oneself through exercising, eating healthy or not completing treatment.

Political economist perspective proponents take a different view about the claim that the sick are negligent about their health (not taking good care of oneself). As Szreter and Woolcocks (2004:00) note that a “political economy approach sees the primary determinant of poor health outcomes as the socially and politically mediated exclusion from material resources”. Therefore, the political economy of health emphasizes an analysis that goes beyond individual explanations of heath, towards a social analysis of health, illness and socio-economic statuses of people (Minkler et al, 1995). Thus, people’s challenges of living with TB and their experiences with the healthcare system is conceptualized through an investigation of structures in the political economy of health (Erstad, 2006:26).

The interpretation of the narratives was done using thematic method as earlier noted. The focus was on how the six bloggers make sense of their everyday TB experiences, and their underlying perceptions and meanings (Harvey and MacDonald, 1993:59; Lune, Pumar and Koppel, 2010:79; Tracey, 2013:05). The process of interpretation is to comprehend and explain the subjective meanings that lie behind the narratives (Terre Blanche et, 1999). Braun and Clarke (2006:15) argue that “thematic analysis involves the searching across a data set be that a number of interviews or focus groups, or a range of texts to find repeated patterns of meaning”. In this study, patient bloggers experiences were interpreted to find repeated patterns of meaning. The secondary aim of this study was to investigate similarities and differences in the six patient bloggers, whether these bloggers are aware of the link between their socio-economic status and their TB status, and whether gender and age play a role in the escalation of ill health or improved health. Therefore, thematic analysis as a method was important in highlighting similarities and differences across the data set and generates unanticipated insights.

The usage of thematic analysis was driven by the political economy of health framework as it forms an important part of this research/study. This form of analysis provided a more detailed analysis of some aspect of the data (the role of socio economic status on those living with TB and how the gender of the TB patient is significant in adhering to the treatment). I focused on one feature, socioe-conomic status and later included a gender variable but particularly looking into TB treatment compliance, in coding the data from the patient bloggers stories on the TB&ME blog. Thematic analysis facilitated me to “theorize the socio-cultural contexts, and structural conditions, that enable the individual accounts that are provided” (Braun and Clarke, 2006: 14). In my study several themes emerged during the analysis, I discovered and as others have ‘themes and concepts embedded’ in the narratives (see Rubin and Rubin, 1995: 226; Singer & Hunters, 1999).

The rationale for using such a method has to do with its usefulness for summarizing key features of a large body of data and offers a thick description of the data set (Braun and Clarke, 2006: 6). Furthermore, this method is flexible and useful for producing qualitative analysis suited for informing policy development. To sum up, thematic analysis provides a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex account of data. In any form of research especially qualitative research, issues of confidentiality, informed consent, anonymity and other ethical considerations are significant, but were not of significant concern in this study, because the six TB patient bloggers have made their experiences easily/readily available on the MSF TB&ME blog site for anyone interested in reading/listening to their stories of living with TB.

The notion of the role of socio economic status on those living with TB is felt through the feelings expressed in the form of blogs, which can be argued to reflect the consequences of being poor, because poor circumstances bring about other social ills such as lack of money to get the best medical care. And, even if the government were to provide best health care to its poorest citizens (it will not be enough to eradicate diseases such as TB in society), because a focus solely on medical factors is an injustice and insult to the sick who cannot afford the best medical care. In other words, medical factors are inadequate in eradicating ill health amongst those sick in society, especially those from poor societies. Thus, feelings expressed by TB patient bloggers highlights the frustrations caused by lack of considering the social factors that give way to easy TB transmissions in society.

## Outline of the Chapters

Chapter 1 provides a definition of TB, how it is transmitted, and how it has become a public health emergency in the world. Global and South African TB statistics are provided, and there is a brief discussion of the factors contributing to the high TB infection rates. This chapter serves as an introduction that explains the aim and the methodology of the study. It also includes a discussion on the TB&ME patient blog a source for data in this study.

Chapter 2 is divided into two parts, the first part provides a contextual analysis of TB from its evolutionary emergence and shows the role that the World Health Organization has played in the fight against the TB epidemic, particularly paying attention to the experiences manifested through challenges of living with TB. This chapter discusses TB from the time it was first declared as a public health emergency in the world, followed by the steps taken, the policies formulated and implemented especially in addressing the needs of the poor that experience challenges of living with TB. The South African TB context is included as it forms a huge part of this paper, within the South African context, the history of TB is discussed and the co-infection of TB-HIV/AIDS. Further, the chapter touches on the South African TB policies. This chapter highlights the need to shift the focus on TB as a medical problem, but more as a social problem. This is because issues of the health structure in South Africa, socioeconomic status, age and gender are often neglected when diagnosing the disease.

The second part of this chapter reviews studies on the challenges faced by those living with TB, especially their experiences with TB as a social disease. It further highlights that TB is a social disease, with "risk factors such as a lack of a sense of control, depression, hopelessness, hostility, lack of confidence, lack of social support, bad social relationships, stressful life events, family conflict, stress at work, bereavement, singleness or divorced rather than married, and job and housing insecurity" (Wilkinson (2005:60). The studies reviewed refutes the assertion that TB studies are best done quantitatively and instead highlights the significance of doing qualitative research by looking at the socio-economic and psychological factors that contribute to ill-health. The reviewed studies highlight the richness of qualitative research in understanding the challenges faced by those living with TB.

Chapter 3 discusses the theoretical framework of the thesis. This chapter focuses on the political economy of health in explaining the roots of ill health/health from the perspective that holistically encompasses not just the health part, but also the political, economic and social aspects pertaining to health. The argument carried in this chapter is that political economy approach sees the primary determinant of poor health outcomes as the socially and politically mediated exclusion from material resources. Therefore, the political economy of health emphasizes an analysis that goes beyond individual explanations of heath, towards a social analysis of health, illness and socio-economic status of people, especially those living with TB.

Chapter 4 discusses the findings from the case study on the six TB patient bloggers, who are in collaboration with MSF. These individuals believe that people should have the opportunity to speak out and share their experiences. Hence, they have done so through blogging on the TB and Me blog. The data collected shows that predominantly poor black individuals are mostly affected by the TB epidemic. Additionally, the study finds that the challenges experienced by TB patient bloggers on the TB&ME blog in collaboration with MSF are of a social nature and encompasses Engel's findings of his study on the conditions of the working class in England -i.e. disease for example TB have a direct association with the working and living conditions of people especially the poor in society. Thus, socio economic status of TB patient bloggers plays a role in the escalation of their ill health. Further, the study found that an issue of gender is central in understanding the notion of living with TB is not only about being black, deprived and having low socioeconomic status, but it is about non- compliance to treatment. This is significant as it highlights the need to not only focus on issues of socioeconomics but gender issues in fighting TB in society. This study finds that challenges experienced by those living with TB are of a negative nature as they entail emotional suffering, loss of self, stigma, gender related factors, marginalization and impact of lack of TB knowledge on treatment regime. However, TB patient bloggers have highlighted that support from loved ones and other stakeholders in the fight against TB alleviates their struggles inherent in living with TB.

Chapter 5 is the conclusion of the findings on the challenges experienced by those living with TB. The principal objective of this research was to investigate whether living with TB had a direct association with the working and living conditions of TB patient bloggers on the TB&ME blog as part of the collaboration with Médecins Sans Frontières/ Doctors without Borders (MSF). Further, the role that socioeconomic status and gender plays in the escalation of ill health or improved health on the part of TB patient bloggers. For example, women were more compliant to TB treatment than men. This is significant as it highlights the need to not only focus on issues of socioeconomics but gender issues in fighting TB in society. This dissertation draws the conclusion that the challenges experienced by those living with TB are a result of social problems due to poor socioeconomic status.

# Chapter 2

# Global TB and Literature Review

## Introduction

This chapter is divided into two parts, the first part provides a contextual analysis of TB from its evolutionary emergence and shows the role that the World Health Organization has played in the fight against the TB epidemic, particularly in relation to the experiences manifested through challenges of those living with TB. This chapter discusses TB from the time it was first declared a public health emergency in the world, followed by the steps taken, the policies formulated and implemented particularly in addressing the needs of the poor that experience challenges of living with TB. The South African TB context is included as it forms a huge part of this paper. Within the South African context, the history of TB is discussed, and the co-infection of TB-HIV/AIDS is included. Further, the chapter touches on the South African TB policies. This chapter highlights the need to shift the focus on TB as a medical problem, but more as a social problem, because issues of health structure in South Africa and socioeconomic status are often neglected when diagnosing the disease.

The second part of this chapter reviews studies on the challenges faced by those living with TB, especially their experiences with TB as a social disease. Further highlights that TB is a social disease, with "risk factors such as a lack of a sense of control, depression, hopelessness, hostility, lack of confidence, lack of social support, bad social relationships, stressful life events, family conflict, stress at work, bereavement, singleness or divorced rather than married, and job and housing insecurity" (Wilkinson (2005:60). The studies reviewed refutes the assertion that TB studies are best done quantitatively and instead highlights the significance of doing qualitative research by looking at the socio-economic and psychological factors that contribute to ill-health. The reviewed studies highlight the richness of qualitative research in understanding the challenges faced by those living with TB (Laubschagne, 2003).

## Conceptualization of TB by the World Health Organization (WHO)

In 1991, a revival of collective consciousness surfaced and efforts to control TB were reinvigorated, resulting in a World Health Assembly (WHA) resolution that saw the recognition of TB as a major global public health problem (WHO, 1993 and WHO, 2006:6). As part of the resolution of this collective consciousness of the world, two targets for TB control were established -i.e. detection of 70% of new smear positive cases, and cure of 85% of such cases, by the year 2000 (WHO, 2006). It was the beginning of an era, whereby the organization came to the realization that TB was a massive public health concern in the world. The realization led to interventions by WHO in the form of policies, programs and plans aimed at addressing TB cases. This resulted in an increasing recognition of tuberculosis as a public-health priority. Thus, WHO intensified their TB prevention, care and control efforts.

For an effective TB control, directly observed therapy (DOT) was introduced (WHO, 2006). DOT was a TB control strategy for most governments in the world when treating persons with active TB disease. This TB strategy in combating the TB epidemic entailed government commitment, case detection by predominantly passive case finding, a system of regular drug supply, a monitoring system for programme supervision and evaluation (WHO, 1994). The rationale for such a mechanism/strategy in fighting tuberculosis was because of the inability to predict who will take medication as directed, and who will not. Further, it was perceived that the DOT strategy decreases/decreased the chances of treatment failure and relapse (Curry, 2003). The strategy also intended for countries to improve national TB control programs (NTPs) and make major progress in TB control (WHO, 2002). The usage of DOT and its programs revolutionized the effectiveness of drug intake amongst patients. Therefore, led to successes in treatment completion (Chaulk, Moore-Rice, Rizzo, & Chaisson, 1995; McKenna, McCray, Jones, Onorato, & Castro, 1998)

The DOT strategy was a major breakthrough in the fight against TB through control measures, but unfortunately, it had its own shortcomings and failed to achieve its objectives. This resulted in WHO implementing new ways/approaches. Thus, in response, "WHO and partners embraced a new six-point Stop TB Strategy that builds on and enhances DOTS to address such new challenges" (WHO, 2011). These strategies entailed "pursuing high-quality DOTS expansion and enhancement, addressing TB-HIV, MDR-TB and the needs of poor and vulnerable population, contribute to health system strengthening based on primary health care, engaging all care providers, empowering people with TB, and communities through partnership, enabling and promoting research (WHO, 2011:12). This highlighted the seriousness and commitment of WHO in combating the TB epidemic.

The highlights of WHO's seriousness and commitment are best shown in the TB&ME project, which is "a collaborative blogging project by patients being treated for multidrug-resistant tuberculosis (MDR-TB) in locations all around the world'. The TB&ME blog provides a platform for TB patients to share their experiences of living with MDR-TB and the treatment that they receive through writing on the blog about the challenges they encounter as TB patients. The narrated stories on the TB&ME blog in collaboration with Médecins Sans Frontières/ Doctors without Borders, tell stories of sadness and despair as part of the challenges that are experienced by those living with TB. According to the MSF website, TB&ME was launched because MDR-TB is a neglected disease. It is argued that there is a need for new diagnostics and improved treatment, because MDR-TB patients are suffering from taking upwards of 20 pills a day for 24 months. This is what many in the pharmaceutical industry would call "drug torture" as there is a high probability of suffering many painful side effects from the toxic drugs. Thus, the relevance of TB&ME blog gives MDR-TB patients an opportunity to tell the world about the issues, which affect their lives, about how treatment and services could be improved and how it feels to have this disease. Further, provides an opportunity for patients to tell the world that MDR-TB exists in their own words, that it is a global problem and to share their experiences with others who might be in the same position.

The strategies proposed by WHO link well with the TB patient bloggers on the TB&ME blog, because most of the TB patient bloggers are part of the list of those that are poor, of color, living in poor neighborhoods, with low paying jobs and lack of material resources to get better health provision and vulnerable population. Therefore, WHO as a global health organization aims to contribute to the health system through strengthening primary health care, engaging all care providers, empowering people with TB, and communities through partnership, enabling and promoting research (WHO, 2011:12). Because of the TB&ME blogging project and many others, about 37 million lives have been saved between 2000 and 2013. Further reported that there has been a 45% decline in TB mortality rate and 41% decline in TB prevalence since 1990 (WHO, 2014). This is because people's stories are being heard and governments and other stakeholders are taking action through finding ways to come up with effective diagnosis and treatment.

## History of TB in South Africa

The era of colonization contributed largely to sources of infection and therefore TB in South Africa is characterized by its history (Chadwick and Cardew, 2008). During colonization, the source of infection was mainly among the lower classes, which were predominantly black people. Further, over about 60% of black South Africans were infected by 1930 (Edginton, 2000). Factors such as poor domestic, working environmental conditions, overcrowded hostel living, poor nutrition and stress were responsible for TB incidences/cases amongst poor black and colored people. Since the 1930s to date the notification rates of TB incidences have fluctuated as they have declined and increased, but in the 21st century despite the progress in preventative measures taken against TB there has been an increase in the number of infection incidences (see: Porteous and Terezhalmy, 2008; Centres for Disease Control and Prevention, 1998).

The increase in the number of infection incidences has led to the discovery of TB accounting for about 80% of all notifiable diseases in South Africa (Edginton, 2000). In the year 2011, there was an estimated 390,000 incident cases of tuberculosis in South Africa and 65% were co-infected with HIV (Global Tuberculosis Report, 2012). In South Africa tuberculosis incidence is on the rise as the number of new cases increased from 981 to 1000 cases per 100,000 people in the year 2010-2013 (WHO, 2013). According to Edginton (2000) about 160 000 South Africans of predominantly poor individuals become ill with TB every year and about 10 000 people die of TB every year. South Africa has recorded the world's second highest rate of new cases (incidence rate) after Swaziland (USAID, 2006). South Africa is part of the world's 22 high-burden TB countries (Erstad, 2006). Green et al (2010) state that South Africa has the "seventh highest incidence of TB in the world and that the incidence of TB has increased" (see also Chehab et al, 2011). The increase in TB incidences is escalating especially in some provinces (Statistics South Africa, 2011 and Scott et al 2010). One province, KwaZulu-Natal, in South Africa has experienced increased extensively drug resistant tuberculosis (XDR-TB).

In a study by Lim et al 2015, it was reported that South Africa is experiencing a widespread drug-resistant tuberculosis epidemic especially in the province of KwaZulu-Natal. The study found that extensively drug resistant tuberculosis (XDR-TB) incidence in KwaZulu-Natal increased to 3.5

cases/ 100,000 (776 cases) in 2011-2012. This exceeds incidence rates of all TB in certain low-incidence. The study concluded that South Africa remain in the top 10 countries with the highest burden of drug-resistant TB worldwide. Therefore, it is significant for South Africa to commit to political commitment, community education and mobilization to impact the epidemiology of XDR-TB not just in KZN but all the other provinces. The population in the study was predominantly poor black South Africans and this goes to show that TB affects mostly those with low economic status. South Africa is facing a massive challenge in dealing with the TB epidemic and people with low economic status are suffering (Edginton, 2000). This is a concern as almost a nearly two thirds of the population in South Africa is infected with TB. Not everyone is at a greater risk of exposure, but the poor are at the centre of infection (Erstad, 2006).

The study highlighted the fact that TB incidences/cases are concentrated amongst poor black and colored people with low socioeconomic statuses. Further, factors such as poor domestic, working environmental conditions, overcrowded hostel living, and poor nutrition are prevalent in South Africa. The high incidence of TB in South Africa is attributed to several factors pertaining to social ills. Poorer communities appear to be at greater risk of exposure and to chronic TB infection (DOH, 1996 cited in Reddy, 2009:16). Farmer (2002:83) in his article of 'the consumption of the poor: Tuberculosis in the 21st century', argued that "we must explore not only the life experiences of those sick with TB, but also the larger social contexts in which they become infected, fall ill, and meet with a series of challenges". Further, asserts that living with both poverty and tuberculosis means poor outcomes. Farmer's words emphasize the importance of external factors and how they can affect the poor negatively in their experiences of living with TB. This calls for studies focused on experiences/challenges faced by those living with TB.

## Co-Infection of HIV and TB

Churchyard et all (2014: 244) points out that "South Africa is one of the world's worst TB epidemics driven by HIV" and is second to HIV as the cause of death in the world. Green et al (2010) adds by stating that one-third of the forty million people currently infected with HIV are co-infected with TB. Akolo et al (2010) and Woldehanna et al (2004) argues that individuals with HIV infection are at an increased risk of developing active tuberculosis. Globally, TB and HIV/AIDS remain two of the leading causes of death resulting from infectious disease (WHO, 2008). The highest number of HIV infections in the world are around about 36 million and one third of the 36 million are co-infected with MDR TB, and 75% of these people reside in sub-Saharan Africa (Prasad et al, 2007; WHO, 2007; Singh ET AL, 1998 and Lucas et al, 1992). The WHO (2010:3) states that, "at least one in four deaths among people living with HIV can be attributed to TB, and many of these deaths occur in resource-limited settings". They further argue that "TB is responsible for more than a quarter of deaths in people living with HIV" (WHO, 2011). In the year 2006, it was estimated that about 9.2 million new cases and 1.7 million deaths from TB occurred in South Africa and of these around 709,000 (7.7%) new cases and 200,000 deaths were estimated to have occurred in HIV positive individuals (WHO, 2008: 1).

The statistics highlight the seriousness of TB and the health threat it has in South Africa. In South Africa, specifically in the province of KwaZulu-Natal, 65% of incident TB cases and over 80% of drug-resistant TB cases are co-infected with HIV (Statistics South Africa, 2011 and Scott et al 2010). Knight et al 2015 further notes that South Africa has one of the highest per capita rates of HIV/AIDS and tuberculosis (TB) incidence in the world. It is noted that HIV increases the susceptibility of the HIV positive person to TB (WHO, 2009). The probability of TB infection amongst HIV positive people is very high as compared to the probability of people that are HIV negative. In other words, the impact of HIV on the TB epidemic is potentially catastrophic. The high prevalence of TB especially amongst people with HIV highlights the escalation of the TB epidemic in the next years to come. WHO (2009) states that TB-HIV co-infection rates are high, with as many as 60% of adult TB patients being HIV-positive. Therefore, an intervention in the form of a collaborative approach emerged, leading to the World Health Organization (WHO) publishing an interim policy on collaborative TB/HIV activities (WHO, 2004). This bold act by WHO was brought about, because of concerns of the dual burden and appeals for guidance in terms of action to be undertaken. Thus, this required national intervention and South Africa did just that through implementation of TB policies.

## South African TB Policies

To address TB, there is a critical need to highlight the socio-economic status of TB patients in TB policies. To eradicate and prevent TB, we need sustained and predictable funding, political engagement and support, communities, people affected and civil society in the driving seat. Therefore, a holistic approach is essential in fighting TB. Further, TB policies are significant in addressing the problem of TB. In response, the South African National Department of Health (NDoH) formulated policy documents focusing on prevention and treatment. This led to the implementation of TB policies in South Africa. These policies aimed to achieve prevention and ensuring easy access to effective, efficient and high-quality diagnosis, treatment and care that reduces suffering (NDoH, 2007). As Evans (2002:198) once said that:

> Although debates on health have often emphasized that good health can only be achieved within the context of social organization, which pays particular attention to poverty, education, housing, economic globalization and other social factors, this observation has often lacked any basis for justifying greater attention to health.

The following South African policies assert that good health can only be achieved within the context of social organization, which pays attention to poverty, socio-economic factors and other social factors, but as Evans asserts "this observation has often lacked any basis for justifying greater attention to health" (Evans, 2002:198).

## Tuberculosis Strategic Plan for South Africa from 2007 to 2011

For a century, notification rates of tuberculosis incidences have declined and increased, but it was only in the year 2004 that the incidence rate was alarming and an intervention necessary (NDoH, 2006). In response, the South African National Department of Health (NDoH) formulated a policy focusing on prevention and treatment as a form of intervention. The policy's objectives were to bring about a reduction in the burden of TB in the country. This led to the introduction of Tuberculosis Strategic Plan for South Africa from 2007 to 2011, which entailed "preventing TB and ensuring that those who do contract TB have easy access to effective, efficient and high-quality diagnosis, treatment and care that reduces suffering" (NDoH, 2007). South Africa is part of the world's 22 high-burden TB countries (Erstad, 2006). Hence, the response in the form of a policy was essential and paramount. Further, Green et al (2010) and Chehab et al (2011) argues that South Africa having the seventh highest incidence of TB in the world and the incidence of TB increasing meant an intervention in the form of Tuberculosis Strategic Plan for South Africa was necessary to combat tuberculosis in South Africa. The policy encompassed adopting a multi-sectoral approach as it is or was a necessity to address availability of adequate resources especially skilled human resources, sustained funding, partnership building, and community mobilization across all the provinces (NDoH, 2007).

## National Strategic Plan on HIV, STIs and TB

An increase in the co-infection of HIV, STIs and tuberculosis led to the South African government in collaboration with other health stakeholders to introduce a holistic intervention in the form of a policy. It was necessary to focus not just on TB, but all the diseases for an effective TB epidemic control. Therefore, in 2012 the South African government produced a National Strategic Plan (NSP) to control the spread of TB with the aim of zero new TB infections and deaths by 2032 and, a halving of the 2012 rates by 2016 (SANAC, 2012). The aim of this policy to combating TB with other closely related diseases was holistic in nature and many said it was ambitious because of the weak health structures in place. In support the statement about ambition, Knight et al (2015) did a study on whether the NSP targets could be reached. The findings of the study revealed that the NSP targets are unlikely to be achieved (Knight et al, 2015). The unlikelihood of the NSP objectives being achieved is a result of issues of social and structural barriers to HIV, STIs and TB prevention that are often neglected in treating, preventing and controlling TB.

There is a need to move away from medical explanations of TB, to more social because TB attacks the poor malnourished or undernourished people, people living with HIV/AIDS, and miners, as they are vulnerable to being infected with TB.

For example, Roberts' (2009) study the *hidden epidemic amongst former miners: silicosis, tuberculosis and the occupational diseases in mines and works act in the Eastern Cape, South Africa*, highlights the TB risk for mine workers as they find themselves exposed to dust underground, poor working environmental conditions, overcrowded hostel living, poor nutritional status and work stress. This makes miners susceptible to TB infection. Therefore, TB should be "a product of a particularly pathological intersection of political, economic, and biological processes that have a wider distribution" (Roberts, 2009:46). This can mean that TB is a social disease with medical aspects. Therefore, notions of poor socio-economic living conditions come into play.

The emphasis on the challenges of those living with TB, particularly how their socio-economic statuses and living conditions are highlighted in the following studies. These studies on TB show that, although the right to health is a social and economic right…this is not case for most South Africans (Erstad, 2006). The following studies highlights the fact that, TB sufferers experience thoughts of suicide, feelings of hopelessness, lack of support, poor living conditions and many other difficulties. As Wilkinson (2005:60) states "tuberculosis is a social disease, with risk factors such as a lack of a sense of control, depression, hopelessness, hostility, lack of confidence, lack of social support, bad social relationships, stressful life events, family conflict, stress at work, bereavement, singleness or divorced rather than married, and job and housing insecurity.

## Resurgence of Tuberculosis in South Africa

Erstad (2006) conducted a study on the resurgence of Tuberculosis in South Africa. The aim of the study was to investigate the socio-economic constraints that influence the decisions of TB sufferers in the health seeking process and therapeutic management of TB in Grahamstown, the Eastern Cape. The study explored TB as a social disease in Grahamstown. Further, investigated health-seeking behavior, particularly how this behavior is shaped/constrained within the context of socio-economic conditions. Also, social and therapeutic support and the broader effects of structural violence. The study highlighted the need to understand the challenges or realities in which the subjects of the study get sick, get well, or not, and live their lives. Anthropological methods were utilized in the study such as participant observation and semi-structured interviews. Patients were interviewed in the clinic facility or hospital, in their homes and in public places. This provided rich data in understanding the challenges that those living with TB experienced. The rationale for participant observation was because "most social experience lies beyond words" (Hastrup & Hervik, 1994:8). Key informants were TB patients and out of all the patients, only eight people with TB were selected from the eight municipal clinics in Grahamstown and from the local TB hospital. The results of the study revealed denial and lack of information (participant's), particularly on how structural poverty and inequality influence their ability to get well and overcome challenges of living with TB. The study showed that denial and being misinformed served as an "indication of their marginalization" (Erstad, 2006: 175). Marginalization in a sense that those living with TB could not even see how their socio-economic and poor living conditions acted as a limitation to their health improving.

The study highlighted that "people make strategic choices in terms of their illness and other responsibilities in life, but that these choices are limited and constrained by structural relationships of power and access to this power, including economic benefits" (Erstad, 2006:2). The limitation and constraints experienced by those living with tuberculosis act as a challenge worsened by their socioeconomic status. Erstad (2006) concludes by saying that it is important to interrogate the macro structural factors that give rise to diseases and further contribute to ill/poor health of patients. She further argues that the right to health is a social and economic right, which is not the reality for most South Africans. The study highlighted the fact that individual experiences of illness are inadequate in understanding the true nature of sickness. Therefore, more must be done in interrogating the structural macro-economic factors in understanding the challenges faced by those living with TB or any other disease. As Farmer (1999 cited in Erstad, 2006: 175) notes how part of the anthropological message should be to allow "sufferers to discover the possible social causes of their suffering and, thus, to be relieved of the blame". Farmer (1999 cited in Erstad, 2006) emphasizes the fact that those living with TB should not think that being sick is their fault, but rather a medical problem and sufferers should be aware of the structural limitations at play, particularly how socio-economic status and poor living conditions contributes to their illnesses. This study fits in well with my study on the challenges of those living with tuberculosis, especially their experiences with the healthcare system. Further, this study is in line with the theoretical framework of political economy of health framework because it sees TB as encompassing the social, economic and political factors. On that note, this study can be said to be relevant to the objectives of my study in understanding the challenges faced by those living with TB, especially their experiences of TB as a social disease.

Erstad (2006) study challenged the debunked the experiences of those living with TB through highlighting the fact that TB or any disease is not the result of one's inability to take care of his/her health, but instead a result of the structural inequality and living conditions of individuals. The study's major strength was on the structural limitations as a challenge faced by those living with TB. Notions of socioeconomic status and poor living conditions played a dominant role in determining the status of one's heath in terms of deteriorating or improving. This study's conclusion is in correlation with my study on the challenges of those living with TB. The correlation is on the negligence and ignorance of the fact that those living with TB are oblivious to the structural poverty and how it contributes to their suffering. Erstad's study serves as an addition to my study as the body of knowledge through highlighting the notion of socio economic statuses of those living with TB and how this, limits their chances of overcoming challenges faced daily. Other studies on the experiences of TB are reviewed in the rest of the chapter, starting with a study on patient's experiences of an intervention to support TB treatment adherence in South Africa.

### Patients Experiences of an Intervention to Support TB Treatment Adherence in South Africa

Atkins et al (2010) conducted a study on 'patient's experiences of an intervention to support tuberculosis treatment adherence in South Africa'. The study reports on patient experiences of a TB treatment programme modelled on the empowerment-oriented antiretroviral treatment (ART) programme. The study investigated patient's perceptions of the programme and its impact on their lives. The study took place in Khayelitsha, an urban settlement on the outskirts of Cape Town and home to 400 000 people, most of whom live in informal dwellings (Dorrington, 2002 cited in Atkins et al 2010). Khayelitsha is a poverty-stricken community and mainly populated by the poor black South Africans, high levels of unemployment, high levels of sickness characterize it and people live in confined spaces. The results of the study identified and revealed three themes: (a) tension between agency and coercion in treatment taking; (b) treatment as a lifestyle change; (c) and the role of the supporter as constraining or facilitating empowerment.

The first theme involved 'agency and coercion in treatment taking'. This meant that patients had to take charge of their own health and ensure that they take their medication and finish the treatment. As one patient said:

> I think people should learn to value themselves and their lives and then they will not stop taking their treatment. People have to love themselves so much that they do not need [a] caregiver to run after them to take their treatment.

The words uttered by the patient accentuates the notion of agency because at the end it is your health and therefore it is in your best interests to take the medication and finish the treatment. Coercion was a factor and this fits in well with my study on the challenges faced by those living with TB, especially their experiences with the healthcare sector. As I mentioned in the introduction that "free healthcare comes at a price in the form of disrespectful and indifferent healthcare workers", this is expressed through patients of TB forced to take medication by healthcare practitioners, who explicitly grind tablets into patients' food and sometimes force them to go to the clinics every day. The study on the 'intervention to support tuberculosis treatment adherence in South Africa' (Atkins et al, 2010) shows this coercive nature through the words of one health practitioner who stated:

> I think that the people who are residing with the stubborn patient should make sure that the patient takes the pill even if it means grinding the pills and put [ting] it into their food.

This shows the level of disrespect and dignity on part of the healthcare practitioners who show little care and sensitivity. This kind of treatment is a form of a challenge for those living with tuberculosis. This is a challenge on part of those living with tuberculosis because it seems as there is no understanding, patience, proper care when it comes to treatment processes. The second theme (treatment as a lifestyle change) entailed what can be said one of the difficult challenges faced by those living with tuberculosis i.e. changing how you live is most problematic as it involves eradicating certain things that an individual use to do such as alcohol consumption and smoking.

As one patient in the study said:

> Another thing is that other people do not want to give up on their lifestyle, for example drinking.

The words speak to the difficulty and unwillingness to give up certain activities such as drinking and smoking, but giving up these two and others is very essential in treatment being a success. Therefore, changing your lifestyle as a tuberculosis patient is very significant and will weld positive results. It was discovered in the study that some tuberculosis patients experience challenges in the form of going back to old negative and unhealthy living, as a result of feeling better or seeing an improvement in their health status.

For example, one of the patients said:

> I think when people start feeling better they go back to their old habits.

The attitude or mentality of the above sentiments and others is very much misleading and can be of harm to the success of the treatment. Therefore, it is important to emphasize the importance of a healthy lifestyle when taking treatment. The last theme (the role of the supporter as constraining or facilitating empowerment). TB patients are admonished to find some one that will play the role of a supporter and that someone can be a close friend or a relative. This supporter can be a constraint or provide empowerment. It was discovered in the study that some supporters were very much a constraint in treatment procedures as they often gossiped or gave up caring fully and just did the supporting part as a form of pity or duty. This impacted heavily on the patients and was a challenge in terms of there was no support structure that will enable the emotional, physical and social support needed to finish the treatment. Other supporters played an empowering role in a sense that they were there every step of the way. This brought about encouragement, motivation and inspired those living with tuberculosis to be more active in their health and taking their treatment.

The study did not consider individuals living conditions but focused heavily on the relation between the patient, healthcare practitioners and the treatment processes. Patients or participants shared their experiences or challenges faced but the context of their experiences was limited and did not go further to include the living conditions and nutritional circumstances that often hinders treatment completion. This study was very relevant to understanding the challenges of those living with tuberculosis, especially they experience with the healthcare sector. My study will add to this body of knowledge on TB especially in encompassing the living conditions and socioeconomic statuses of those living with TB. Further, how living with TB has direct association with the conditions of the poor and marginalized in society. Roberts study will show how the conditions of the poor and marginalized in society give rise to the spread of TB through looking at miners, who are predominantly black, poor with poor sanitation and poor neighborhoods characterized by overcrowding, crime, and unemployment. All these factors can be said to contribute to the TB epidemic.

### The Hidden Epidemic Amongst Former Miners

Roberts' (2009) study on the Hidden Epidemic Amongst Former Miners (Silicosis, Tuberculosis and the Occupational Diseases in Mines and Works Act in the Eastern Cape South Africa), highlights the TB risk for mineworkers as they find themselves exposed to dust underground and the poor working/living conditions. She explored the experiences of mineworkers living with TB. The aim of the research was to assess current and historical surveillance of the pneumoconiosis in former miners, in particular silicosis, silico-tuberculosis, and TB. The study also aimed to assess the impact of the burden of lung disease and disability on the public health system and on the labour-sending communities from which the miners come and to which they return. The main objective was thus to investigate health systems surveillance of the pneumoconiosis in former underground gold miners. The study comes at a time of agony in the mine sector of South Africa because miners have the highest rates of TB infection in the world (Stuckler et al, 2011). For instance, "the annual incidence of tuberculosis amongst mineworkers is 4200/100,000 and this is between four and seven times higher than the general population of South Africa" (Roberts, 2009:46).

Roberts (2009) noted that there have been increasing retrenchments in the last decade and thus increasing numbers of mineworkers returning to the traditional labour sending areas of South Africa and Southern Africa. The retrenchment means that mineworkers are now sick (may have TB) and therefore cannot work. Feelings of hopelessness were expressed by former mine workers, who were living with TB. The study highlighted that TB attacks the very poor malnourished or undernourished people, people living with HIV/AIDS, and miners are most vulnerable to infection due to their working and living conditions. Therefore, TB should be seen as "a product of a particularly pathological intersection of political, economic, and biological processes that have a wider distribution" (Roberts, 2009:46). In other words, TB should be conceptualized holistically, and poor socio-economic living conditions should not be neglected. The following study moves away from macro level analysis of experiences with TB, to more micro level analysis and looks at the emotional experiences of the chronically ill as they loss themselves. Both TB patients and chronically ill individuals experience similar struggles and challenges of living with a disease. In the process of living with a disease, these individual's loss themselves and Charmaz in her study shows how this happens.

### Loss of Self: A Fundamental Form of Suffering in the Chronically Ill.

Charmaz's (1983) study, *Loss of self: a fundamental form of suffering in the chronically ill*, examined how illness shapes situations in which the person (ill person) learns new definitions of self and often relinquishes old ones. Data was drawn from 73 in-depth interviews with 57 chronically ill persons in Northern California who have various diagnoses such as cardiovascular disease, diabetes, cancer, multiple sclerosis, lupus erythematosus and so forth. Interviewees varied in age, income and type of illness. The age range was from 20 to 86 years, with the largest proportion ranging from 40 to 60 years. Charmaz (1983: 168) concluded that:

> Physical pain, psychological distress, and the deleterious effects of medical procedures all cause the chronically ill to suffer as they experience their illnesses. However, a narrow medicalized view of suffering, as solely defined as physical discomfort, ignores or minimizes the broader significance of the suffering experienced by debilitated chronically ill adults. The nature of that suffering is, the loss of self-felt by many persons with chronic illnesses.

Further, the study highlighted the fact that the sources of suffering/experiencing the loss of self, amongst the chronically ill, develop out of the conditions and context of experiencing illness. Charmaz (1983) focused on four themes: living a restricted life, experiencing social isolation, discrediting from others and burdening others. The results of the study revealed that "chronically ill persons evince a heightened self-concern about the person they see themselves becoming and about valued self-images from the past which they have lost, sometimes irretrievably" (Charmaz, 1983:190). Further, chronic illness seems to foster greater dependence on others. Charmaz concluded by saying that "the language of suffering these severely debilitated people spoke was a language of loss. They seldom talked of gaining a heightened consciousness of the world, revelations about self or insights into human nature from their experiences" (1983:191).

The study highlighted the need to debunk the experiences of living with a disease especially those individuals with chronically illnesses. Further, showed how ill people loss control of themselves due to being sick/living with an illness. The study contributed to the large body of knowledge already available about the experiences of the chronically ill through highlighting the terrible feeling manifesting into a challenge of not being in control of your body and mind as you lose yourself in the process of living with a disease.

The study also highlighted the extreme suffering that chronically ill individual's experience. It further, showed that chronically ill individuals do not only suffer but in the process of suffering lose themselves. The experiencing of losing oneself is unbearable for the chronically as they loss not only control over their bodies and minds, but loss hope and experience despair. It can be said that, the study focused more on the emotional and psychological harmful effects that illness can have on an individual. It was a micro level analysis and therefore did not take into account the structural limitations attached to experiencing illness. However, it did not include factors that might have contributed to the chronically ill getting better or worse. Factors such as the socio-economic statues of participants, their living environments and their race. There is a gap that my own research on the challenges experienced by those living with Tuberculosis will fill-i.e. include the macro structural limitations as factors contributing to ill-health or improved health. Also, looking at the disease not from a medical perspective, but social as the disease is a social disease. Issues of stigma and isolation are of importance in understanding some of the challenges experienced by those living with TB. Thus, the following study looks at the experience of patients with active TB

## Isolation and Stigma: The Experience of Patients with Active Tuberculosis.

Kelly (1999) conducted a study on isolation and stigma: the experience of patients with active Tuberculosis. The aim of the study was to explore how a sample of patients with active tuberculosis experienced their illness. The study was guided by questions from Kleinman's (1980) explanatory model, and 28 semi structured interviews were conducted in public health clinics. The results of the study revealed that patients understood tuberculosis through the medical model and perceived themselves as disease vectors. Further, after their diagnosis became known, almost all patients felt that their family and friends avoided or shunned them. Patients responded to these attitudes by isolating themselves and becoming secretive about their illness. The study highlighted the consequences of living with TB as it results in negative behavior on pats of the patients of TB. Hence, Kelly (1999:238) concluded by asserting that “tuberculosis was an illness that caused embarrassment, isolation, stigma, and self-identification as a transmitter of disease”.

The study was constructive in highlighting the internal mixed emotions that patients experience as part of living with TB, and how these internal feelings manifest themselves externally through acts of isolation, avoidance and feeling embarrassed due to be judged and being confused with having AIDS. This study is like Charmaz’s (1983) study on the loss of self as it interrogates the emotional experience and challenges of those living with TB. However, it did not include factors that might have contributed to the chronically ill getting better or worse. Factors such as the socio-economic statues of participants, their living environments and their race. There is a gap that my own research on the challenges experienced by those living with Tuberculosis will fill, that is the macro structural limitations as factors contributing to ill-health or improved health. Also, looking at the disease not from a medical perspective, but social as the disease is a social disease.

## Conclusion

This chapter firstly, highlighted the role that the World Health Organization (WHO) has played in the fight against TB. Further, showed how TB&ME blog fit with WHO discussion on TB or the fight against TB. It has also provided a brief history of TB in South Africa, the co-infection of TB and HIV/AIDS and discussed the South African Health TB policies. Issues of structural constrains and socioeconomic status were included in this chapter, because TB is not just a medical problem, but also a socio-economic problem that requires a holistic approach encompassing the political and economic aspects to health/diseases. Secondly, this chapter discussed studies on TB from a qualitative research approach to capture the challenges faced by those living with tuberculosis, especially their experiences with the healthcare system. Factors such as lack of a sense of control, depression, hopelessness, hostility, lack of confidence, lack of social support, bad social relationships, stressful life events, family conflict, stress at work, bereavement, being single or divorced rather than married, and job and housing insecurity have been shown to be associated with living with TB.

These factors are at the core of the challenges that those living with TB experience. Socio-economic status of patients of TB have been shown to be dominant in the lives of many. The studies highlighted the fact that individual experiences of illness are inadequate in understanding the true nature of sickness. Therefore, more must be done in interrogating the structural macro-economic factors in understanding the challenges faced by those living with TB or any other disease. Further, studies showed an element of predominantly racial, economic and political category, where poor blacks with low socio-economic status in society have TB and are marginalized. This shows that poor black people are at a greater risk of exposure due to their livelihood style and very poor standards of living (Erstad, 2006). According to Farmer (2002:184) "those who experience tuberculosis as an ongoing concern are the world's poor, whose voices have systematically been silenced" Therefore, a political economy of health perspective must be applied to illness or experiences and challenges of illness/diseases, in order to interrogate the structural macro limitations pertaining to experiences of illnesses. Thus, the following chapter focuses on the theoretical framework.

The feelings expressed in the form of blogs are reflections of the consequences of being poor, because poor circumstances bring about other social ills such as lack of money to get the best medical care. And, even if the government were to provide best health care to its poorest citizens (it will not be enough to eradicate diseases such as TB in society), because a focus solely on medical factors is an injustice and insult to the sick who cannot afford the best medical care. In other words, medical factors are inadequate in eradicating ill health amongst those sick in society, especially those from poor societies. Thus, feelings expressed by TB patient bloggers highlights the frustrations caused by inconsideration of the social factors that give way to easy TB transmissions in society.

# Chapter 3

## Theoretical Framework

The present study is framed within the theoretical field of political economy of health. Hans Baer (1982:1) conceptualized the political economy of health as referring to "a critical endeavor which attempts to understand health related issues within the context of the class and imperialist relations inherent in the capitalist world-system" (1982: 1). Baer argued that the political economy of health serves as a critique of contemporary health reforms that tends to be exclusionary and more capital oriented. Szreter and Woolcocks (2004:00) assert that a "political economy approach sees the primary determinant of poor health outcomes as the socially and politically mediated exclusion from material resources". Therefore, the political economy of health emphasizes an analysis that goes beyond individual explanations of heath, towards a social analysis of health, illness and socio-economic statuses of people (Minkler et al, 1995). Thus, people's challenges of living with TB and their experiences with the healthcare system is conceptualized through an investigation of structures in the political economy of health (Erstad, 2006:26).

The political economy of health "has a long, if often subdued, history in the study of health inequalities and the role of neoliberal economic policies in escalating health inequalities" (Bambra, 2011). The roots of this theoretical framework can be traced back to the publication of Engels' study *The condition of the working class in England in 1844/5* (Annandale (1993:4). Engels' work entailed an analysis of diseases in the population, and he concluded that diseases had a direct association with the relation of production under capitalism. He argued that the cause of illness and death amongst the working class was due to the working condition of the workers such as poor housing, crowding, insufficient ventilation, chronic food shortage, excessive drinking, and the misdistribution of medical practitioners. Engels' work highlighted the need to move from individual explanations towards a social analysis of health, illness and socio-economic statuses of people. Thus, from this perspective, health and healthcare could be understood only in relation to the political and economic framework (Annandale, 1993:4).

Quinonez (2004:21) states that a significant contribution of political economy of health involves an understanding of "how political economic realities impact health and diseases through their shaping of health service structures and delivery mechanisms". This emphasizes the notion of medical intervention alone being insufficient for the eradication of disease. As Navarro (1976: 441) asserts, "changes in the nature, form, and distribution of resources in the medical sector is exclusively determined by the economic needs of the capitalist system". The health system is more concerned about the maximization of profit and not the health concerns of the people. As Baker (2010: 84) asserts that "socially disadvantaged groups have higher medical needs yet frequently receive less health care" (see also Gilson and McIntyre, 2007). Socially disadvantaged is a nice phrase for black people as they are the majority of ill individuals with low socio-economic status, unemployed, staying in overcrowded places and are socially vulnerable. Issues of healthcare play out at both the structural level, and at the individual level where illness is experienced which makes the political economy of health a relevant framework for this study. As Farmer (2002:197) notes that "critical perspectives on tuberculosis must link ethnography to political economy and ask how large-scale social forces become manifest in the morbidity of unequally positioned individuals in increasingly inter connected populations". As Crawford (cited in McKinlay, 1985) observes:

> Health is neither an outcome of normal life activities, such as one's work, upbringing or current lifestyle, but rather an unaffordable luxury that must be achieved through self-control, denial, and will power. The political economy of health is therefore concerned with the association of capitalism, production, distribution, and consumption of health services and how these processes reflect the class relations of the larger societies within which medical institutions are embedded".

Another proponent of political economy of health, Rudolf Virchow (cited in Waitzkin, 1981: 84-85) asserted that ill health is associated with economic deprivation and political powerlessness. He further provided an alternative through a recommendation that entailed a series of profound economic, political, and social changes such as increased employment, better wages, and local autonomy in government, agricultural cooperatives, and a more progressive taxation structure. Virchow saw the origins of ill health in societal problems, and therefore it was essential to change the conditions that permitted ill health to occur.

Healthcare is structured along capitalist notions, whereby profit maximization is a priority and proponents of the political economy of health assert that capitalism does not simply cause illness and disease, but in some instances, may contribute to better health standards. In other words, the affluent can easily get healthcare without any hurdles but as for the poor it has becomes a struggle.

The notion of illness has been solely focused on the medical aspects/factors, while ignoring the role of political, economic, and social factors (Berliner 1975; Brown 1979).

Different economies have emerged over the years and course of history, but the free market/neoclassical political economy has been harmful especially for the poor groups in society. This form of economy has provided the rich with proper healthcare but at the expense of the poor. The political economy of health argues against such economic practices, as they are unfair to those that have low socioeconomic statuses in society. There is a strong correlation between a person's position in the social structure and their health. In other words, those of the middle or upper class tend to have better healthcare outcomes as compared to the lower class (Lundberg, 2006). Neoliberal economic policies across the world have led to a situation whereby health care becomes a commodity consumed by the rich under the system of capitalism because they can afford it.

In conclusion, the political economy of health perspectives has highlighted the need to encompass not only the macro level analysis of health/ill health, but also the meso and micro level analysis of health inequities. Dreitzel (1971) argued that "sociology, however, has to go beyond the self-interpretations and rationalizations of our world, as taken for granted, and uncover the socio-economic mechanisms which are at work behind". The consensus among proponents of the political economy of health approach is that health policy, both in terms of prevention and curing, faces irreconcilable dilemmas under the existing capitalist world-system.

# Chapter 4

## Analysis and presentation of findings

### Introduction

Thematic analysis method was used in this study, as it offers an accessible and theoretically flexible approach to analyzing the data (Boyatzis, 1998; Braun & Clarke, 2006; Roulston, 2001). Thematic analysis proved to be an essential component of the study, because it helped to minimally organize and describe the data set in (rich) detail. This chapter presents the main findings from the case study on the six TB patient bloggers, who are in collaboration with MSF. These individuals believe that patients should have the opportunity to speak out and share their experiences. Hence, they have done so through blogging on the TB&Me blog. The aim was to examine and interpret the experiences of six South African individuals who have shared their challenges of living with TB through writing about their experiences on the TB&ME blog. Further, whether living with TB has any direct association with the living conditions of the six TB bloggers. Interpretation through utilization of thematic methods was employed, because there was a great concentration on how six patient bloggers make sense of every day aspects of their TB condition and their underlying perceptions and meanings (Harvey and MacDonald, 1993:59; Lune, Pumar and Koppel, 2010:79; Tracey, 2013:05).

Related to this, the secondary aims were to investigate the role that socioeconomic status play in the escalation of ill health or improved health on the part of TB patient bloggers. The focus was on the blogged narrated experiences in the form of writing on the TB&ME blog of individuals with TB, because the belief is that patients should have the opportunity to speak out and share their experiences. In this study, names of the TB patient bloggers were not used, instead lamentations expressed were widely used as an addition to the themes identified. The challenges experienced by the six South African TB patient bloggers are available on the MSF (TB&ME blog) website for viewing. The data analysis revealed several themes that were present in the lives of the six TB patient bloggers on the TB&ME blog. These included significantly ideas about gender related factors, being black and poor, emotional suffering, loss of self, the impact of lack of TB knowledge on treatment regime, stigma, social solidarity and support. These are described next.

### Compliance: Gender Differences

TB patient bloggers showed that there are differences between men and women in compliance to TB treatment and finishing it on time. Out of the six bloggers, only three highlighted their TB success stories. As one female TB patient blogger wrote:

> It is now exactly 30 days before it's a year since I completed my TB treatment and was declared TB free. Well, it honestly feels great to have reached this far

Another female blogger went on to write:

> Now I am finished with TB. To celebrate the freedom I have experienced this past year, I ran a 10km race this weekend, about a year after stopping treatment, to remind me of how far I have come by God's grace. My feet burned, but it was worth it. I also started scuba diving again and had no problems with my lungs!

Surprisingly, out of the six TB patient bloggers, three were women. This highlights a big problem in society that needs attention in order to understand, why some people finish their treatment while others do not (i.e. women tend to comply and finish their treatment compared to men). A question of gender compliance and how it contributes to improved health becomes a significant factor interrogate, especially if we are looking at how one gender (females) tends to comply and finish the treatment as compared to the other gender (men). Issues of gender compliance become relevant in the fight against TB, because the reality is that women have an inclination of complying with their treatment structure and finishing it, whilst men on the other hand are non-compliant. Hence, do not finish their treatment on time and therefore success rates amongst men are very low. The analysis tells us that it is not only about being black, deprived and having low socioeconomic status, but that it is matter of not sticking to treatment. This is significant as it highlights the need to not only focus on issues of socioeconomics, but gender issues in fighting TB in society.

### Inner Pain

In the words of the late Nelson Mandela, "the wounds that cannot be seen are more painful than those that can be seen". Most TB patient bloggers experience this kind of emotional suffering and it kills them internally. Thus, making it difficult to overcome the challenges because if you die internally, it is a slow death as feelings of despair results and the fight against the disease becomes difficult to win. Charmaz (1983:168) in her study argued that a "narrow medicalized view of suffering, as solely defined as physical discomfort, ignores or minimizes the broader significance of the suffering experienced by debilitated ill adults”. This means physical suffering experienced by those living with TB, is as much significant as emotional suffering experienced by the same people. There is ignorance on the broader significance of the suffering experienced by debilitated ill adults, such as the marginalization experienced by those living with TB.

The marginalized and poor in society often have the worst form of emotional suffering and the emotional pain is escalated by denied material resources such as health equity and economic power. This links with Baker (2010: 84) assertion, “socially disadvantaged groups have higher medical needs yet frequently receive less health care” (see also Gilson and McIntyre, 2007). Socially disadvantaged is a nice phrase for black people as they are the majority of ill individuals with low socio-economic status, unemployed, staying in overcrowded places and vulnerable. TB patient bloggers are amongst people with wounds that cannot be seen due to their marginalization as a result of being poor and having a low socio-economic background. There is a link with Quinonez (2004:21) assertion of “how political economic realities impact health and diseases through their shaping of health service structures and delivery mechanisms”. This emphasizes the notion of medical intervention alone being insufficient for the eradication of disease, because programs already in place are of a physical nature instead of an emotional one. Therefore, one patient blogger expressed her suffering of living with TB by writing:

> Is when the drama and sorrow, loneliness, stress happens.

Another went on to lament by writing:

> I got liver failure due to the TB medication and was hospitalized for 75 days, of which I spent about a month in ICU. I had diarrhea at least three times a day and thus I was very thin and weak.

The lamentation of patient bloggers highlights the worst form of suffering and shows the challenges of dealing with TB on daily basis, especially if you are black staying in a poor neighborhood, are unemployed and have a low paying job. These factors contribute immensely to the difficulty of overcoming the challenges of living with TB. As one TB patient blogger wrote:

> 18 months of that HORRIBLE treatment that almost took my life and threatened to take my hearing, my liver function, my kidney function and my life, feeling chest pains, coughing, sweating at night and forgetting a lot of things.

These patient bloggers endure the pains both emotionally and physically. This kind of suffering can be defeating, because of the poor circumstances TB patient bloggers find themselves in.

This is confirmed by one TB patient blogger who wrote:

> I found it hard to suddenly not have freedom or abilities that I used to have and felt very vulnerable. I don't think a healthy person can imagine even when trying, how it feels to be so sick (I even now find it hard to imagine, it feels unreal). My world became very small as I just lay in the bed most part of the day".

The words are of someone suffering and experiencing emotional pain is the worst form of challenge that can be experienced by those living with TB. In other words, feelings become a burden for the six patient bloggers. These overwhelming feelings of pain, sadness and anxiety are escalated by the lack of social support and economic support as one becomes unemployed due to being sick and repeated visits to the hospital. A lack of many things is the norm for most of the TB patient bloggers because they have been denied an opportunity to gain material resources and health equity. According to Farmer (2002:197) "critical perspectives on tuberculosis must link ethnography to political economy and ask how large-scale social forces become manifest in the morbidity of unequally positioned individuals in increasingly inter connected populations".

Most TB patient bloggers find themselves marginalized by the health sector, as it does not take into account their emotional suffering. Visits to the hospital and clinic is very emotionally challenging as it reminds some of the TB patient bloggers of living a life that is unstable and unpredictable. As one of the patient bloggers wrote:

> I stayed for six months in the hospital, and then I finished three months at home. After I finished those nine months, I started feeling sick again. I went back to the clinic.

All this is physically and emotionally strenuous for these patient bloggers and their low socioeconomic status escalates the suffering and pain. Feelings such as expressed by one TB blogger were prevalent among other bloggers, she wrote:

> I just wanted to get through the day when I was so sick, anything above that would make me feel overwhelmed

The emotional pain as part of suffering is fully characterized by one patient blogger who wrote that his experiences of living with TB:

> Speak of a journey, one of loneliness, pain, tears and finally salvation.

Another gives an account of what TB in life has made him become:

> I had to quit school and sit at home doing nothing which did not fit my personality as I like being active in life.

Overcoming all these factors associated with being sick with TB is huge challenge for the patient bloggers, because the future becomes unpredictable and gloomy. Feelings of despair become prevalent amongst the patient bloggers as expressed in their experiences of living with TB. Their marginalization due to the poor circumstances that they find themselves in makes them interrogate and realize that economic powers are necessary to overcome the challenges. This links in well with one proponent of political economy of health, who asserted that ill health is associated with economic deprivation and political powerlessness (Rudolf Virchow cited in Waitzkin 1981). The emotional suffering of those living with TB, leads to loss of self as they experience the challenges of being discredited, social isolation and burdening others. As Charmaz (1983) in her 'loss of self' concept illustrates.

### Loss of Self

Kathy Charmaz (1983) argues that ill persons observe their former self-images crumbling away without the simultaneous development of equally valued new ones. This is true for TB patient bloggers, especially from the moment they are informed of their TB status and the treatment they need to follow. Thus, these patient bloggers begin to introspect, retrospect and then come to the realization that they will never be the same. In other words, 'their former self-images are crumbling away' (Charmaz, 1983). Most of these TB patients are predominantly poor and depend on the state for welfare benefits. Because of the capitalist system, the state's health care system has been influenced to become more concerned about maximization of profit and not the health concerns of the people. As Navarro (1976:441) asserts, "changes in the nature, form, and distribution of resources in the medical sector is exclusively determined by the economic needs of the capitalist system". Therefore, the treatment and support TB patient bloggers receive is not of higher standard and this makes it easier for their former self-images to crumble away without the simultaneous development of equally valued new ones (Charmaz, 1983). Thus, TB patient bloggers experience loss of self through leading restricted lives, experiencing social isolation, being discredited and burdening others (Charmaz, 1983). The socio-economic status and living conditions add stress to the already stressful life of living with TB.

As one patient blogger wrote:

> They told me that I have XDR, and then they told me that the treatment I am going to take it would end after two years. On that day, I told myself this is the end of the world for me.

Hopelessness results and negative thinking commences, this often escalates the loss of self-process. Many TB patient bloggers shared their experiences of losing themselves and the following is what one of them wrote:

> If I want to wash some clothes, I cannot wash the clothes by myself because I get tired so fast. For a long time, I could not get up out of bed by myself so I relied on others a lot, as I lost a lot of muscle mass and was weak. It was hard not to be able to bath myself. I remember and feel bad to say it, but I was jealous of the young girl in the bed next to me who could walk around the nursing station as I was stuck in bed.

Another one wrote:

> Sometimes I cannot sleep at night. When I am sleeping, there are times that I think I will never wake up again when this shortness starts; I will not feel no air to breathe then. I will try to breathe slowly to be better.

Further wrote:

> I must not walk fast as I have very little energy and feels, and gets tired regardless of the hours I slept the previous night.

The aforementioned accounts in the form of lamentations highlights the loss of self through living restricted lives, experiencing social isolation, being discredited and burdening others (Charmaz, 1983). The accounts portray the fact that these TB patient bloggers cannot do much as they are limited due to being unemployed, or have low paying jobs, which means inability to access nutritious food. This is confirmed by Szreter and Woolcocks (2004:01) who noted that a “political economy approach sees the primary determinant of poor health outcomes as the socially and politically mediated exclusion from material resources”.

**Oblivious**

Most patient bloggers TB diagnosis comes across as a shock. This highlights the notion that people are ignorant or misinformed concerning certain diseases such as TB. Erstad (2006), study results revealed that most participants (those living with TB) lacked information/were misinformed about TB. Further, the study highlighted that being misinformed served as an indication of their marginalization. The shock of knowing their TB status, results in disbelief and a short period of denial. Questions such as why me, why now and many others are being asked internally. The information that they will be on treatment for almost two years is too much to bear. This brings about anxiety and feelings of fear because they have never thought that they could ever have TB. One patient blogger wrote the following:

> They told me am going to be on treatment for 2 years and injection for 6 months. Keep in mind this is my first time to have TB, I never have it before …Why now?.

Another went on to write:

> I still remember when I was told that I had TB - of all the sicknesses I thought I might be having, TB was not even on my mind.

The comments or assertion above accentuate the importance in teaching people about TB and the steps needed to be taken in informing people about some diseases, including the treatment. Taking pills is the most challenging thing that patient bloggers experience because taking in about 21 pills a day is not an easy thing. One patient blogger testified and wrote that:

> I felt nauseous every day from the TB treatment; sometimes just taking the pills out of the bottle would give me goosebumps already.

Another wrote:

> Taking the treatment at start was very difficult because of the side effects that come with the pills. After taking the pills, I could not do anything at home I just felt so tired, dizzy and wanted to vomit all the time.

TB patient bloggers do not only have the challenge of emotional shock and pills intake, but importantly food intake. Food intake, because what is not taken into account is that these people are poor and therefore the notion of nutritional food becomes a predicament. A predicament due to lack of jobs and therefore lack of ability to buy proper food that will contribute to improved health. This links in well with WHO strategies on, addressing the needs of poor and vulnerable population, contributing to health system and strengthening based on primary health care, engaging all care providers, empowering people with TB, and communities through partnership, enabling and promoting research (WHO, 2011:12). This tackles poverty and enables those living with TB to have access to means of food and other basic resources. Further, the issue of poverty, treatment and care links in with the South African National Department of Health's policy preventing TB and ensuring that those who do contract TB have easy access to effective, efficient and high-quality diagnosis, treatment and care that reduces suffering (NDoH, 2007).

One patient blogger shared her story and wrote that she was already:

> Suffering to swallow the treatment pills and taking injection every day. This is a challenge that many would choose not to indulge in because it is not pleasant, in fact, it comes across as a predicament for TB patient bloggers along with other negative factors associated with living with TB.

## Stigma

TB patient bloggers have all had a negative experience with stigma directed at them because of living with TB. People in their communities exercise the stigma through their negative and prejudiced attitudes, which often leads to social isolation and refraining from public activity. This links in well with Kelly's (1999) study on isolation and stigma: the experience of patients with active TB. The study revealed that patients of TB responded to negative attitudes expressed by others by isolating themselves and becoming secretive about their illness. Most TB patient bloggers are aware of the negative stereotypes associated with TB, and being poor escalates the negative attitudes people have of them. The stigma is more felt by the poor in society, because poor people especially those that are sick have a history of being stigmatized by others. Thus, most of these patients, experience stigma as a problem manifested into a challenge, because people begin to treat you differently and make you feel inadequate due to not just the status of your sickness but importantly also the status of your socio-economic status in society. This kind of attitude from others hinders many of patient bloggers success in getting better or fighting the disease. One TB patient blogger shared her experience and wrote that she is:

> Carrying a dangerous infection to community.

This kind of internal talk from one of the TB patient blogger highlights the fact that external negative attitudes from others in society can make TB patient bloggers feel like outsiders in their own communities. Further, make them feel like they should not be part of society and that it is all their fault they are sick. All these feelings are negative and bad as they contribute to patients getting worse in their ill health. Hence, Kelly's (1999:238) study concluded by asserting that "tuberculosis was an illness that caused embarrassment, isolation, stigma, and self-identification as a transmitter of disease". Then, it can be said that negative attitudes from others further marginalizes and makes those living with TB feel extremely inadequate, unappreciated and less of a human. Because of all the negative attitudes from others, one patient blogger shared something important by writing:

> The attitude around TB needs to change. Society needs to understand that anybody can contract TB. If we change our attitude and approach TB with an open mind and understanding, we will have less people avoiding treatment because they are scared of being stigmatized. We can have all the treatment, the best in the world but for as long as people do not understand the nature of the disease and how it can be cured. We are fighting a losing battle.

The words above are from someone who has experienced stigma on a first hand harsh experience and she is trying to make people aware of the importance of information about the diseases out there.

### Tender Loving Care and Solidarity

Patient bloggers throughout their experience with TB and the challenges they face, have come to appreciate the significance of support in their journey to recovery. Support has come to be the pillar of strength and has carried them forward in their challenge against TB, because when you are poor and without a job, nobody really cares about you. You lose your value as a person in society and people become indifferent. Hence, support during a time of living with TB becomes essential. For instance, one of the patient bloggers expressed himself by writing that:

> My mother and uncle told me that this is not the end of the world. It is where I told myself that I must be strong. I must take my medication the way the doctor told me.

Support from family members is paramount as it goes a long way in providing patients of TB with the needed hope to continue striving for better health through primary individuals such as family members. A patient blogger shared her experience of how she disclosed her illness and how wonderful and encouraging the family member responded/reacted. She wrote that:

> I called my mother and told her that I had TB, all she said was "Oh well, TB is curable so you will be fine my child.

With that kind of reaction, this patient blogger further went on to share how she:

> Wishes that families of people with TB could give that kind of support that I got.

She was emphasizing the fact that being sick and lonely is the worst form of challenge anyone can go through. She further, wrote:

> Nobody wants to be sick and alone.

The notion of support is prevalent in the stories shared by TB patient bloggers, and they have all come to the realization that TB, as an illness requires support from loved ones. Because you cannot fight the disease alone, especially as a poor person that is faced with social problems such as poor living conditions, lack of nutritional food, lack of opportunities/jobs etc. They are very much aware of the two-dimensional support that encompasses the emotional and physical. They have shown that it is the emotional support of family and friends through encouraging, motivating and inspiring them to believe in themselves. All this support brings about physical improvement in their health. They have shown that despite the structural limitations in relation to living with TB, support can be the best thing that can happen to you. Hence, they showed appreciation for all the support received. As one blogger wrote:

> I realized how blessed I was to have a loving and supportive family and friends - wow.

The phenomenon of mutual support becomes a reality especially amongst the sick. This takes the form of social cohesion or rather what many would/might call solidarity. This form of support is very holistic and encompasses many stakeholders ranging from not just TB patients, but also others. The rationale for this kind of support stems from the fact that we cannot fight this TB epidemic alone as individuals or organizations, but as a collective group. If we are united we stand against TB, but if divided we will fall and lose the fight against TB. Social cohesion is relevant to the support that fosters cohesion amongst all the stakeholders. To support the above assertion, one TB patient blogger wrote:

> One major problem is that many believe that the fight is fought only in the hospitals and the clinics by medical doctors and other health care workers.

The above shows the inadequacy of the healthcare such as few clinics, hospitals and medical practitioners. To emphasize the notion of social cohesion and solidarity from a holistic approach, one patient blogger wrote that:

> This fight needs to be fought by us all, not just by the health care workers and the patients but the community at large.

In addition, another TB patient blogger wrote:

> The government needs to play its part, the policy makers need to play their part, the drug developers need to play their part.

This shows that we need one another to overcome the challenges of living with TB, because individually people are poor to do it on their own and the structural limitations will hinder any progress if it is done individually, but collectively it can be done.

### Race Card and Poverty

Patient bloggers on the TB and ME Blog in collaboration with Médecins Sans Frontières/Doctors without Borders (MSF) South Arica are predominantly black. This is due to the high prevalence of TB rates amongst poor black people. Most of the TB patient bloggers are from residences that are characterized by poor sanitation, unemployment, overcrowding, confined spaces, despair, lack of social support, bad social relationships etc. This makes TB incidences to be on the high, because TB germs spread easily and quickly. The risk factors tie in well with Friedrich Engel's assertion that the cause of illness is a result of the working and living conditions of the workers such as poor housing, crowding, insufficient ventilation, chronic food shortage, excessive drinking, and the maldistribution of medical doctors (Engels, 1945 in Annandale, 1993). As Erstad (2006) in the study on the resurgence of tuberculosis in South Africa confirms the need to understand the challenges or realities in which the study participants get sick, get well, or not, and live their lives. Majority of the bloggers made it clear that the living conditions makes TB to spread faster and easier to contract. For instance, most of the patient bloggers live in Khayelitsha, an informal settlement on the outskirt of Cape Town.

Social problems are escalated by the low socio-economic status of people in the neighborhood. In other words, the TB patient bloggers are both black and part of the working class. Further, their experiences of TB and the challenges they encounter are linked with their socio-economic status in society. The study on the resurgence of tuberculosis in South Africa show that "people make strategic choices in terms of their illness and other responsibilities in life, but that these choices are limited and constrained by structural relationships of power and access to this power, including economic benefits" (Erstad, 2006:2).

Therefore, in order to understand suffering it is important to move from individual explanations towards a social analysis of health, illness and the socio-economic status of individuals (Annandale, 1993). Further, Annandale (1993:4) argues that "health and healthcare could be understood only in relation to the political and economic framework." A social analysis of health does not only involve the macro structural analysis, but also the micro level of analysis, whereby people's internal feelings such as their emotions are considered relevant in understanding the challenges of those living with TB. This often encompasses experiences of emotional pain and suffering.

## A Conclusion

The TB bloggers narratives in the form of writing on a blog reveal that challenges experienced by those living with TB are associated or rather are escalated by factors such as the structural limitations encompassing class and health inequality. This is a result of the structural poverty that most people in society such as the TB patient bloggers experience as part of their living arrangements that entail poor working and living conditions, lack of opportunities/jobs and the low socioeconomic status. The socio-economic status of people escalates the suffering and makes it hard to overcome some of the challenges of living with TB. Further, an issue of gender is central in understanding the fact that it is not only about being black, deprived and having low socioeconomic status, but that it is also about not sticking to treatment. This is significant as it highlights the need to not only focus on issues of socioeconomics but gender issues in fighting TB in society. The next chapter concludes the study.

# Chapter 5

# Discussion and Conclusion

Judging from the TB&ME blog, where TB patient bloggers shared their experiences of living with TB, it was evident that most experiences of these individuals were predominantly negative and had significant social consequences. One factor that came out quite explicitly was the gender-based difference in TB treatment compliance. The study found that women had a higher probability of finishing their treatment compared to men. This finding highlights the fact that there is a need to move away from notions and perceptions of TB being mainly a black disease affecting those from a low socio-economic status. The focus should also be on gender-based treatment compliance issues. Further, the class struggle of the narrators contributed to their ill or improved health outcomes. Szreter and Woolcocks (2004) argue that being ill/poor health is not an individual problem, but that it has its roots in class inequality.

This class inequality often results in health inequality and access to healthcare. Most whites and rich blacks enjoy quality health outcomes and healthcare, while the poor, mainly blacks have poor health outcomes and poor healthcare. In other words, the notion of socio economic status becomes important in understanding the challenges faced by those living with TB. This is because TB is a social disease with risk factors such as a “lack of a sense of control, depression, hopelessness, hostility, lack of confidence, lack of social support, bad social relationships, stressful life events, family conflict, stress at work, bereavement, singleness or divorced rather than married, and job and housing insecurity” (Wilkinson, 2005: 60). These risk factors make it hard for TB patients to overcome their challenges and living with TB unbearable. Thus, notion of socio-economic status becomes relevant as it correlates with the race and living arrangements.

Most of the TB patient bloggers on the TB&ME blog are black, with a low socio-economic status and live poor neighborhoods. These factors are at the center of the TB epidemic, as majority of black people are infected with TB and they often have low paying jobs or are unemployed. The bad working conditions with low pay and unemployment on the rise, makes the socio-economic status to become low, leading to poor standards of living such as overcrowding, confined spaces and poor sanitation. As noted earlier, most of the TB bloggers stay in poor neighborhoods such as Khayelitsha. Their predicament links with the call for an emphasis on the analysis that goes beyond individual explanations of heath, towards a social analysis of health, disease and socio-economic statuses of people (Minkler *et al.*, 1995). This is because disease (e.g. TB) has a direct association with the relation of production under capitalism. This direct association was clearly highlighted in Engel's study of the condition of the working class in England (Engels, 1945 cited in Annandale, 1993:4). Engels argument links well with TB patient bloggers, because the cause of their illnesses, and importantly impediment to overcoming their challenges, is related to the macro structural inequalities. Therefore, health and healthcare must be understood within the political and economic framework (Annandale, 1993: 4).

Being poor and struggling to make ends meet adds to the emotional and physical challenges experienced by those living with TB. The bloggers spoke about the emotional stress and feelings of loneliness, this in addition to the social problems such as poor sanitation, bad living conditions, poor healthcare service and lack of social support. Thus, social marginalization escalates the suffering for TB patient bloggers. This echoes Nelson Mandela, when he said, "the wounds that cannot be seen are more painful than those that can be seen". As one blogger noted that living with TB would be to "speak of a journey, one of loneliness, pain, tears and finally salvation". This expresses pain that is like a wound that cannot be seen. Physically, the bloggers spoke about the fatigue due to walking to the clinic or hospital, and that this caused them to miss check-ups.

The participants experienced what Charmaz (1983) calls a 'loss of self'. The 'loss of self' is when ill individuals observe their former self-images crumbling away without the simultaneous development of equally valued new ones (Charmaz, 1983). For the TB bloggers, their socio-economic statuses acted as a hindrance to the development of equally valued new ones, because being poor makes it difficult to get financial help from others. Thus, participants became socially isolated and their condition burdened their families. Furthermore, their lives altered and things was no longer the same, as one blogger said:

> If I want to wash some clothes I cannot wash the clothes by myself because I get tired so fast. For a long time, I could not get up out of bed by myself so I relied on others a lot as I lost a lot of muscle mass and was weak. It was hard not to be able to bath myself.

The above expresses the feeling of losing themselves in the experience of living with TB. Lack of knowledge was common, and this highlights general misinformation about TB among black people. The ignorance about the disease can be due to lack of material resources and sources of information in poor neighborhoods. Stigma was prevalent amongst those living with TB, because society tended to give them an attitude and treated them as less humans. Stigma had negative consequences for the participants as it led to social isolation and refraining from social activity. As Kelly (1999) found that patients with active TB responded to negative attitudes expressed by others by isolating themselves and becoming secretive about their illness. This shows how stigma exert power over those living with TB and how challenging this can be. Despite all the negative consequences of living with TB and the challenges encountered, it is significant to note that the TB bloggers also spoke about support from loved ones and others interested in the fight against TB, and how this alleviates their struggles inherent in living with TB. At least, this was the only positive thing they experienced as patients of TB and support was constructive, because being sick and lonely is emotionally and physically draining.

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